# REPORT 2020

# A STRATEGIC ANALYSIS OF IMPACT OF COVID-19 ON PERSONS WITH DISABILITIES IN INDIA



Collaborative Research Study SACDIR - IIPH Hyderabad CBM India Trust and Humanity & Inclusion







# A Strategic Analysis of Impact of COVID-19 On persons with disabilities in India

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**Report prepared by:** 

Indian Institute of Public Health, Hyderabad, Public Health Foundation of India, ANV Arcade, 1, Amar Co-op Society, Kavuri Hills, Hyderabad, India.

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#### Disclaimer

The findings and recommendations of the study are entirely of the research team based on the information collected during the COVID-19 pandemic situation. The findings may not reflect similarity in post lockdown era. We have made every effort to ensure that the information is correct to the best of our knowledge at the time of the publication. However, we do not take responsibility for errors and/or omissions within the study.

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#### **Executive Summary**

The COVID-19 pandemic is proving to be a challenge for achieving the SDGs. How far this will impact the deliverables especially those that are time-bound is difficult to state now. The challenge is of Herculean proportions for many low- and middle-income countries like India. The health system is fragmented - quality can be inconsistent and coverage inadequate. The meagre wages and fragmented health systems compromise the situation even more. And within countries like India, the steep differentials between regions, sex and disadvantaged populations including Persons with disability can be further detrimental to their wellbeing if not recognized and managed in a timely manner.

It was therefore felt that there is a need to understand the effect of the COVID-19 pandemic on lives of Persons with disability, their care and support systems, nutrition, livelihoods, social participation, mental health and access to health and education services. The specific objectives of the study were to assess the level of disruption on the living conditions of Persons with disability due to COVID-19 and related restrictions and to generate evidence to inform actions for future pandemics or emergency preparedness.

A cross sectional, mixed-methods approach, using a purposive snowballing technique was adopted for the study. Data was collected from across the country using tools like telephonic semi structured interviews and focus group discussions facilitated through the network of NGO partners providing care and support for Persons with disability. persons with disabilities, NGO leadership, government program officers and caregivers of Persons with disability were included. The cross-sectional survey was repeated for a 2<sup>nd</sup> time, 6 weeks after the first interview on a randomly identified 25% sub sample to discern any change in trends over this period.

#### Quantitative Findings

A sample of 403 respondents were included in the study, from 14 states. The median age of Persons with disability who responded was 28 years with an interquartile range (19, 36.5 years) and 60% were males. 51.6% had physical impairments, 16.1% had visual impairments, 10.9% had intellectual impairments and only 9.2% had speech and hearing impairment.

Four out of five (74.6%) persons with disabilities using assistive devices sanitized their devices regularly. Soap and water were used most commonly. Use of alcohol-based sanitizers was significantly higher among those with visual impairment.

#### Health Care

Overall, 2 out of every five people (42.5%) with disability reported that lockdown had made it difficult for them to access routine medical care. Among those with a pre-existing medical condition (which was 12.7%), 58% stated facing difficulty in accessing routine medical care. Therefore, persons with disabilities with antecedent medical problems suffered significantly more than those who did not have an antecedent health condition. Nearly a quarter reported difficulty in getting their medications while 28% reported postponing their scheduled medical appointments because of the lockdown. More than half the Persons with disability perceived that continuous lockdown would have a deleterious effect on their health.

Just above a third (35%) reported the need of out-patient services at hospitals/clinics during lockdown of whom more than half (55.6%) had difficulty in accessing out-patient services. 16.6% stated that they needed emergency medical care during the lockdown among whom 45% had difficulty in accessing the services. Of the 35.7% needing medicines during the lockdown, nearly half (46%) stated that they faced problems in accessing the same. 58% of those who needed regular blood pressure monitoring could not get it done during the lockdown. A third of those who stated needing regular blood sugar estimations expressed their lack of access to such a service. 5.2% of respondents with disability stated that they needed a surgical procedure of whom 47.6% could not attend for the same due to the lockdown. Of those needing surgical intervention, three fourths had speech and hearing impairment while 9.5% had visual impairment.

#### Rehabilitation Services<sup>1</sup>

Among the 17% needing rehabilitation services, 59.4% failed to access the same. Reported difficulties in access were same across the different groups of disability, thereby highlighting that concerns of persons with disabilities are similar across disabilities. Most people needing

<sup>&</sup>lt;sup>1</sup> Rehabilitation is defined as "a set of measures that assist individuals, who experience or are likely to experience disability, to achieve and maintain optimum functioning in interaction with their environments." (WHO, 2011)Rehabilitation is instrumental in enabling people with limitations in functioning to remain in or return to their home or community, live independently and participate in education, the labour market and public life.

rehabilitation services said it was for physiotherapy which was compromised during the lockdown.

#### Mental Health

The important psychological reactions to COVID-19 pandemic vary from fear and anxiety, panic, feelings of hopelessness to depression. Fear of getting infected with novel corona virus and loss of income were affecting persons with disabilities the most. 81.6% reported experiencing moderate to high levels of stress. This shows that there is an urgent need to ramp up mental health support services for persons with disabilities.

Stigma followed by discrimination and effect on family relationships were leading psychosocial problems reported by Persons with disability. Isolation, abandonment, and violence were other worrying psycho-social problems reported showing the lack of empathy during the difficult times.

Among the 34.5% who stated that they needed information on mental health issues, only 25.9% had access to such services. Only 20% were able to get regular mental health counselling or therapy related services during the COVID-19 outbreak and lockdown, and 11.4% faced problems getting their regular psychiatric medicines.

Mental Health concerns of caregivers of Persons with disability were also ascertained and important leads were observed. Half of them felt moderately stressed caring for children or other family member with disability. 58.2% were unhappy that the therapy sessions for their child with disability has ceased during the lockdown.

#### Activities for Daily living

Just over four out of every five people (81.6%) with disability stated that they needed assistance for daily living and family carers supported most. Because of the family support, 55.8% felt that they can manage if such a situation of lockdowns arose again.

#### Livelihoods

As expected, livelihoods were adversely affected due to the lockdown. 84.2% stated that their daily lives had been impacted. The lack of mobility both in rural and urban areas led to distress. For a third (34.3%), even drinking water supplies were affected. A third (33.1%) also

mentioned that their pensions were affected. Around 45.7% of persons with disabilities were forced to borrow money during the lockdown mainly for livelihood. 84.7% had to borrow or request for support for food to cope with financial crisis. 18.2% reported that loans were advanced by inclusive cooperative societies.

#### Education

An overwhelming proportion (73.3%) stated that children were distressed with school closures and it had affected learning (school level education). It should be remembered that school closures do not impact only the academics but also have profound impact on school meal programs, special education, therapy, counseling and peer-support and kinship.

#### Social Participation

Social participation and empowerment activities were affected in more than half the respondents with disabilities. The maximal impact was on regular functioning as members of Disabled People's Organizations (DPO). 54.2% of the respondents with disability felt that working/participation at the community level and Panchayati Raj Institutions (PRI) will be affected after the covid-19 pandemic.

Overall, it was observed that the impact of COVID 19 was the same irrespective of any age group, gender, or marital status. The impact of Corona virus pandemic on access to rehabilitation services and participation in social empowerment activities differed significantly among people having different type of impairments. Due to COVID-19, occupational status had a significant adverse impact on access to all routine services. Pensioners reported an adverse effect of COVID-19 on all domains while persons with disability with children reported adverse impact in relation to accessing medical services, rehabilitation, and mental health.

#### Qualitative Findings

We conducted 11 in-depth interviews (IDIs) and 2 focus group discussions (FGDs) in the lockdown period and 2 FGDs after easing of lockdown. People with disabilities, 'carers' and relevant stakeholders shared a wealth of information in their own words on the impact of lockdowns on their lives. Lockdown has had a profound impact on Persons with disability. The major domains affected were livelihood and mental health. Lockdown had a negative psychological impact on Persons with disability and one of the most common reason was

economic difficulties. Some Persons with disability stated that COVID-19 had broken their confidence and resolve. Many faced difficulties in accessing necessities such as food, mainly vegetables and pulses, whereas the government provided rice. Access to medicines was difficult mainly due to travel restrictions in their region. In addition to difficulties in livelihood and the profound psychological impact, the lack of information in accessible formats was highlighted by most interviewees as was the lack of public transport when they needed to access general health services and treatment. What was disconcerting being that there were reports of large number of children with disabilities being abandoned by their parents and had to reside in institutions.

Communication was badly affected during the COVID-19 pandemic as NGOs were unable to reach Persons with disability needing health services or consultations. A major concern that was raised was the lack of an inclusive response during COVID-19 as the needs of Persons with disability was not given adequate attention when guidelines on COVID-19 response were released. Another issue that was all pervasive was the financial impact of COVID-19 on Persons with disability and their families. Not only were incomes compromised but even withdrawing their money from their bank accounts was a challenge. The adverse financial situations led to using family savings earmarked for other purposes for feeding themselves and keeping themselves alive and secure; this could also lead to borrowing money for health services and treatment if any family members fall sick. This expenditure which can be potentially catastrophic renews the need for universal, inclusive health care which protects all, including persons with disability from catastrophic health expenditures.

The responses by stakeholders on government future preparedness believed that the governments may not be prepared for another wave of COVID-19 or a similar health emergency. Respondents opined that it would have been better if adequate time for preparing for the lockdown and its consequences was given at the beginning so that adequate arrangements for food and support could have been made. Stakeholders indicated that government should address the livelihoods of Persons with disability and their family so that lockdowns such as the current one has minimal impact on Persons with disability lives.

#### Adaptation to COVID-19 and the lockdown and unlocking process

Trends over the COVID-19 timelines were compared by ascertaining responses from Persons with disability at two time points during the life course of COVID-19 in India. Positive trends

were observed once strict lockdown restrictions were withdrawn. Difficulty in accessing emergency medical care reduced significantly once restrictions were lifted. There was also a significant difference in Persons with disability being able to access rehabilitation services. One striking feature observed was that contrary to popular perception, online consultation was not very attractive both during the lockdown, or later on, and this should be a good indicator for planning response services.

There were significant differences reported in stigma and discrimination which reduced significantly after the unlock process started. The mental health status and apprehension about getting infected also reduced significantly after the lockdown curbs were lifted. However, a substantial proportion of Persons with disability exhibited stress both during and after lifting of the lockdown. On similar lines, there was no significant difference in relation to caregiver's mental health during lockdown and after easing of lockdown. This aspect needs targeted attention for the future.

Regarding items pertaining to education, livelihood, and social empowerment, there was no statistically significant difference in proportions before and after easing of lockdown. This could be because the process of getting back to pre-lockdown state has not yet been seen or achieved with many restrictions including on public transport still in place in many regions of across India. If the assessment is repeated a few months after all restrictions are withdrawn, it will give a better idea of people's perceptions after the pandemic completely ceases.

The apprehension of visiting a hospital for care persists as was seen in the study where 72.9% hesitated to go to hospital because of fear of contacting COVID. 86% were scared to go out and meet others. 78.1% did not fear the lack of companionship, both during and after the lockdown. Some program managers opined that the public health system was concentrating only on COVID-19, to the determinant of other health conditions at all levels of care from a Primary Health Centre to a district hospital. Concerns were also expressed about the cost of services being charged by hospitals.

The findings of this study have highlighted the concerns of Persons with disability, their care givers and the health and developmental systems due to COVID-19. These observations should be used to prepare protocols and guidelines to tackle such emergencies in the future. Advocacy with the governments is critical so that the response to such a health or non-health

emergency in the future can be quickly mounted and operationalized. An inclusive plan to mitigate the adverse impact should be in place quickly and implemented immediately rather than losing a lot of time in the response cycle. Some key recommendations include:

- a) Special assistance and disabled-friendly COVID-19 protocols must be available and accessible to them.
- b) Provide supplies such as medicines, disinfectants, masks etc. for Persons with disability to protect themselves as well as others in their families from COVID-19 infections.
- c) Information on rehabilitation, therapy support and other specific services must be made available to them in accessible formats.
- d) Enable tele-rehabilitation and support needs of Persons with disability, especially children who were receiving services through the RBSK programmes.
- e) Online counselling must be started in management of stress and fear and anxiety.
- f) Respective State Government must ensure Relief measures, special financial assistance, subsidies, furlough schemes, access to interest free loans for improving or at least to maintain current livelihoods.
- g) Loans available from cooperatives, and the obstacles to availing such loans must be quickly cleared.
- h) Best practices such as organic farming and dairy and the income from these initiatives must be promoted rapidly.
- i) The government should ensure that pensions are not negatively impacted in future.
- j) Online education for children in schools must be provided in accessible formats. To avoid the pressure of buying smart phones by parents, education must be provided in formats that are easy for parents to receive, both economic and technology wise. For example, Special educators could prepare individualised education plans for children and train the parents through phone or a school website podcast to deliver this to their children at home.
- k) Provision of free internet services for Persons with disabilities who require access to internet for education must be explored.
- Prioritise Persons with disability when developing a program or strategy to combat emergency situations like the pandemic.
- m) Include Persons with disability in the development and implementation of any plan, policies, strategies and programmes

## **List of Abbreviations**

ASHA	Accredited Social Health Activist		
AWW	Anganwadi Worker		
COVID-19	Corona Virus Disease 2019		
DPO	Disabled Peoples' organization		
FGD	Focus Group Discussion		
IDI	In-Depth Interviews		
IIPHH	Indian Institute of Public Health - Hyderabad		
MGNREGA	Mahatma Gandhi National Rural Employment Guarantee Act		
NCPEDP	National Centre for Promotion of Employment for Disabled		
	People		
NDMA	National Disaster Management Authority		
NGO	Non-Governmental Organization		
NSAP	National Social Assistance Programme		
PHC	Primary Health Centre		
PPE	Personal Protective Equipment		
PRI	Panchayat Raj Institution		
RBSK	Rashtriya Bal Swasthya Karyakram		
SACDIR	South Asia Centre for Disability Inclusive Development &		
	Research		
SDG	Sustainable Development Goals		
WASH	Water, Sanitation and Hygiene		

# A Strategic Analysis of Impact of COVID-19 On persons with disabilities in India

#### Background

Persons with Disabilities are more vulnerable and are at higher risk from Corona Virus Disease 2019 (COVID-19). It is not because of their disability but because they generally experience co-morbidities and other underlying conditions (Turk & McDermott 2020, UN 2020). Restrictions imposed because of the pandemic lockdown exposes persons with disabilities to substantial additional risk because of disruption to essential services and support (Negrini 2020, Kuper H 2020, WHO 2020). This is especially true for a country like India where access to health, rehabilitation and social care services are very limited (GVS Murthy 2020, GVS Murthy 2014, GVS Murthy 2018, GVS Murthy 2020). Furthermore, one must not forget that disability is both the cause and consequence of poverty (Ambati N 2009, D'Souza 2018).

The COVID-19 pandemic and consequent lockdown have come with multitude of challenges for persons with disabilities. The extension of lockdown and suspensions of all forms of activity has also led to marginalisation of persons with disabilities and they continue to face penury and deprivation. Some of the key challenges are discussed below:

Access to Healthcare: In order to impose lockdown, the public transport facilities were suspended throughout the country (which has still not been restored in many parts). This affected access to health care services for Persons with disability, elderly, Persons with disability, among whom those with mental health issues suffered the most. There were gaps in access to general health services as well as specific health services such as dialysis services, blood transfusion, leprosy management, chemotherapy and rehabilitation services. Access to health care services for Persons with disability is already a challenge in India – owing to inaccessible physical infrastructure, facilities and information. The restriction or sometimes, shutting down of essential health services has made the access even more challenging, due to restricted transport networks. The two-way association of disability and non-communicable diseases (NCDs) is well established. People living with NCDs can develop impairments, and disability itself can be a risk factor for NCDs. The underlying health conditions and exclusion from health care services during lockdowns render Persons

with disability more vulnerable to multiple health conditions including NCDs. (Prynn & Kuper, 2019)

As per the survey conducted by WHO in 155 countries during the 3-week period in May 2020, it is confirmed that impact of COVID pandemic is global and low- and middle-income countries are the worst affected. The report states that prevention and treatment services for non-communicable diseases have been severely disrupted since the COVID-19 pandemic. More than 53% of the countries surveyed have had partially or completed disturbed services for treatment of hypertension; 49% for treatment of diabetes and diabetes related complications; 42% for treatment of cancer and 31% for cardiovascular emergencies. Particularly, India has reported 30% fewer acute cardiac emergencies reaching health facilities in rural areas in March 2020 compared to previous years. (WHO, Rapid assessment of service delivery for NCDs during the COVID-19 pandemic, 2020)

The attempt to convert already overburdened public health facilities into dedicated COVID facilities, without alternate arrangement endangered many lives. In 94% of the countries surveyed the resources – human resource and financial are diverted towards mitigation of COVID-19 and many public screening programs were also disrupted. (WHO, Rapid assessment of service delivery for NCDs during the COVID-19 pandemic, 2020).

**Rehabilitation services:** Rehabilitation includes interventions that are required when a person experiences or is likely to experience functional limitations due to a health condition or ageing, injuries, trauma etc. The functional limitations are difficulties in seeing, hearing, communicating, mobility, having relationships, thinking and so on. The rehabilitation services include occupational therapy, physiotherapy, speech therapy, cognitive behavioural therapies, prosthetics and orthotics and special education. In India, the facilities providing these services are already scarce and are located in the tertiary level centres; and in urban and peri-urban areas. This makes accessing rehabilitation services particularly challenging for Persons with disability. As per WHO some countries have more than 50% of people who require rehabilitation services do not receive them. (WHO, WHO.int, 2019).

In India, a majority of the Persons with disability reside in rural areas where accessibility, availability, and utilization of rehabilitation services is the major challenge. (Saya, Roy, & Kar, 2012) Lack of physiotherapy, speech therapy among children with disabilities can affect their both physical and mental health. (Chari, et al., 2020).

**Mental health care:** A country-wide survey of over 2000 Persons with disability across 23 states and Union Territories in India, revealed that 75% of the persons with disability were living with emotional challenges such as anxiety, depression and suicidal thoughts. Lockdowns, and the subsequent loss of employment and financial crisis could cause severe socio-economic distress and is a contributing factor for symptoms of mental health illness, anger and anxiety. (Kocchar, Bhasin, Kocchar, & Dadlani, 2020).

The lockdown which was initially proposed for 21 days was eventually extended for another 3 weeks. The longer lockdown and quarantines are known to be pre-dominant stressors which have direct correlation with the mental health of the individuals. (Brooks, et al., 2020). Longer quarantines have a direct correlation with the mental health outcomes and the duration of the lockdown is a predominant stressor affecting the mental health of individuals (Brooks et al., 2020).

Furthermore, for persons with mental illness or epilepsy, reduced access to medication could lead to relapse of symptoms, as can the compounded stress. For persons with substance use disorders, sudden withdrawal leading to seizures, delirium, agitation, and even suicide have been described. (NIMHANS, 2020). It has been recorded that the substance abuse increases in people during and after a pandemic (Clay & Parker, 2020) and in a study it was seen that 26.3 % of respondents started consuming more alcohol/drugs/tobacco. (Kocchar, Bhasin, Kocchar, & Dadlani, 2020)

**Impact of disruption in daily routine:** Several changes in day-to-day activities, redistribution of home chores, loss of job and greater time spent with those living together, reactions can range from boredom and moodiness to anger, irritation, and frustration. Unpredictable, uncertainty and a sense of loss of control are the pathogenic agents for anxiety, panic, and depression. (NIMHANS, 2020) Another emerging concern during COVID -19 Pandemic and lockdown is surge in suicide cases, In India over 300 people committed suicide during lockdown period. Of these 80% committed suicide because of stigma, isolation, loneliness and fear of being infected. (Rana, 2020). Social isolation of the elderly population has led to genesis of concerns like neurocognitive, auto-immune cardiovascular and mental health. (Santini, et al., 2020)

Access to Education: It is generally perceived that children are not at a heightened risk of this pandemic but the crisis has had profound impact on their wellbeing, particularly for children with disabilities. The lockdown has also put them at an unfair disadvantage in the field of mainstream education. (UNSDG, 2020). Additionally, many State governments in India have a mid-day school meal program which provides for a third of their daily calorie requirements and half their protein requirements. These programs were suddenly stopped with closure of schools. School sports which contribute to improving health status also suddenly ceased.

According to Census 2011 there are 40 Lakh learners with disabilities in the age group 5-19 years, who have been disproportionately impacted by sudden changes in the teaching learning methods. Even after months of COVID-19 pandemic and lockdowns, no dedicated arrangements have been made or announced by concerned departments or the ministries about structure and accessible delivery mechanisms or educational services for children with disabilities during the pandemic.

**Livelihood:** As the lockdown progressed, over 23.7% of the workforce in India is rendered unemployed and has pushed millions into poverty and deprivation. Nearly 10 crore jobs were reported as lost, within the first five days of the lockdown. Besides, some industries, offices, shops, hospitality sector and the vast informal sector have collapsed due to the shutdown with little chances of immediate recovery. An estimated 121.5 million jobs were forfeited by the lockdown in its first month, in April 2020. This loss narrowed down to 100.3 million in May and then dramatically to a much smaller, 29.9 million in June. July 2020 saw a further reduction in this loss of jobs to 11 million. (CMEI, 2020). Whether this afforded any benefit to Persons with disability is unknown.

Only 21 % of all employment in the country is in the form of a salaried job which are more resilient to economic shocks compared to the unorganised sector like a daily wage labourer. As a result, job losses among them accounted for only 15 per cent of all job losses in April 2020. Among the persons with disabilities aged 15 years and above, worker population ratio in usual times is a mere 22.8% (MOSPI, 2018).

The EVARA survey report also states that 64% of the Persons with disability are facing financial crisis with 60% of them having no income. Furthermore, owing to disruption in the disbursement of disability pension, many Persons with disability did not receive any pensions

from months. (Kumar, Aparajita, & Suman, 2020). In a survey done by Help Age India with sample size of over 5000 elderly (aged 60 years and above), 65% of respondents stated that COVID 19 has impacted their livelihoods, 61% of those impacted this way were from rural areas and 39%% from urban areas. (The Elder Story: Ground reality during COVID-19, 2020). Moreover, 62% of the respondents reported to be suffering from chronic diseases require management of specific protocols of medical consultation, rehabilitation and medication. In another survey done by NCPEDP covering 1,067 persons with disabilities - 73% Persons with disability reported that they were facing particular challenges due to imposed lockdown; 57% reported facing a financial crisis; 13% spoke of challenges in accessing rations, while 9% were facing obstacles in access to healthcare and medical aid.

**Response in India: Too little, too few:** Persons with disabilities account for 2.21% of India's population as per 2011 National census (Census of India 2011). In the budget estimates for the fiscal year 2019-20, support services for persons with disabilities amount to 0.22% of public expenditure, which translates to 0.03% of gross domestic product. Only 7.6% of working-age adults with disabilities are covered under the Indira Gandhi National Disability Pension Scheme that is one of the five schemes under National Social Assistance Programme (NSAP). In contrast, state schemes cover 42.78% of persons with disabilities aged between 18 and 59 years (NSAP 1995).

Gaps in social protection measures for persons with disabilities: Although the government of India announced top up on NSAP pensions to current beneficiaries, it converts to a value of only 14 USD per individual for a duration of three months. This is below 20% of 1.9 USD per day poverty line criteria in 22 states. In the absence of ration cards which are mandated to receive food kits, Persons with disability utilized the immediate cash transferred through advance pension benefits (as announced in the states of Jammu and Kashmir, Delhi, Tamilnadu, Himachal Pradesh and Odisha), depleting their emergency reserves within four months. Kerala is the only state to adopt a universal approach for ensuring food security.

Maharashtra and Tamil Nadu are grappling with a huge upsurge in cases post nation-wide lockdown and have either dysfunctional or partially operating helplines neglecting the needs of persons with disabilities in rural areas. In Delhi and Maharashtra, a myriad of issues like backlogs in usual pension payments, problems with Jan Dhan (People's Wealth) accounts and absence of payment points for those without bank accounts expose the systemic deficits in reaching out to the most vulnerable in times of absolute need. Additional literature and relevant citations are presented in **Annexure** -1.

With this background and given the multi-layered vulnerability and risk exposures experienced by persons with disabilities in India, there are numerous contributory conditions for them to experience detrimental effects from this pandemic situation (Jesus TS 2020). There is no information related to how persons with disabilities combat the pandemic situation and remain safe and healthy in India (Srilakshmi B 2020). It is likely that they experience more hardships to access information related to prevention than from the risk of COVID-19 infection itself (Srilakshmi B 2020). Especially because the general information available from governments on COVID-19 is not in an accessible disabled friendly format (Khetarpal 2020).

In this prevailing situation, it is absolutely crucial to gain insights of the impact of COVID-19 and the related lock-down measures imposed on persons with disabilities in India. With timely funding and support from CBM and Handicap International, IIPH-SACDIR undertook this initiative. This research study helps to understand the impact of the pandemic situation and the needs of persons with disabilities in India to combat the same. This exercise was to also provide useful insights on how best to strategically develop preparedness and mitigation plans and meet the needs of the persons with disabilities in India not just for this pandemic but for any similar catastrophes in the future.

#### Specific Objectives of the study

- Determine the level of disruption in the lives of persons with disabilities during lockdown due to COVID19 and during the phased opening up in the country.
- Understand how the availability of funds for persons with disabilities related to welfare / development would be impacted.
- Generate evidence and to inform actions for health emergency preparedness in future for persons with disabilities.

#### Methods

**Study Design:** A cross sectional, mixed-methods approach was adopted to identify and understand the answers for the proposed objectives. Using purposive sampling, a quantitative survey as well as qualitative in-depth interviews and focus group discussions were conducted. The questions and sub-questions for specific groups of participants targeting the objectives were developed based on the community-based inclusive development matrix developed by CBM UK. More details related to the framework of questions and sub-questions are provided in Table -1.

#### **Context:**

The study was initiated during the COVID-19 pandemic and with the government-imposed lockdown restrictions in place pan India. As this situation restricted active direct household survey and face to face interviews, the study was carried out using alternate strategies such as telephonic surveys and tele-interviews using Zoom/ Go-to meeting platforms.

#### **Participants**

#### a) Persons with disabilities

Inclusion Criteria-Persons with all disabilities were included in the study. Exclusion criteria- severe co-morbidities, severe psychiatric illness, persons on ventilator support, terminal illnesses etc.

- b) NGO heads/ leaders/ programme managers working for persons with disabilities in India.
- c) **Policy makers and government officials** from the department of Social Justice and Empowerment and Health and Family Welfare in India.
- d) Caregivers of persons with disabilities

i	Strategic Analysis of Impact of COVID 19 on CBID and Persons With Disability				
Focus Themes List of Key areas for Qu		List of Key areas for Questioning	Stakeholders		
1	Access				
1.1	Information	Accessing Public Health Information - Especially Hand Hygiene, Social Distancing, Quarantine, Self- Isolation	Persons with disability, Carers,		
1.2	Necessities	Availability and Access to Food, Water, Medicines, Stores, disinfection of assistive products and environment, Transport, TV, internet.	Project managers, Government Authorities		
1.3	Services	Availability and Access to COVID 19 specific services, General health services and Specific rehabilitation services, Exacerbations due to lockdown.			
2	Participation				
2.1	Work	Engaging in paid / self-employment / Volunteer, Work, Contingency plans, Furlough plans, Barriers faced.	Persons with disability, Carers, DPOs		
2.2	ADL	Personal Care Needs, Management of Personal care, Basic Protection Measures, Hand Hygiene Measures, Contingency plans, Barriers faced.			
2.3	Leisure	Time / Stress Management, Ability to cope with the situation.			
2.4	Community conversation	Engaging with friends, family and other social groups of interest e.g. Religious activities, webinars, meetings etc.			
2.5	Contribution to COVID 19 Activities	Media engagement, Preparing and publishing articles in newspaper, journal, media etc. sharing good practices and information			
3	Communicati				
3.1	on Contacts/	Contacting Helpline, Friends and others for Social	Persons with		
5.1	staying connected	support, Staying updated with latest information, Access NEWS, Available Communication devices and Facilities etc.	disability, Carers, DPOs, Government		
3.2	Messages accessible	Format and Content of the Messages, Sensitivity to Culture and Context, Types of media used, Exclusive Considerations for persons with disabilities	Authorities		

# Table-1: Questions and Sub-Questions related to the objectives

3.3	Authenticity / Clarity	Sources of messages, Language, Clarity of the messages, Quality of Translation and Interpretation etc.	
4	Networks		
4.1	DPOs	Awareness Raising, Contribution to support persons with disabilities during lock down, Approaches and Methods of Contribution, Contribution to COVID 19 activities	Persons with disability, DPOs, Government
4.2	Other Community groups	Awareness Raising, Contribution to support persons with disabilities during lock down, Approaches and Methods of Contribution, Contribution to COVID 19 activities	Authorities
4.3	Support / Exchange of Good practice	Any Specific Contribution that can be translated to other context, Innovations, Guidelines, Policies etc.	
5	Compassion	Compassion	Compassion
5.1	Protect / Promote Well being	Inclusion and Considerations provided for Persons with Disabilities in current COVID 19 / Lock down plans, actions and policies.	Persons with disability, Carers,
5.2	Encourage Safety / Hope	Provision of Information, Communication, Treatment, Screening/Testing, Access to Health and Other Services during the pandemic	Project managers, Government Authorities
5.3	Social- distancing / Self Protection	Considerations especially for persons with disabilities, Any innovative approaches, Exclusive Guidelines for persons with disabilities	

Figure-1: States where the study was conducted – Depicted in Yellow



#### **Quantitative Methods:**

**Quantitative Survey:** To achieve the objectives, a quantitative survey to assess the impact of COVID-19 pandemic and the lock-down restrictions on persons with disabilities was carried out.

**Data collection tool**: A structured survey tool was exclusively developed for the purpose of the study based on the questions and framework for community based inclusive development matrix provided in Table-1. The questions were developed by domain experts. Technical feedback and suggestions from CBM and Handicap International were incorporated,

especially from people implementing disability programs in the field. The survey tool had several questions categorized into specific sections within the assessment. The survey tool was specific to persons with disabilities and their carers. The survey tool was translated in Hindi for convenience. The survey tool used is provided under **Annexure-2**.

**Online Training and Piloting:** The survey tool was piloted before the data collection to check for inaccuracies and was revised accordingly. The survey was conducted by five trained interns of the master's in public health program at the Indian Institute of Public Health Hyderabad (IIPH-H). All the interns who were involved in the survey underwent a formal training (in-person/online) on the survey methods and on the administration of the tool before they actually started conducting the survey. As mentioned earlier, the survey was telephonic, and informed consent was obtained and recorded from the participants before they participated.

**Sampling strategy:** The sampling frame included Persons with disability from the areas where CBM and its partner NGOs were implementing programs. CBM currently caters to the needs of approximately 140,000 persons with disabilities across India through its partner organizations. Since there is no precedence of impact of a pandemic to this scale, the level of disruption (impact) was considered as the outcome.

**Phase 1:** The sample size was calculated based on the assumption that the level of disruption was 50%, relative precision of 10% and non-response rate of 5%. The minimum number of participants required for the quantitative survey was calculated to be 404. This assumption was expected to ensure a sample size that is adequately powered to capture the required information and generate robust evidence.

**Phase 2:** A minimum sample size of 100 participants was the target for the repeat survey (25% of original sample). A stratified random sampling with near to equal distribution of participants across each state was selected.

**Data collection:** The quantitative survey was carried out telephonically. The participants were purposively selected for the quantitative survey with support from CBM India. As already mentioned, five public health interns were trained for data collection. The data was collected using the quantitative survey tool developed for the study. Verbal informed consent was obtained, and the consent was audio recorded for each participant. Data collection happened at two different points in time - once during the lockdown restriction and the other

was 6 weeks later, when the lockdown restrictions were eased partially in each of the study sites.

**Data Analysis:** Descriptive analysis with frequencies / proportions was calculated for the variables of interest within the quantitative survey in each of the domains of assessment. For selected variables of interest, a comparative analysis was carried out using appropriate statistical tests. Data from the lock-down phase of the quantitative survey was compared with the post-lock down phase of the survey to understand the difference in proportion in two different time points.

#### **Qualitative Methods:**

**Data collection tool for Persons with Disability**- A semi structured guide was exclusively developed for the purpose of the study. The questions were developed by domain experts, with feedback and suggestions from people implementing disability programs in the field. Responses from the quantitative survey helped in identifying topics and issues that needed a more in-depth understanding and additional insights and were noted as key aspects that emerged from the survey. This helped shape the interview guide. The guide had a total of ten domains categorized into specific sections within the assessment tool.

**Data collection tool for key informants**- Program managers, NGO workers and government officials and policy makers in the field of disability was developed similarly.

**In-depth Interviews and Focus Group Discussions:** To gain in-depth insights related to the answers provided in the quantitative survey, all the different types of participants: Program managers, Administrators, Policy Makers and Government officials were either interviewed in-depth or were involved in a participatory Focus Group Discussion (FGD) through zoom calls. Separate topic guides were developed specifically for each type of participants and each group of participants for the FGDs. An experienced Qualitative researcher conducted the in-depth interviews and FGDs. The topic guides/ tools used for qualitative data collection are provided as Annexure **-3 &4.** 

#### Sampling for qualitative study component:

Participants were purposively identified for the purpose of the qualitative interviews and FGDs. CBM, Humanity & Inclusion (HI) and their partners helped with participant selection, and a snowballing approach was used for data collection.

**Data collection:** The qualitative In-depth interviews and FGDs were carried out telephonically and using Zoom calls/ Go-To events platform respectively. An experienced qualitative researcher collected the data using specific topic guides and discussion guides for specific set of participants. Verbal consent was initially obtained to provide information and with each participant accepting to participate in the study a written informed consent was obtained from the participant with support from CBM partners in each of the states for the qualitative interviews and FGDs. The interviews and FGDs were audio-recorded with consent from participants.

**Data Analysis:** The Qualitative data was analysed using the Framework approach. The dataaudio was first transcribed verbatim into local language and then translated into English after familiarization with the audio recording. Codes were then identified after reading first few transcripts and then those codes were used as a template for other transcripts and new codes if any were also identified. Codes were grouped into categories or themes. An in-depth analysis was carried out for each of the themes and subthemes that emerged from the transcripts.

**Ethics approval**: This study was approved by the Institute Ethics Committee of the Indian Institute of Public Health Hyderabad.

#### **Results**

#### Phase 1

The results are presented in two parts: During lockdown (lockdown: phase 1) and after easing of the lockdown (post-lockdown: phase 2), with quantitative and qualitative results being presented separately for each phase.

#### Part -1: Quantitative Results of Lockdown (Phase 1)

The main results for quantitative analysis are presented under the following sections: characteristics of the study population, use of assistive devices followed by results on 6 key domains including medical care, rehabilitation, mental health, education, livelihood, and social empowerment.

#### **Characteristics of the study population**

A total of 403 participants were surveyed in the study. About half (50%) of the persons with impairments were aged between 19 to 37 years and majority were males (60.3%). In terms of type of impairments, 51.6% had physical impairments, 16.1% had visual impairments, 10.9% had intellectual impairments and 9.2% had speech and hearing impairment. The distribution of respondents who were married (n=141, 48.6%) and never-married (n=143, 49.3%) were similar, with 89.4% (n=126) having children. Only 12.3% had formal employment. The average disability pension received per month was INR 700 (US\$ 9.4). **Table 2** provides the characteristics of the study population.

Variables	Categories	N(%)
Age (years)		28(19,36.5)*
Sex	Male	243(60.3%)
SEX	Female	160(39.7%)
	Physical Impairment	208(51.6%)
	Visual Impairment	65(16.1%)
	Intellectual Impairment	44(10.9%)
Type of Impairment	Speech and Hearing Impairment	37(9.2%)
	Multiple Impairment	37(9.2%)
	Developmental Impairment	7(1.7%)
	Mental Impairment	5(1.2%)
	Self employed	121(30.5%)
	Student/volunteer	94(23.7%)
Occupation(n=397)	Stays at home/Unemployed	82(20.7%)
	Daily wage labour	51(12.8%)
	Formal employed	49(12.3%)
Marital status	Never married	143(49.3%)

 Table 2. Characteristics of the study population

	Married	141(48.6%)
	Divorced	3(1%)
	Widowed	3(1%)
Number with children		
(n=141)		126(89.4%)
Median Impairment		
pension received per		700(500, 1000) <sup>a</sup>
month (rupees)		
<sup>a</sup> Median (Interquartile rang	<i>(e)</i>	

#### Distribution of type of Impairment with age

The median age of those with visual and physical Impairment were 31.5 and 31 years respectively. Likewise, the median age of those with mental and intellectual Impairment were 26 and 20.5 years, respectively. Participants with development Impairment had median age of 19 years (**Table 3**).

Type of Impairment	Median Age (Q1, Q3)
Visual	31.5(22,42)
Physical	31(22,39)
Mental	26(14,31)
Multiple	22(17,29)
Intellectual	20.5(15,28)
Speech and Hearing	20(12,30)
Developmental	19(18,35)
Q1: first quartile, Q3: Third Quartile	

Table 3. Age and type of Impairment

#### **Distribution of participants across states**

30% of the persons surveyed were from central part of India followed by eastern (20.8%) and western region (17.4%). Out of the total 403 participants, 17.3% were from Maharashtra followed by other states, less than 5% were from Meghalaya, Assam, Bihar, AP, Tamil Nadu, Telangana, and Delhi. **Table 4** provides distribution of persons across states. District wise distribution has been provided in <u>Annexure-5</u>.

Table 4. Distribution of respondents across region and states

Regions	N(%)	States	N(%)
		Chhattisgarh	35(28.9%)
Central	121(30%)	Madhya Pradesh	36(29.8%)
		Uttar Pradesh	50(41.3%)
East	94(20,90/)	Bihar	16(19%)
East	84(20.8%)	Jharkhand	23(27.4%)

		Odisha	45(53.6%)
North	59(14.6%)	Delhi	6(10.2%)
norui		Uttarakhand	53(89.8%)
North East	37(9.2%)	Assam	18(48.6%)
norui East		Meghalaya	19(51.4%)
		Andhra Pradesh	15(46.9%)
South	32(7.9%)	Tamil Nadu	9(28.1%)
		Telangana	8(25%)
West	70(17.4%)	Maharashtra	70(100%)

#### **Assistive devices**

About 35% of the respondents used assistive devices, of which the use of mobility devices was the most common (61.2%). Majority (74.6%) sanitized their assistive device, most of them at least thrice a day (87.6%). Water & soap, sanitizer, only water and cotton/ cloth were commonly used to sanitize the assistive devices. **Table 5** provides details on usage and sanitization of assistive devices by the respondents.

Items	Categories	N(%)	
Use of any assistive device	Yes	140(35%)	
(n=400)	No	260(65%)	
	Devices for Hearing		
	Impairments	17(12.5%)	
Type of assistive device using	Devices for Visual		
Type of assistive device using currently (n=136)	Impairments	28(20.6%)	
	Mobility Devices	86(63.2%)	
	Hand Prosthesis	1(0.7%)	
	Multiple devices	4(2.9%)	
Sanitizing the assistive device	Yes	100(74.6%)	
(n=134) (6 participants have not responded)	No	34(25.4%)	
Number of times sanitizing the	$\leq$ 3 times	86(87.8%)	
assistive device in a day (n=98) (1 participant did not respond)	> 3 times	12(12.2%)	
	Only water	20(20.2%)	
	Soap and Water	39(39.4%)	
Method used to sanitize the	Sanitizer	22(22.2%)	
assistive device (n=98)	Cotton/ Cloth	16(16.2%)	
	Any other Liquids/ Disinfectants	2(2%)	

Table 5. Usage and sanitization of assistive devices

#### Sanitization of assistive devices across different disabilities

Majority of persons who reported sanitizing their assistive devices had physical impairment (59%) followed by visual impairment (19%). Majority with physical impairment used soap and water followed by only water, whereas persons with visual impairment mainly used sanitizers to disinfect the assistive device.

Items	Categories	Developm ental	Intellectual	Mental	Multiple	Physical	Speech and Hearing	Visual
Sanitizing the assistive device (n=134)	Yes (n=100)	1(1%)	2(2%)	0(0%)	8(8%)	59(59%)	11(11%)	19(19%)
	No (n=34)	1(2.9%)	1(2.94%)	0(0%)	2(5.9%)	14(41.2%)	4(11.8%)	12(35.3%)
Number of times sanitizing the assistive	≤ 3 times (n=86)	1(1.2%)	2(2.3%)	0(0%)	8(9.3%)	48(55.8%)	11(12.8%)	16(18.6%)
device in a day (n=98)	> 3 times (n=12)	0(0%)	0(0%)	0(0%)	0(0%)	9(75.0%)	0(0%)	3(25.0%)
Method used to sanitize the assistive device (n=101)	Soap and water (n=39)	1(2.6%)	1(2.6%)	(0.0%)	3(7.7%)	30(76.9%)	1(2.6%)	3(7.7%)
	Sanitizer (n=22)	0(0%)	1(4.5%)	(0.0%)	1(4.5%)	12(54.5%)	1(4.5%)	7(31.8%)
	Only Water (n=21)	0(0%)	0(0%)	(0.0%)	1(4.8%)	14(66.7%)	2(9.5%)	4(19.0%)
	Cotton or Cloth (n=16)	0(0%)	0(0%)	0(0%)	2(12.5%)	3(18.8%)	7(43.8%)	4(25.0%)
	Any other Liquids/ Disinfectant (n=2)	0(0%)	0(0%)	0(0%)	1(50.0%)	0(0%)	0(0%)	1(50.0%)

**Table 6.** Sanitization of assistive devices across different impairments

#### **Medical Care & Treatment**

Majority of the persons with disabilities did not report of any pre-existing medical conditions (87.3%). However, 42.5% reported that lockdown has made it difficult to get routine medical treatment. Likewise, 53.5% said that continuous lockdown might affect their health in future (**Table 7**). Out of 170 who had difficulty in accessing routine medical treatment, more than half of them (59.4%) had physical impairment, followed by visual impairment (16.5%), indicating that, persons with physical impairment were most affected in accessing the routine medical treatment.

Table 7. Impact of lockdown on medical care & treatment

Items	Categories	N(%)
Persons with medical conditions	Yes	51(12.7%)
(n=403)	No	352(87.3%)
Lockdown has made it difficult to get routine	Yes	170(42.5%)
medical treatment	No	230(57.5%)
(n=400)	110	230(37.370)
Continuous lockdown will affect the health in	Yes	215(53.5%)
future (n=402)	No	187(46.5%)

#### Impact of lockdown on Persons with disability with pre-existing medical conditions

12.7% (n=51) who reported pre-existing medical conditions, 58% reported difficulty in getting routine medical treatment, 22% reported that they had difficulty getting their medicines due to lockdown and nearly 70% thought that continuous lockdown will affect their health in future (**Table 8**). Almost 28% reported that they had postponed regular medical appointments because of lockdown as indicated in Table-8.

**Table 8.** Impact of lockdown on medical care & treatment among Persons with disability

 with pre-existing medical conditions

Itoma	Catagonias	<b>Medical Condition</b>		
Items	Categories	<b>Yes</b> (n=51)		
Lockdown has made it difficult to get routine	Yes	29(58%)		
medical treatment (n=50)	No	21(42%)		
Continuous lockdown will affect the health in	Yes	35(68.6%)		
future (n=51)	No	16(31.4%)		
Are you able to get the medicines you	No	9(22%)		
regularly take? (n=41)	Yes	32(78%)		
Has lockdown affected your health insurance	Yes	1(10.0%)		
scheme? (n=10)	No	9(90.0%)		
Are you getting the same kind of care now,	Yes	32(66.7%)		
like before? (n=48)	No	16(33.3%)		
Have you postponed regular medical	Yes	14(27.5%)		
appointments because of lockdown? (n=51)	No	37(72.5%)		
Have you postponed getting medical help	Yes	11(21.6%)		
because of lockdown (n=51)	No	40(78.4%)		

#### Access to out-patient services

About 35% (n=142) reported the need of out-patient services at hospitals/clinics during lockdown (**Table-9**). Of the participants in need of the services, more than half (55.6%) had difficulty in accessing the services. There were significant differences across occupations in terms of access, unemployed persons had greater difficulty compared to students or employed

Persons with disability. There was no significant difference across age groups or gender (Table-9).

Parameter	Number reporting need of the service	Number reporting difficulty in access (%)	Number reporting no difficulty in access (%)	χ2 P value
Access to out-patient services	142	79(55.6%)	63(44.4%)	-
Gender				
Females	61	38(62.3%)	23(37.7%)	$\chi^2 = 2.0$
Males	81	41(50.6%)	40(49.4%)	p value=0.17
Age Group				
≤40 years	124	69(55.6%)	55(44.4%)	$\chi^2 = 0.001$
>40 years	18	10(55.6%)	8(44.4%)	p value=0.99
<b>Occupational Category</b>				
Unemployed	22	17(77.3%)	5(22.7%)	$-v^2 - 0.1$
Student	26	18(69.2%)	8(30.8%)	$-\chi^2 = 9.1$ - p value= <b>0.01</b> *
Employed	92	43(46.7%)	49(53.3%)	p value_ <b>0.01</b>
Type of Impairment				
Mental	1	1(100.0%)	0(0.0%)	
Developmental	3	3(100.0%)	0(0.0%)	
Multiple	13	9(69.2%)	4(30.8%)	
Visual	21	12(57.1%)	9(42.9%)	-
Speech and Hearing	11	6(54.5%)	5(45.5%)	
Physical	76	41(53.9%)	35(46.1%)	
Intellectual	17	7(41.2%)	10(58.8%)	

 Table 9. Impact of lockdown on access to out-patient services

## Access to Emergency Medical Services

16.6% (n=67) reported the need of emergency medical services during lockdown (**Table-10**). Of the people who needed the emergency services, nearly 45% had difficulty in accessing the services required. There was no significant difference across age groups, gender or occupations (Table-10).

 Table 10. Impact of lockdown on access to emergency medical services

Parameter	Number reporting need	Number reported difficulty in accessing (%)	Number reported no difficulty in accessing (%)	χ2 P value
Access to emergency medical services	67	30(44.8%)	37(55.2%)	
Gender				
Males	33	14(42.4%)	19(57.6%)	$\chi 2 = 0.15$
Females	34	16(47.1%)	18(52.9%)	p value=0.70

Age Group				
$\leq 40$ years	60	29(48.3%)	31(51.7%)	$\chi^2 = 2.94$
>40 years	7	1(14.3%)	6(85.7%)	p value=0.08
<b>Occupational Category</b>				
Student	11	5(45.5%)	6(54.5%)	
Employed	48	21(43.8%)	27(56.2%)	$-\chi^2 = 0.01$ - p value=0.99
Unemployed	7	3(42.9%)	4(57.1%)	- p value=0.99
Type of Impairment				
Developmental	1	1(100.0%)	0(0.0%)	
Intellectual	12	8(66.7%)	4(33.3%)	-
Speech and Hearing	5	3(60.0%)	2(40.0%)	-
Physical	33	14(42.4%)	19(57.6%)	
Multiple	5	2(40.0%)	3(60.0%)	_
Visual	11	2(18.2%)	9(81.8%)	_
Mental	0	0(0.0%)	0(0.0%)	

## Access to Medicines

35.7% (n=144) reported the need of accessing medicines during lockdown (**Table-11**). Of the people who were in need, about 46% had difficulty in getting the medicines. There was no significant difference across age groups or gender or occupations (Table-11).

Parameter	Number reporting need	Number reported difficulty in accessing (%)	Number reported no difficulty in accessing (%)	χ2 P value
Access to Medicines	144	67(46.5%)	77(53.5%)	
Gender				
Females	66	31(47.0%)	35(53.0%)	$\chi 2 = 0.009$
Males	78	36(46.2%)	42(53.8%)	p value=0.92
Age Group				
≤40 years	116	54(46.6%)	62(53.4%)	χ2 =0.02
>40 years	27	13(48.1%)	14(51.9%)	p value=0.88
Occupational Category				
Unemployed	17	10(58.8%)	7(41.2%)	
Employed	94	43(45.7%)	51(54.3%)	$-\chi^2 = 1.28$ - p value=0.58
Student	33	14(42.4%)	19(57.6%)	- p value=0.38
Type of Impairment				
Mental	2	2(100.0%)	0(0.0%)	
Multiple	1	1(100.0%)	0(0.0%)	-
Physical	14	8(57.1%)	6(42.9%)	-
Visual	15	7(46.7%)	8(53.3%)	
Intellectual	22	10(45.5%)	12(54.5%)	-
Speech and Hearing	69	30(43.5%)	39(56.5%)	-
Developmental	21	9(42.9%)	12(57.1%)	-

Table 11. Impact of lockdown on accessing medicines
About 12 participants reported the need for accessing regular blood pressure monitoring. Of those, 58% (n=7) reported difficulty in accessing it, with two-thirds of them being male (**Table 12**)

Parameter	Number reporting need	Number reported difficulty in accessing (%)	Number reported no difficulty in accessing (%)
Need for accessing regular	12	7(58.3%)	5(41.7%)
blood pressure monitoring		. (2002.77)	-()
Gender			
Males	9	6(66.7%)	3(33.3%)
Females	3	1(33.3%)	2(66.7%)
Age Group			
$\leq 40$ years	6	4(66.7%)	2(33.3%)
>40 years	6	3(50.0%)	3(50.0%)
<b>Occupational Category</b>			
Unemployed	1	1(100.0%)	0(0.0%)
Employed	8	5(62.5%)	3(37.5%)
Student	3	1(33.3%)	2(66.7%)
Type of Impairment			
Visual	1	1(100.0%)	0(0.0%)
Physical	1	1(100.0%)	0(0.0%)
Speech and	6	4(66.7%)	2(33.3%)
Intellectual	3	1(33.3%)	2(66.7%)
Mental	0	0(0.0%)	0(0.0%)
Developmental	1	0(0.0%)	1(100.0%)
Multiple	0	0(0.0%)	0(0.0%)

Table 12. Impact of lockdown on access to blood pressure monitoring

About 14 participates reported the need for accessing regular diabetes monitoring, a majority of them being male. About 35% had difficulty accessing it (n=5) (**Table 13**)

Parameter	Number reporting need	Number reported difficulty in accessing (%)	Number reported no difficulty in accessing (%)
Need for accessing regular diabetes monitoring	14	5(35.7%)	9(64.3%)
Gender			
Males	11	5(45.5%)	6(54.5%)
Females	3	0(0.0%)	3(100.0%)

 Table 13. Impact of lockdown on access to regular diabetes monitoring

Age Group			
≤40 years	10	2(20.0%)	8(80.0%)
>40 years	4	3(75.0%)	1(25.0%)
<b>Occupational Category</b>			
Employed	10	2(20.0%)	8(80.0%)
Student	4	3(75.0%)	1(25.0%)
Unemployed	0	0(0.0%)	0(0.0%)
Type of Impairment			
Intellectual	4	2(50.0%)	2(50.0%)
Developmental	3	1(33.3%)	2(66.7%)
Speech and Hearing	7	2(28.6%)	5(71.4%)
Visual	0	0(0.0%)	0(0.0%)
Multiple	0	0(0.0%)	0(0.0%)
Physical	0	0(0.0%)	0(0.0%)
Mental	0	0(0.0%)	0(0.0%)
Sample size too small to p	erform test		

About 21 participants reported a need for accessing surgical procedure and a majority of them were employed. Almost half of them (n=10) reported difficulty in accessing it. (**Table 14**)

Parameter	Number reporting need	Number reported difficulty in accessing (%)	Number reported no difficulty in accessing (%)
Need for accessing Surgical procedure	21	10(47.6%)	11(52.4%)
Gender			
Males	11	6(54.5%)	5(45.5%)
Females	10	4(40.0%)	6(60.0%)
Age Group			
≤40 years	18	8(44.4%)	10(55.6%)
>40 years	3	2(66.7%)	1(33.3%)
<b>Occupational Categor</b>	' <b>y</b>		
Employed	17	7(41.2%)	10(58.8%)
Unemployed	1	1(100.0%)	0(0.0%)
Student	3	2(66.7%)	1(33.3%)
<b>Type of Impairment</b>			
Mental	0	0(0.0%)	0(0.0%)
Developmental	1	0(0.0%)	1(100.0%)
Multiple	0	0(0.0%)	0(0.0%)
Visual	2	1(50.0%)	1(50.0%)
Speech and Hearing	15	8(53.3%)	7(46.7%)
Physical	1	0(0.0%)	1(100.0%)
Intellectual	2	1(50.0%)	1(50.0%)

 Table 14. Impact of lockdown on access to surgical procedures

#### Access to Rehabilitation services

About 17% (n=69) reported the need of rehabilitation services (**Table-15**). Of the people who were in need, majority (59.4%) had difficulty in accessing the required services. There was no significant difference across age groups or gender or occupations (Table-15).

Parameter	Number reporting need	Number reported difficulty in	Number reported no difficulty in	χ2 P value
Need for ecoseine		accessing (%)	accessing (%)	
Need for accessing Rehabilitation services	69	41(59.4%)	28(40.6%)	
Gender				
Males	41	22(53.7%)	19(46.3%)	$\chi^2 = 1.39$
Females	28	19(67.9%)	9(32.1%)	p value=0.24
Age Group		× /		*
$\leq 40$ years	63	38(60.3%)	25(39.7%)	χ2 =2E-04
>40 years	5	3(60.0%)	2(40.0%)	p value=0.99
<b>Occupational Category</b>				-
Employed	44	25(56.8%)	19(43.2%)	
Unemployed	12	7(58.3%)	5(41.7%)	$-\chi^2 = 0.64$ - p value=0.72
Student	13	9(69.2%)	4(30.8%)	- p value=0.72
Type of Impairment				
Mental	1	1(100.0%)	0(0.0%)	
Developmental	8	1(12.5%)	7(87.5%)	-
Multiple	0	0(0.0%)	0(0.0%)	-
Visual	12	8(66.7%)	4(33.3%)	
Speech and Hearing	40	26(65.0%)	14(35.0%)	-
Physical	4	3(75.0%)	1(25.0%)	-
Intellectual	4	2(50.0%)	2(50.0%)	-

Table 15. Impact of lockdown on rehabilitation services	Table 15.	Impact of	lockdown on	rehabilitation	services
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**Table-16** shows results on the impact of lockdown on rehabilitation services and therapy support services. About 82(20.3%) participants reported of receiving rehabilitation and therapy services during lockdown. Most of them received physiotherapy (69.5%) followed by speech therapy. Most (70.7%) Persons with disability opine that the government has not given any special considerations to Persons with disability during the lock down, especially in terms of access to vital information, rehabilitation /therapy support services.

Which of the following therapies do you receive?	Physio Speech Others	57(69.5%) 13(15.9%) 6(7.3%)
(n=82)	More than one	7(7.3%)
Has the government given any special considerations to Persons with	Yes	118(29.3%)
disability during the lock down, especially in terms of access to vital information, rehab/therapy support services?	No	285(70.7%)

 Table 16 Impact of lockdown on rehabilitation services and therapy

### **Mental Health**

The psychological reactions to COVID-19 pandemic may vary from fear and anxiety, panic, feelings of hopelessness to depression. In addition, people may face problems in family relationships, discrimination, violence, etc., In the present study, the psychological impact of COVID-19 was measured and has been described in 3 sections: (a) Impact on Mental health & well-being of Persons with disability, (b) Access to Mental health services and (c) Psychological impact on caregivers

#### a) Impact on Mental health & well-being of Persons with disability

We asked participants what was bothering them the most during the lockdown. Fear of infection (69%) and loss of income (65.4%) was most commonly reported fear followed by, fear of infecting others (59.6%), fear of dying (50%), lack of support (45.5%), gender-based violence (5.7%), and interruption of care giver (8%). **Table 17-19** displays impact of lockdown on participants' mental health.

Items	Not at all	Moderately	A lot
Fear of Infection(n=403)	125(31%)	195(48.4%)	83(20.6%)
Fear of infecting others(n=403)	163(40.4%)	220(54.6%)	20(5%)
Fear of dying (n=402)	201(50%)	186(46.3%)	15(3.7%)
Lack of support (n=403)	220(54.6%)	161(40%)	22(5.5%)
Gender based violence (n=401)	378(94.3%)	15(3.7%)	8(2%)
Loss of income (n=401)	139(34.7%)	142(35.4%)	120(29.9%)

Table 17. Impact of lockdown on participants' mental health

We also measured the level of stress and anxiety among the participants. 81.6% participants experienced moderate to high level of stress. 71.1% experienced moderate to high levels of

anxiety, 74.4% felt overwhelmed with the situation and 72.4% had feelings of uncertainty about future.

Items	Not at all	Moderately	A lot
Stressed	74(18.4%)	235(58.5%)	93(23.1%)
Overwhelmed	103(25.8%)	259(64.8%)	38(9.5%)
Anxious	116(28.9%)	236(58.9%)	49(12.2%)
Uncertain	111(27.7%)	227(56.6%)	63(15.7%)

**Table 18.** Level of stress & anxiety since the COVID-19 outbreak

#### Weighted mean score

The weighted average score was obtained for each 3-point Likert scale item related to mental health. The Likert scale was weighted as not at all =1, moderately=2 and a lot=3. The weighted mean score was defined as  $\frac{\sum_{i=1}^{3} (Number \ of \ response \times weight)}{Total \ number \ of \ responses}$ .

Overall, loss of income and feeling stressed was most highly rated (rank-1) with a weighted mean score of 2. This was followed by uncertainty about future and fear of infection of the virus (**Table 19**).

Items	Not at all (1)	Moderately (2)	A lot (3)	Number of responses	Weighted mean	Rank
Loss of income	139	142	120	401	2.0	1
Stressed	74	235	94	403	2.0	1
Fear of Infection	125	195	83	403	1.9	2
Uncertain	111	227	64	402	1.9	2
Overwhelmed	103	259	40	402	1.8	3
Anxious	116	236	50	402	1.8	3
Fear of infecting others	163	220	20	403	1.6	4
Fear of dying	201	186	15	402	1.5	5
Lack of support	220	161	22	403	1.5	5
Gender based violence	378	15	8	401	1.1	6
Interruption of care giver	325	22	6	353	1.1	6

Table 19. Weighted average score of the items related to mental health

**Table- 20 & 21** indicates the association of demographic factors with mental health components. There was significant difference across age groups ( $\leq$ 40 years' vs >40 years) and occupation (employed vs unemployed vs student) in relation to fear of infection, fear of infecting others, feelings of stress, overwhelmed and uncertainty about future. We found no significant gender difference across different mental health questions.

Demographic Fear of factors Infectio	Fear of Infection	Fear of infecting others	Fear of dying	Lack of support	Gender based violence	Loss of income	Interruption of car	Stressed	Over- whelmed		Anxious Uncertain
Gender	0.89	0.57	0.76	0.19	0.08	0.15	0.16	0.55	0.29	0.20	0.12
Age Group <sup>F</sup>	$0.04^{*}$	$0.04^{*}$	0.34	0.73	0.09	0.10	0.53	$0.02^{*}$	$0.01^{*}$	0.27	$0.02^{*}$
Occupational Category <sup>F</sup>	$< 0.001^{*}$	$<0.001^{*}$	$0.001^{*}$	$< 0.001^{*}$	0.80	$< 0.001^{*}$ 0.20	0.20	<0.001*	<0.001* 0.14	0.14	$<0.001^{*}$
Type of Impairment <sup>F</sup>	0.06	$0.01^{*}$	0.18 0.05	0.05	0.41	<0.001* 0.58	0.58	0.21	0.35	0.71	0.24
Chi-square test	of association	ı p values are r	eported; F	:Fishers exa	uct test; *statu	istically sign	Di-square test of association p values are reported; F.Fishers exact test; *statistically significant at 5% level of significance	vel of signific	ance		

Table 20. Association of demographic factors with fear, stress, and anxiety

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	lable 21. A	ssociation o	I able 21. Association of demographic factors with participant's mental health	actors with ]	participan	t's mental he	alth
Demographic factors	Problems in relationship	Change in family dynamic s	Abandonment Isolation Stigma Violence	Isolation	Stigma	Violence	Discrimination
Gender <sup>F</sup>	0.54	$0.004^{*}$	0.36	0.24	0.12	0.99	0.11
Age Group <sup>F</sup>	0.72	0.83	0.72	0.65	0.69	0.36	$0.04^{*}$
Occupational Category <sup>F</sup>	0.61	$0.02^{*}$	0.10	0.007*	$0.001^{*}$ 0.44	0.44	0.77
Type of Impairment <sup>F</sup>	0.97	0.09	0.32	0.33	0.13	0.99	$0.02^{*}$
F: Fi *stat	F: Fishers exact test p values are reported *statistically significant at 5% level of sign	p values are i int at 5% leve	F: Fishers exact test p values are reported *statistically significant at 5% level of significance				

**Table -22** depicts psychosocial problems faced by Persons with disability since the covid-19 outbreak. 22.3% faced stigma and 13.2% experienced discrimination, 13.4% had changes in family dynamics, problems in relationships (5%), isolation (4.7%), abandonment (3%) and violence (1.7%).

Items	Yes N(%)	No N(%)
Problems in relationship(n=402)	20(5%)	382(94.8%)
Change in family dynamics(n=400)	54(13.5%)	346(86.5%)
Abandonment	12(3%)	389(96.8%)
Isolation	19(4.7%)	383(95.3%)
Stigma	90(22.4%)	312(77.6%)
Violence	7(1.7%)	395(98.3%)
Discrimination	53(13.2%)	349(86.8%)

 Table 22. Psychosocial problems faced by Persons with disability since the COVID-19

 outbreak

### b) Access to Mental health services and emotional support

Majority (65.5%) did not need the access to information related to mental health & care, psychological or emotional support and services. Among the ones who needed, only 25.9% had access to any kind of mental health services. Among 103 who did not have access, 61.2% were males, 91.3% were less than 40 years old and majority (52.4%) had physical impairment. Only 20% were able to get regular mental health counselling or therapy related services during the COVID-19 lockdown. Among 44 persons who did not get regular mental health services, 65.9% were males, 95.5% were less than 40 years, and 47.7% had physical impairment.11.4% faced problems getting their regular psychiatric medicines. Most participants reported that they are getting emotional and practical support from family (94.9%),1.8% from friends and 2.5% from multiple sources **Table 23** provides details on the access mental health services and emotional support.

Table 23 Access to mental health services and emotional support

Items	Categories	F (%) N=403
Do you have access to information	Number reporting need	139(34.5%)
related to mental health & care,		36(25.9%)
psychological or emotional support and	access	30(23.770)
services? Ex: Mental health helpline, online counselling, stress management tips etc.) (n=139)	Number reported did not have access	103(74.1%)
Have you been able to get regular mental	Number reporting need	55 (13.6%)
health counselling or therapy related	Number reported accessed	11(20%)

services during the COVID-19 outbreak? (n=110)	Number reported did not access	44 (80%)
Did you face only machine for cotting	Number reporting need	35(8.7%)
Did you face any problem for getting your regular psychiatric medicine if	Number reported faced problem	4(11.4%)
prescription date was old and you cannot get recent prescription?	Number reported did not face problem	31(88.6%)
	Number reporting need	395(98%)
	Only family	375(93.1%)
From whom are you getting emotional or	Only friends	7(1.7%)
practical support from family and friends during COVID-19 outbreak?	Family, friends, and colleagues	10(2.5%)
	Family and ASHA	2(0.5%)
	Others	1(0.2%)

### c) Psychosocial impact on caregivers

**Table 24** displays the results related to mental health of caregivers. As a caregiver/parent, 49.5% were getting enough professional support like earlier during the lockdown. 55. 7% felt moderately stressed caring for children or other family members at home with Impairment, 21.9% reported higher level of stress in taking care of persons with disabilities 58.2% felt unhappy that the therapy for their child had to be stopped during lockdown.

Table 24 Mental Health Impact of COVID-19 on caregivers

Items	Categories	N(%)
As a caregiver/parent, are you getting	Yes	45(49.5%)
enough professional support like earlier during this covid19 outbreak? (n=91)	No	46(50.5%)
As a caregiver, are you feeling stressed,	Not at all	51(22.4%)
anxious, or depressed with caring for	Moderately	127(55.7%)
children or other family members at home with Impairment? (n=228)	A lot	50(21.9%)
As a parent or caregiver, did you feel	Not at all	56(41.8%)
unhappy when the therapy for your child	Moderately	63(47.0%)
had to be stopped during lockdown? (n=134)	A lot	15(11.2%)

#### **Activities for Daily Living**

During the lockdown, the family was a pillar of support and assistance especially for daily activities. Out of the total 403, 329(81.6%) needed assistance in daily activities, most of them supported by their family members (95.1%). More than half (55.8%) perceived that

they will be capable of managing themselves in case of another lockdown. **Table 25** indicates the impact of lockdown on daily activities.

Items	Categories	F (%) (N=403)
The number of people reporting that they were helped in daily activities		329 (81.6%)
· · · ·	ASHA	7(2.1%)
Who helped you in your daily	Paid caregiver	2(0.6%)
Who helped you in your daily $activities (n-220)$	Volunteer	4(1.2%)
activities (n=329)	Family	313(95.1%)
	Others	3(0.9%)
Do you think that you will be capable	Yes	225(55.8%)
of managing yourself in case of	No	99(24.6%)
another lockdown?	Not sure	74(18.4%)

Table 25. Impact of lockdown on Activities of daily living

## Livelihood

Majority (84.2%, N=320) of the participants mentioned that lockdown impacted their daily activities pertaining to livelihood. 57.1%. respondents reported that the supply chain of material that they had developed was affected due to lockdown. 60.3% of participants reported that the supply of farm inputs like seeds, fertilizer, and pesticides were impacted. 51.1% of participants had no difficulty in getting the required updates for their business (such as price, suppliers' information). 76.2% of participants reported that lack of transportation affected the movement of input and output supply due to lockdown. (**Table 26**).

 Table 26. Impact of lockdown on livelihood (supply chain, farm inputs, transportation,

 undeteel

updates)		
Items	Yes N(%)	No N(%)
Has the lockdown impacted your daily activities pertain to livelihood? $(n=380)$	320(84.2%)	60(15.8%)
Supply chain of material that you have developed $(n=70)$	40(57.1%)	30(42.9%)
supply of farm inputs like seeds, fertilizer, and Pesticides? $(n=58)$	35(60.3%)	23(39.7%)
transportation of input and output supply due to lack of transportation? $(n=101)$	77(76.2%)	24(23.8%)
facility of water supply $(n=102)$	35(34.3%)	67(65.7%)
Are you getting updates that you require for your business ( such as price, suppliers)	46(48.9%)	48(51.1%)

( <i>n</i> =94)			
Are you able to sell your produce/products? $(n=93)$	48(51.6%)	45(48.4%)	

The lockdown affected the pensions / remittance among 33.1%. Around 45.7% were borrowing money because of lockdown, mainly for livelihood (65.2%). The main method by which they were coping with the financial crisis situation was through borrowing food/ money from relatives/ friends/ neighbours. Only 9.2% of participants thought they will accept any job for low pay because of poor income after lockdown ends. Only 18.2% thought loan/funds were available with inclusive cooperatives (**Table 27**)

Items	Categories	N(%)
Has the lockdown affected the Pensions /	Yes	94(33.1%)
Remittance? $(n=284)$	No	190(66.9%)
Are you getting your full wages / pay during	Yes	58(33.7%)
lockdown situation? $(n=172)$	No	114(66.3%)
Are you borrowing money because of	Yes	181(45.7%)
lockdown? $(n=396)$	No	215(54.3%)
	Children studies	6(3.3%)
	Farming	7(3.9%)
	Ladies group	2(1.1%)
For what? $(n=181)$	Livelihood	118(65.2%)
	Medicines	17(9.4%)
	Business	31(17.1%)
Do you think you will accept any job for low	Yes	8(9.2%)
pay because of poor income after lockdown ends? $(n=87)$	No	79(90.8%)
Are loan/funds available with inclusive	Yes	4(18.2%)
Cooperatives? $(n=22)$	No	18(81.8%)
	reducing size/ no. of meals eaten/	8(5.1%)
	changing diet to cheaper/ less- preferred foods	11(7.0%)
How are you (person with Impairment) coping	selling off some household possessions and/or livestock	5(3.2%)
with the financial crisis situation? $(n=157)$	borrowing food/ money from relatives/ friends/ neighbors	133(84.7%)

Table 27. Impact of lockdown on livelihood (pensions, wages, loans)

## Education

73.3% of the respondents (parents only) felt that on being confined to home the children felt distressed. 70.5% said that schools being shut down, has affected the child learning. 65.9% of the schools are not providing online teaching to children. Among the ones who received online teaching only 9.3% said that the teaching was not in accessible formats (**Table 28**). Among four who reported that the online teaching was not in accessible format, two had speech and hearing impairment, one each had development and physical impairment.

 Table 28. Impact of lockdown on Education

Items	Yes N(%)	No N(%)
On being confined to the home, did the children feel distressed? $(n=165)$	121(73.3%)	44(26.7%)
Since all schools are closed, has it affected the child learning? $(n=132)$	93(70.5%)	39(29.5%)
Is the school providing online teaching to children? $(n=126)$	43(34.1%)	83(65.9%)
If yes, is it in accessible formats? $(n=43)$ Missing data=1	38(88.4%)	4(9.3%)

## Social participation and empowerment

Lockdown seems to have impacted participation in social empowerment activities: 54.2% said it impacted work as PRI members, 52.9% agreed that it impacted village relief work and 74.6% said it impacted working as a DPO member (**Table 29**).

Items	Categories	N(%)
Has lockdown affected your participation in	the following	
a) Panchayat Raj Institution (PRIs) as	Yes	103(54.2%)
Members? (n=190)	No	87(45.8%)
	Yes	117(52.9%)
b) Village relief work? (n=221)	No	104(47.1%)
	Cannot Answer	180(44.8%)
c) Social mobilization with other	Yes	129(59.4%)
community members for community issues? (n=217)	No	88(40.6%)
d) Participation in village level	Yes	117(54.4%)
COVID response and planning? (n=215)	No	98(45.6%)
e) Disabled people organization (DPO)	Yes	197(74.6%)

Table 29. Impact of lockdown on participants' social empowerment

meetings (n=264)	No	67(25.4%)
f) Do you feel that after lockdown,	Yes	199(74.0%)
working with community and PRIs will change? (n=269)	No	70(26.0%)

#### Impact of lockdown among Persons with disability in different areas of health

The lockdown had impact more than 80% of the persons with impairment in terms of medical (81.4%), rehabilitation (88.6%), mental health (86.4%), education and livelihood (86.1%). However only 52.3% of the persons were impacted in the areas of Social empowerment (**Table 30**).

Table 30 Distribution of percentage of impact of lockdown among Persons with disability in

	IMPACT	
Domains	Yes	No
	N(%)	N(%)
Medical <sup>a</sup>	328(81.4%)	75(18.6%)
Rehabilitation <sup>b</sup>	357(88.6%)	46(11.4%)
Mental health <sup>c</sup>	348(86.4%)	55(13.6%)
Education and Livelihood <sup>d</sup>	347(86.1%)	56(13.9%)
Social Empowerment <sup>e</sup>	193(52.3%)	176(47.7%)
a:answered 'yes' to any 3 out of 14 question		

each domain

b: answered 'yes' to any one out of 4 questions

c: answered 'yes' to any 4 out of 24 questions

d: answered 'yes' to any 3 out of 15 questions

e: answered 'yes' to any 2 out of 6 questions

## Association of demographic factors with impact of lockdown

Age in years (below 40/above 40), sex (male/female), type of impairment (developmental, intellectual/mental/physical/speech and hearing/visual), occupation (employed/unemployed /student), marital status (married/never married), having children (yes/no) and receiving pension (yes/ no) were the factors considered for the analysis. There was a statistically significant association with 'type of impairment' with rehabilitation (p value=0.005) and 'impact on social empowerment' (p value=0.03). Lockdown had an impact on 91.9% of persons with visual impairment, similarly, among the ones who had speech and hearing impairment (92.3%). Likewise, among persons with multiple impairment, 62.9% were impacted because of lockdown.

There was a statistically significant association with type of occupation with impact on medical care & treatment (p value=0.003), mental health (p value=0.005) and social

empowerment (p value<0.001). Majority (86.4%) of the employed were impacted in terms of access to medical facilities followed by those who were unemployed (79.8%) and students (70.2%). Among persons having children, 86.8% reported to have been affected mentally compared to 73.8% who did not have children. The impact in terms of social empowerment, rehabilitation, mental health, education and livelihood was more. **Table 31** provides the association of factors with impact of lockdown.

			Table	Table 31: Factors associated with impact of lockdown IMPACT	ciated wi	th impact of lock IMPACT	DCKdown				
Variables	Categories	Medical	P value	Rehabilitation	P value	<b>Mental</b> health	P Value	Education and Livelihood	P Value	Social Empowerment	P value
		Yes		Yes		Yes		Yes		Yes	
A de (vearc)	<40	323(81.8%)	0 31 <sup>F</sup>	351(88.9%)	0.14	342(86.6%)	0 19 <sup>F</sup>	341(86.3%)	0 20 F	190(52.5%)	0.68 F
(cm)() ver	≥40	4(66.7%)	10.0	4(66.7%)	<u>تر</u>	4(66.7%)	(1.0	4(66.7%)	07.0	2(40.0%)	0000
   C	Male	203(83.5%)		214(88.1%)	Ţ,	207(85.2%)		214(88.1%)		111(50.0%)	
Sex	Female	125(78.1%)	0.17	143(89.4%)	0.0/	141(88.1%)	0.40	133(83.1%)	0.10	82(55.8%)	0.28
	Developmental	7(100.0%)		4(57.1%)		5(71.4%)		6(85.7%)		2(33.3%)	
	Intellectual	28(63.6%)		32(72.7%)	1	35(79.5%)		33(75.0%)		22(62.9%)	
	Mental	4(80.0%)		4(80.0%)		5(100.0%)	,	5(100.0%)		0(0.0%)	
Type of	Multiple	176(84.6%)	0.05 F	189(90.9%)	0.005	180(86.5%)	OLAF	180(86.5%)	O JA F	110(56.1%)	0 02 F
impairment	Physical	31(83.8%)		34(91.9%)	۲.	33(89.2%)	0.0 †0.0	34(91.9%)	0.74	13(38.2%)	- <b>CU.U</b>
	Speech and Hearing	54(83.1%)		60(92.3%)		57(87.7%)		59(90.8%)		26(42.6%)	
	Visual	28(75.7%)		34(91.9%)		33(89.2%)		30(81.1%)		20(60.6%)	
	Employed	191(86.4%)		203(91.9%)		202(91.4%)		188(85.1%)		131(60.9%)	
Occupation	Unemployed	67(79.8%)	$0.003^{\rm F}$	0.003 <sup>F</sup> 72(85.7%)	0.05	67(79.8%)	0.005	72(85.7%)	0.75	33(44.6%)	<0.001
	Student	66(70.2%)		78(83.0%)		76(80.9%)		83(88.3%)		27(35.5%)	
Marital	Married	122(85.9%)	000	131(92.3%)	000	125(88.0%)	15	126(88.7%)	30.0	65(47.8%)	10.0
status	Never married	204(78.8%)	- 0.08	226(86.6%)	- 0.08	223(85.4%)	0.40	221(84.7%)	C7.0	125(54.3%)	17.0
Having	Yes	114(83.8%)	200.0	123(90.4%)	0.001	118(86.8%)	0.001	119(87.5%)	0 72	58(45.7%)	0.51
children	No	85(69.7%)	/ 0.0.0	91(74.6%)	T00.0 -	90(73.8%)		105(86.1%)	c/.n	40(41.2%)	10.0
Receiving	No	214(83.9%)	000	231(90.6%)	0.03	228(89.4%)	0 60	223(87.5%)		139(56.7%)	2000
pension	Yes	43(93.5%)	60.0	46(100.0%)	Ł	43(93.5%)	0.00	35(76.1%)	1.01	36(78.3%)	0.00.0
F: Fishers exact test		, - -				,					

Table 31: Factors associated with impact of lockdown

Note: Chi square test was performed. Frequency with row percentage is reported

#### Part -2: Qualitative Results - Lockdown Phase

In-depth interview (IDIs) and focus group discussions (FGDs) recordings were transcribed, and transcripts were analysed. The analysis approach was deductive, the thematic analysis was conducted according to ten pre-set coding categories/themes (difficulties in daily life, access, services, participation, communication, compassion, networks, finances, government response and positive impact). **Table-32** depicts the profile of the respondents.

	1	1	1	
		IDIs	FGDs*	Total
Number	of IDIs & FGDs	11	4	15
Total Nu	umber of participants	11	16	27
Sex	Male	9	13	22
	Female	2	3	5
1 70	20-40 years	3	8	11
Age	41-60 years	8	8	16
	Government Official	3	2	5
	Program Managers/ Advisor/NGO-	5	8	13
Sector	In charge			
	Persons with disabilities	3	_	3
	Carers	-	6	6

Table 32. Profile of In-depth Interviewees and Focus Group Discussion Respondents

\*Total 4 FGDs, 2 FGDs during lockdown period and 2FGDs after lockdown was eased.

The qualitative results are presented theme wise, mainly in the form of quotes from various participants and a brief summary has been provided for each of the themes.

**THEME-1: Difficulties in daily life and management** describes problems faced by Persons with disability during lockdown, it includes personal care needs and management, basic protection measures such as hand hygiene and the barriers they faced, psychological impact, discrimination, abandonment and fear of infection. Stakeholders described that COVID-19 itself has not caused much impact as much as the lockdown has on people's lives. With regard to basic protection measures, the findings indicated that it would take time for people to follow distancing and hand hygiene measures. Lockdown has negative psychological impact on Persons with disability and one of the most common reason is economic difficulty.

## THEME-1: DIFFICULTIES IN DAILY LIFE & MANAGEMENT

## **Personal Care Needs and Management**

- "For people with VI, they need support of handrails, people, they can get infected easily because of touching people and surfaces" (Program Manager, Female)
- "COVID itself hasn't caused much impact to them as much as the lockdown has" (ASHA, PRI Member & Caregiver, Female)
- "Persons with disability's biggest challenge is that they are in need of help!" (Program Lead, Male)
- "It is a gradual journey for such Persons with disability to become self-dependent. Their livelihood got affected very seriously due to lockdown. Due to this situation, they began losing hope and motivation which was gained after years of hard work". (NGO in-charge, Male)

## **Basic Protection Measures, Hand Hygiene Measures, Barriers faced**

 "People may want to help persons with VI, but now they are scared even to give a hand". (Program Manager, Female)

"I ask them to wash the hands but not everyone pays heed. Only few of them wash their hands for 20 seconds. When I ask them to wear the masks, they don't listen, saying that nothing happens to us, it's a disease in another country, when time comes everyone has to die!" (ASHA, PRI Member & Caregiver, Female)

- "These practices take a longer time, and we can't teach them about these things in 10 days" (Program Lead, Male)
- "When there was pollution, we were supposed to wear mask but now when the air is pure, we are using masks". (Govt Official, Male)
- "Our children are prone to infection and their immunity is less. We ensured that children are away from the elderly". (Caregiver, NGO In-charge, Male)

#### **Psychological impact**

- **4** "It has critical negative psychological impact on them" (Govt Official, Male)
- 4 "Misery has added more to the miserable" (ASHA, PRI Member& Caregiver,

*Female*)

- "People who came out of this stigma with lots of effort and motivation are suddenly demotivated again". (NGO in-charge, Male)
- "They are psychologically disturbed as stored ration gets consumed. If we have food security and cash for 1 year, we can maintain our mental health in these difficult conditions". (NGO in-charge, Male)

## **Discrimination/Violence**

- "Persons with disability are asked to stay at home, in one corner, within the four walls". (Program Manager, Female)
- When some persons with disabilities were going to the district headquarters to buy medicines, on the way they were stopped by the police and they were beaten up". (Program Officer, Male)
- "Parents are not able to make enough money, they get irritated, they fight among themselves and take their anger on disabled children". (Senior Advisor, NGO, Male)
- If in a house if I have a child with disability, I abuse that child, who will report? (Senior Advisor, NGO, Male)

#### Abandonment

*Many who are in institutional facilities, were abandoned and their parents do not want to take them. (Senior Advisor, NGO, Male)* 

## Fear of infection

- "We go to the market to buy vegetables and feed our kids, but we get to know through the information, that corona is spreading through vegetables as well as tomatoes". (ASHA, PRI Member & Caregiver, Female)
- 4 "And If I go to the vegetable vendor, I feel afraid if he has COVID-19? Because vegetables come through 10 places, we are unable to buy vegetables. So, these are difficulties faced relating to food". (ASHA, PRI Member& Caregiver, Female)
- "Hospitals for general health are a very dangerous place for Persons with disability, and they may get affected with COVID-19" (Govt Official, Male)

**THEME-2: ACCESS** and availability to basic necessities such as food & water, medicines, stores, disinfection of assistive products, TV/internet; Access to information, transport, and other alternative arrangements. Findings from interviews indicated that many faced difficulties in accessing basic necessities such as food mainly vegetables and pulses whereas rice was provided by the government. Access to medicines was difficult mainly due to travel restrictions in the region. Regarding access to information, most of the information was not available in an accessible format and the reasons for hand washing or maintaining distance were not clear through the informational messages.

## **THEME-2: ACCESS**

Basic Necessities: Availability and Access to Food & Water

- "I have not eaten food for 8 days, the persons with disabilities told me" (ASHA, PRI Member & Caregiver, Female)
- "My husband has been at home for the past 4months and we are managing somehow. We have a small shop; we earn Rs. 100-250 a day and that is being used for groceries and food. If someone is sick how can they borrow pulses, rice from someone and make their livelihood? Last time we got 25kgs of rice, 5 kg/person. But only rice would not suffice our needs" (ASHA, PRI Member& Caregiver, Female)
- Government system should understand that rice and wheat flour is not enough as there is no fuel to cook. Villages are managing with help of wood. With empty cylinders' people did not know where to go". (Program Officer, NGO, Male)

## **Basic Necessities: Availability and Access to Medicines**

- People did not get their tablets for mental health issues. We had to speak to vendors. Only those with contacts with suppliers got the medicines. (Program Manager, Female)
- \* "Those who are on medication for mental health or serious disorder were completely dependent on free medicines, which had dried up, they could not go to the district hospital". (Program Manager, Male)
- "Medicines still cost the same but now we also have to pay the police (with lathi stick!)" (Program Officer, NGO, Male)

Other necessities: Stores, disinfection of assistive products and environment, TV, internet.

- "Wheel chairs or callipers for children need to be designed properly so they are sanitized regularly". (Program Officer, NGO, Male)
- "Braille things which has to be touched. So how will you protect them? So, we have to think all these". (Program Officer, NGO, Male)

Information: Access to accurate information in accessible formats, Authenticity / Clarity, Format and Content of the Messages, Sensitivity to Culture and Context, Types of media used

- Information is not in accessible formats. Awareness is given, but reasons are not explained. Be at home is not enough. Why should people maintain distance, or be isolated?" (Program Manager, Female)
- "Information was only in Hindi or English or regional language, not in the local dialect, and especially difficult for rural people to follow". (Program Manager, Female)
- **4** *"In rural areas, people could not understand the seriousness of the infection. They*

were told not to go out, without proper explanation. Its unthinkable for rural people not to meet each other". (Program Manager, Female)

- Some NGOs started webinars on various aspects on COVID preparedness, which is useful for people who have access to smartphones". (Program Manager, Female)
- "We have developed videos about COVID-19 with subtitles and sign language".
   (Govt Official, Male)
- We translated COVID-19 messages in Odia and Santhali tribal language (handwritten) and distributed to 70 groups of persons with disabilities". (Program Officer, Male)

## Transport

- "Accessible transport is not available, and it is a huge issue. Persons with disability need an escort, and hospitals were not allowing them in. without the escort, some Persons with disability cannot manage at all". (Program Manager, Female)
- \* "The problem was how to reach the railway station and bus stands. So, we did not think about this that there will be Persons with disability who will need additional kinds of support". (Senior Advisor, NGO, Male)
- # "Bed ridden people need attenders/caregivers, during the lockdown no outside caregiver was allowed. We have asked the district collectors to issue passes to caregivers". (Govt Official, Male)

## Alternative arrangements to meet these challenges?

We are somehow managing and helping each other. If a family does not have enough food to eat, we help. If we have a roti (flat bread made of whole wheat) we share to overcome hunger and work in unison". (ASHA, PRI Member& Caregiver, Female)

**THEME-3: SERVICES** included availability and access to general health services, COVID-19 services, mental health services, specific rehabilitation services, education and school services and the exacerbations due to lockdown. Most stakeholders indicated that most of the medical care was exclusively reserved for COVID-19 and there was shortage of ambulances for Persons with disability. The minimum support and assistance required for Persons with disability have not been added to COVID-19 screening and treatment plan. It was observed that most of the rehabilitation services have come to a halt due to lockdown, similarly with education and therapy services in the community.

## **THEME-3: SERVICES**

## Availability and Access to General Health Services

- In this time all medical care was exclusively reserved for COVID. There was a huge shortage of ambulances for persons with disabilities, now they cannot go to a normal hospital because of these restrictions". (Govt Official, Male)
- "Not everyone has bike or a bicycle, there are difficulties in reaching the hospitals". (ASHA, PRI Member & Caregiver, Female)
- "If someone has cough or fever, they are confused if they need to go to the hospital". (ASHA, PRI Member & Caregiver, Female)
- "The minimum support required for persons with disabilities have not been added to the COVID treatment plan". (Program officer, NGO, Male)
- "We should request hospitals to reserve one room for disabled people in coordination with different organisations" (NGO in-charge, Male)

Availability and Access to Mental health services/therapy

"One good thing is that Department of Persons with disability and the RCI, have put the list and contact details of Psychologists, but how many people will be able to access?" (Senior Advisor, NGO, Male)

Availability and Access to COVID 19 specific services

Gram Panchayath has supplied the masks (2 each) to all the families however, not everyone wears it, as most of them are illiterates and do not know the significance of wearing a mask as they are not habituated". (ASHA, PRI Member & Caregiver, Female)

Availability and Access to Specific rehabilitation services

- "Even if his callipers is broken, he can't go the centre. He will most certainly deteriorate". (Program Manager, Female)
- "The district early intervention centre RBSK has stopped services including weekly therapies. So, our workers who did home visits found that contractures were developing. A physiotherapist's assistance also cannot reach them". (Program Officer, NGO, Female)

**Education & School** 

- "Teachers are unable to deliver online courses, they are not ready, not equipped, don't know how to do it. We must invest in digital literacy skills of teachers". (Program Officer, NGO, Male)
- "Parents are worried. Their child was happy earlier, going on a wheelchair to school. Schools have stopped, their child cannot interact with other children".
   (Program Officer, NGO, Female)
- "After 10 days they became restless at home and then they are not obeying the parents and time spending at home became difficult" (Caregiver, NGO In-charge, Male)

Exacerbations due to lockdown.

- "In this COVID time, many small diseases have troubled people very much".
   (ASHA, PRI Member & Caregiver, Female)
- "She died due to a simple stomachache, immediately, she couldn't get the right doctor". (ASHA, PRI Member & Caregiver, Female)
- "There are restrictions on camps ...there is no access to eye care services, it will lead to worsening disability". (Program Officer, NGO, Female)
- # "Behavioural issues are being reported, especially those with intellectual disability, autism, ADHT, they have reported difficulty in managing". (Program Officer, NGO, Female)

**THEME-4: PARTICIPATION** in work and Livelihood, leisure, stress management, community activities. Many reported losses of job and unemployment due to lockdown, not only among Persons with disability but among caregivers of Persons with disability and children with disabilities at home. Participation in leisure and community activities had drastically come down due to travel restrictions as well as fear of infection among people.

## **THEME-4: PARTICIPATION**

Work & Livelihood: Engaging in paid / self-employment / Volunteer, Work, Contingency plans, Barriers faced.

- "If the Persons with disability is not a government employee, they lost the job".
   (Program Officer, NGO, Male)
- I am Persons with disability, and I work from home. Our organisation is incredibly supportive. I am able to interact with my colleagues for work and sometimes, just to chat, over coffee". (Program Manager, Female)
- "All the work has stopped. Even if we go out for farming or labour work, everyone is scared". (ASHA, PRI Member& Caregiver, Female)
- Livelihood has been affected, with children at home" (Program Manager, Female)

## Leisure

- "Covid-19 has broken our confidence, if 5 people are there, they are joking and somebody coughs or sneezes, automatically these 4 people, they may not tell on the outside, but they fear about getting corona". (Govt Official, Male)
- "So that kind of trust has broken. Proximity is affected. The closeness is not there now". (Govt Official, Male)

## Time / Stress Management Ability to cope with the situation.

"We run a day care facility for children with ID, and had to close it during lockdown. We got several calls from parents asking when we will reopen. They are unable to manage the children". (Program Manager, Male)

## **Community activities**

- "The best way to include Persons with disability is to make them master trainers and involve them in programs and surveillance". (NGO in-charge, Persons with disability)
- "We are working collaboratively and formed a crisis Covid'19 network and we are reaching out to all the villages and who are doubly hit by COVID and Cyclone" (Senior Advisor, NGO, Female)
- We advised disabled tailors (who were not receiving any order due to lockdown) to start making masks (with help of money from SHG and cooperative), thousands of masks were made which after our collaboration with different village panchayat these masks were distributed to villagers from gram panchayat". (NGO in-charge, Male)

**THEME-5: COMMUNICATION** included staying connected with friends and other for social support, helpline and staying updated with latest information. Communication was a challenge during the lockdown. The biggest difficulty was reaching the Persons with disability by NGOs/government to fulfil their needs. Helpline was set up however not many could access it.

## **THEME-5: COMMUNICATION**

## Staying connected: Friends and others for Social support

- "Some of my friends, all young women, were in hostels during the lockdown. They were extremely low. I used to call them often, just to say we are with them. It's nothing serious, but their self-esteem dropped, and they started going into a shell". (Program Manager, Female)
- "If we don't help each other that's not good. We conquer the challenges with unity, only we know how we feel!" (ASHA, PRI Member& Caregiver, Female)

## **Contacting Helpline**

 "The biggest challenge was to reach Persons with disability and fulfil their needs. We developed a helpline number with a psychologist for counselling and guidance". (Govt Official, Male)

Staying updated with latest information, Access NEWS, Available Communication devices and Facilities etc.

- "I am literate little bit, so I keep learning some information using my mobile, news, or hearsay. I try to educate people that it's a contagious disease so please be careful". (ASHA, PRI Member& Caregiver, Female)
- 4 "I get information from TV and mobile and text messages. Also, when I go to the

meeting, I get to know new information". (ASHA, PRI Member& Caregiver, Female)

**THEME-6: NETWORKS** describes how the various networks of Persons with disability ensured that new activities were undertaken during lockdown. They included, as the subthemes suggest: Awareness Raising, Contribution to support persons with disabilities during lock down, Approaches and Methods of Contribution, Contribution to COVID 19 activities, Support / Exchange of Good practice. It was reported many DPOs made significant contribution during lockdown in helping Persons with disability. Many NGOs helped Persons with disability in providing necessities such as food kits, dry ration as well as psycho-social support.

## THEME-6: NETWORKS

#### Awareness Raising

"Our biggest strength is our DPO. The investment that we did over the years to build their capacity has helped us a lot during this time". (Program Manager, Female)

Contribution to support persons with disabilities during lock down

- "Uuring peak lockdown, it was difficult to supply tings to Persons with disability because we didn't have PPE. After that, it became easy and we supplied all basic things". (Program Manager, Male)
- "We formed a WhatsApp group of 120 people individuals and NGOs. They distributed food, ration" (Senior Advisor, NGO, Male)

## **Approaches and Methods of Contribution**

- "They are still doing it, if somebody needs food, somebody will ensure that that person gets it". (Senior Advisor, NGO, Female)
- \* "During the lockdown more than 100 of our DPO leaders helped the government and block level officials". "They are working with Block Development Office and visiting different villages, Panchayats etc. to that ensure people are getting ration with government support. There are good examples from many states where because of these Persons with disability, many Persons with disability accessed government support". (Program Manager, Female)
- "This is perhaps the best example we have seen, where no one was left behind in areas of Persons with disability. And that really helped a lot". (Program Manager, Female)

## **Contribution to COVID 19 activities**

"We provided food kit, dry ration and psycho-social support, we also supported the local health centre, PHC, ASHA/AWW to ensure that they are protected. We provided PPE". (Govt Official, Male)

## Support / Exchange of Good practice

- "All the schools are closed and none of our partners are able to... because of the lockdown. However, they are extending online services to those students".
   (Program Manager, Female)
- "The special educators are visiting some of the houses, ensuring social distancing and protocols are maintained. We have given counselling and home activities to the children and the parents to engage the children and maintain their well-being". (Program Officer, Female)

**THEME 7: COMPASSION** included promoting well-being, inclusion and considerations provided for Persons with disability in current COVID-19 lockdown plans and actions, safety and hope and self-protection. Many stakeholders reported that many of the guidelines released by the government during the COVID-19 outbreak was not inclusive, they did not consider Persons with disability as part of the community and they need assistance in terms of travel or COVID-19 screening or treatment. Caregivers reported that if the government can be compassionate and treat the problems faced by Persons with disability as their own, then all Persons with disability will be comfortable and maintain good health and well-being.

## THEME-7: COMPASSION

## Protect / Promote Well-being- Inclusion and Considerations provided for persons with disabilities in current COVID 19 / Lock down plans, actions and policies.

- "If the government considers Persons with disability's problems as that of its own families, then nobody will be unhappy". (ASHA, PRI Member& Caregiver, Female)
- \* "MHA came out with guidelines. But they contained nothing about Persons with disability. We wrote to the Department of Empowerment of Persons with disability. Then the Department of Empowerment of Persons with Disability came out with a detailed guideline. So, what happens these guidelines are but they become standalone guidelines for persons with disabilities, which means these are not inclusive". (Senior Advisor, NGO, Male)

**Encourage Safety / Hope** – during provision of Information, Communication, Treatment, Screening/Testing, Access to Health and Other Services

"Many DPO members are actually helping Persons with disability to access medicine sincerely. They are going to the town and getting medicines for them". (Program Manager, Female)

# Social-distancing / Self Protection - Considerations especially for persons with disabilities

- "No one maintains the social distancing; they feel nothing will happen. Not every person will have the same thought process". (ASHA, PRI Member & Caregiver, Female)
- "If anybody comes at home, we say cover your face or maintain distance. Few of them follow, and few only hear, but don't follow". (ASHA, PRI Member& Caregiver, Female)

**THEME-8: FINANCES** included access to financial support and pensions, family savings at individual level and funding cuts at NGOs level. The economic impact faced by Persons with disability was reported by all stakeholders during the in-depth interviews as well as focus group discussions. Pensions were affected, loss of livelihood mainly among Persons with disability with small businesses and petty shops. Persons with disability had to face hardships not only through loss of income but the inability to travel to draw money from banks or to get essential groceries. Many had to utilise their family savings during the lockdown. Funding cuts was reported by stakeholders working in the NGO sector.

## **THEME-8: FINANCES**

## Access to services and financial support, Pensions

- We know what are going through, the biggest problem which we have is the economic impact". (ASHA, PRI Member & Caregiver, Female)
- **4** "Social pension was largely affected". (Senior Advisor, NGO, Male)
- "We were already working on organic farming, so food security was intact. Some people who owned petty shops took risk and sold stuff through the back door". (Senior Advisor, NGO, Male)
- 4 "And similarly, some issues like disability pension will be given in advance for March and April and in May and June they didn't get the pension. So everybody thought it is additional pension, while actually it is only advance. When Persons with disability asked for their May pension, Government said you already got it, in advance. But people had spent the money. (Senior Advisor, NGO, Male)
- "This was a system failure. People did not know... lockdown was on March 20 and Holi was on March 10, UP and Bihar celebrate holi and Diwali with fervour. Most pockets got empty during Holi" (Program Officer, Male)
- "The hardship during lockdown was only loss of job, or not having amount in their hands or not able to go to the bank and draw the money or provisions and essential items not available. For unavoidable medical needs, we are covering these areas through our helpline assistance". (Government Official, Male)
- "What I heard regarding social security schemes is that, while some people have got the amount, they are unable to go to the bank or ATM". (Program Officer,

Female)

## **Family savings**

- "The whole root cause is the economic situation!" (ASHA, PRI Member& Caregiver, Female)
- "My child fell ill and I had no money, I save money without my husband's knowledge, which I had to take out and use. My husband would have earned if there was no lock down and I would never have utilized my savings, but that could not happen because of the situation. Lockdown has affected very badly". (ASHA, PRI Member& Caregiver, Female)

## Funding cuts to NGOs

- "NGOs re struggling to get funds. Just like the Government helps business groups, it should support NGOs working for Persons with disability". (Program Manager, Female)
- "Big companies feel it is better to give CSR funds to some Department, to earn the good will of the Minister, who will later help the big company's business. They are not bothered about NGOs". (NGO in-charge, Persons with disability)

**THEME-9: GOVERNMENT RESPONSE** included needs assessments and data, any innovations, guidelines and policies in response to COVID-19 pandemic and any other specific plans and programmes to meet the needs of Persons with disability. Through the interviews it was indicated that the government may not be prepared for the next wave and the current situation could have been better for Persons with disability if there was adequate time for Persons with disability to prepare for the lockdown and make basic arrangements to get adequate food, water and medicines. Stakeholders indicated that government should address the livelihoods of Persons with disability and their family so lockdowns such as the current one has minimal impact on Persons with disability lives.

## **THEME-9: GOVERNMENT RESPONSE**

## Needs Assessment, Data

- "The right information does not reach the government". (ASHA, PRI Member & Caregiver, Female)
- "My suggestion is they (govt) have to reach persons with disabilities homes and investigate in detail. Especially if such a lock down occurs, they need to verify what is necessary, basic necessities such as food and grains, livelihood, education? Keeping these in mind they should do the survey and collect data, then the problem will either reduce or will vanish away. (ASHA, PRI Member & Caregiver, Female)

#### Innovations, Guidelines, Policies etc.

- "Persons with disability are always portrayed as the problematic people. Instead, involve them at all levels and they will solve problems". (NGO in-charge, Persons with disability)
- "Combine DPO and grassroots level government workers, train them together".
   (Program Manager, Female)

#### Specific plans/programmes made to meet the needs of persons with disabilities

- "Dairy could make profit despite the lockdown because we were helping with procuring and distributing locally. (Program Manager, Male)
- "Buniyad Kendra is active and we had 38 mobile therapy vans also, with equipment for physiotherapy, like, then wheelchairs which went to remote areas to give services". (Program Manager, Male)
- "We had grievance redressal, 62 webinars conducted for Persons with disability, everything was supplied to their doorstep" (Program Manager, Male)
- We don't have Persons with disability with COVID, but we arranged for quarantine facilities according to the needs of the disabled. We have got the order from the court". (Government Official, Male)
- Some of the States have done well in providing pension and other schemes to the Persons with disability. But many States have issues with ration card and PDS system". (Senior Advisor, NGO, Male)

## Support and promote exchange of good practice

We made WhatsApp group for exchange of information. We connected vegetable and milk vendors with people who needed, thereby reducing impact on livelihood (PM, Male)

#### **Preparedness for Next Wave**

- Government is not prepared for the next wave. They should involve Gram sabhas and bring in different agendas including disability, it they are serious about planning for next disaster". (NGO in-charge, Persons with disability)
- "If I were in the authority, then before I decide on lockdown, I would make arrangements, these are the basic arrangements, people must get food, water, medicines and shelter. Everybody is not like me, having a comfortable life and house. (Senior Advisor, NGO, Male)
- "Very important to have the rights of persons with disability in every DDMA (District Disaster Management Authority). Every district should have a list of Persons with disability so that they know where is this disaster, where this person is, what his or her requirements, and arrange for it". (Senior Advisor, NGO, Male)
- $\downarrow$  "When the government plans rehabilitation programmes, it must consider the

organized and unorganized sectors. There should be a focus on really addressing the livelihood of Persons with disability and their family. People must actively participate in the income generation programme so they can still cope and manage the situation. But currently not much is happening, that area should be strengthened". (Program Manager, Male)

**THEME-10: POSITIVE IMPACT** included findings on positive impacts of the COVID-19 pandemic outbreak and lockdown among Persons with disability and their family. Many reported that Persons with disability and families are spending less and saving more and not buying non-essential items. Families are spending more time together than earlier and children with their parents. Reduction in alcohol use and lesser disputes among family members.

## **THEME-10: POSITIVE IMPACT**

## Positive impacts of the Covid-19 outbreak and Lockdown/post lockdown

- We have practised sustainability. We use normal wooden stick and rope for exercises. We use local materials found in our backyard. We use wet sand /clay to make toys for children with ID. If it breaks, we can make it again" (Caregiver, NGO In-charge, Male)
- "We learnt many things- how to use technology, how to bond with our family, how to live without luxurious things. (Program Manager, Male)
- "Yes, as we are not buying many things from the market, we are saving some money. (ASHA, PRI Member & Caregiver, Female)
- \* "The best thing is that the consumption of alcohol has reduced, some say up to 80% of people who drink had stopped during lockdown. There was peace in the house without any disputes. But, for the past 15 days, alcohol sale has started, and the disputes started again. During the lock down there use to be at peace and happiness as alcoholics were inactive." (ASHA, PRI Member& Caregiver, Female)
- Children got to see a different face/ personality of their parents" (Program Manager, Ngo, Male)
- "If there are no small community-based institutions in our community, then we will never be able to manage such crisis" (Program Manager, NGO, Male)

#### Phase II: Easing of lockdown/ Post-lockdown (July 2020)

#### **Quantitative results**

A total of 107 persons with impairment were included for the phase II (referred to as easing of lockdown/ gradual opening of lockdown/ Unlock phase). Here we present the paired comparisons between 'during lockdown' with 'after easing of lockdown'. McNemars test and marginal homogeneity test was performed to compare the proportions before and after the opening of lockdown.

#### **Medical and Rehabilitation services**

The results show that majority of the persons did not need the medical services during lockdown and after easing of lockdown. 60% of the persons found difficulty in accessing the emergency medical services during lockdown; and after the easing of lockdown, the percentage reduced significantly to 40% (p value <0.001). Likewise, during lockdown, 75% found it difficult to access the rehabilitation services, and after easing of lockdown: the percentage reduced significantly to 41.7% (p value=0.03). **Table 33** displays the items related to difficulty in accessing the medical services

Itoma			After	easing of loc N(%)	ekdown	P value
Items		Categories	Yes	No	Did not need	
	- 🔅	Yes	19(17.8%)	2(1.9%)	8(7.5%)	_
Outpatient	N(%)	No	10(9.3%)	4(3.7%)	7(6.5%)	0.10
clinics		Did not				- 0.19
	low	need	1(0.9%)	3(2.8%)	53(49.5%)	
Emorgonou	ockdown	Yes	0(0.0%)	3(2.8%)	12(11.2%)	
Emergency medical	Ľ	No	1(0.9%)	1(0.9%)	10(9.3%)	- <0.001*
services	ြရ	Did not				- <0.001
services	During	need	1(0.9%)	1(0.9%)	78(72.9%)	
	Du	Yes	7(6.6%)	5(4.7%)	7(6.6%)	
Medicines		No	8(7.5%)	14(13.2%)	7(6.6%)	- 0.73
Medicilles		Did not				- 0.75
	_	need	5(4.7%)	5(4.7%)	48(45.3%)	
Rehabilitation		Yes	4(3.7%)	5(4.7%)	4(3.7%)	0.03*

 Table 33. Difficulty in accessing any of the following medical and rehabilitation services

 during lockdown and after unlock/easing of lockdown

services	No	0(0.0%)	3(2.8%)	10(9.3%)	
	Did not				
	need	1(0.9%)	7(6.5%)	73(68.2%)	
Decular blood	Yes	1(0.9%)	0(0.0%)	0(0.0%)	
Regular blood	No	0(0.0%)	0(0.0%)	3(2.8%)	
pressure monitoring	Did not				-
monitoring	need	1(0.9%)	0(0.0%)	102(95.3%)	
	Yes	1(0.9%)	1(0.9%)	1(0.9%)	
Regular sugar	No	0(0.0%)	1(0.9%)	3(2.8%)	<0.001*
monitoring	Did not				<0.001
	need	0(0.0%)	0(0.0%)	100(93.5%)	
	Yes	0(0.0%)	0(0.0%)	1(0.9%)	
Surgical	No	0(0.0%)	0(0.0%)	5(4.7%)	
procedures	Did not				-
	need	0(0.0%)	0(0.0%)	101(94.4%)	
Are you able to get the medicines you regularly take? (n=91)	Yes	19(20.9%)	3(3.3%)	10(11.0%)	
	No	5(5.5%)	4(4.4%)	7(7.7%)	
	Did not need	14(15.4%)	1(1.1%)	28(30.8%)	0.38
	Yes	2(1.9%)	0(0.0%)	6(5.6%)	
Is online	No	0(0.0%)	0(0.0%)	10(9.3%)	0.14
consultation	Did not				0.14
helpful for you	need	5(4.7%)	1(0.9%)	83(77.6%)	

## **Mental Health**

Only 4.7% of the persons had problems in relationship during lockdown. After the unlock/easing, it decreased to 1.9%. However, this difference is statistically not significant (p value=0.25). Of the total 107, a third (33%) of the persons had experienced stigma and 17.8% had experienced discrimination during lockdown. After the unlock/ easing phase it decreased to 7.5% (p value <0.001) and 3.7% (p value<0.001) respectively (**Table 34**)

<b>Table 34.</b> Proportion of participants experiencing various issues during lockdown and unlock
phase /easing of lockdown phase

Items	n		After eas	0	P value
	lov	Categories	Yes	No	
Drahlang in valationship	cke _	Yes	2(1.9%)	3(2.8%)	0.25
Problems in relationship	Č Č	No	0(0.0%)	102(95.3%)	0.25
Change in family		Yes	1(1.0%)	7(6.7%)	0.00
dynamics	irii	No	6(5.8%)	90(86.5%)	0.99
Abandonment	DI	Yes	1(0.9%)	5(4.7%)	0.06
Abandonment		No	0(0.0%)	100(94.3%)	0.06

Isolation	Yes	0(0.0%)	7(6.6%)	0.18	
Isolation	No	2(1.9%)	97(91.5%)	0.18	
Stigmo	Yes	6(5.7%)	29(27.4%)	<0.001*	
Stigma	No	2(1.9%)	69(65.1%)	<0.001	
Violence	Yes	1(0.9%)	1(0.9%)	0.99	
v Iolence	No	0(0.0%)	104(98.1%)	0.77	
Discrimination	Yes	4(3.7%)	15(14.0%)	<0.001*	
Discrimination	No	0(0.0%)	88(82.2%)	<0.001	
Mcnemars test					
*Statistically significant a	at 5% level of signific	cance			

#### Impact on Mental health & well-being

24.3% of the persons were afraid of infection during the lockdown, while only 8.4% feared infection after easing of lockdown (p value<0.001). Irrespective of the lockdown or release, 47.7% of the persons were afraid of infection. Out of the total 107, only 2.8% were not afraid of infection. The results indicate that there was a statistically significant difference in the proportion of persons who were bothered about interruption of care giver pre- and post-lockdown(p=0.027). **Table 35** shows the participants' feelings during and after easing of lockdown

What is bothering most?	you		After eas	sing of lockdo	own N(%)	P value
Items		Categories	Not at all	Moderately	A lot	
		Not at all	3(2.8%)	14(13.1%)	9(8.4%)	
Fear of Infection		Moderately	5(4.7%)	35(32.7%)	16(15.0%)	< 0.001*
		A lot	1(0.9%)	8(7.5%)	16(15.0%)	
Econ of infecting		Not at all	14(13.1%)	15(14.0%)	6(5.6%)	
Fear of infecting others		Moderately	19(17.8%)	40(37.4%)	4(3.7%)	0.82
oulers	<b>%</b>	A lot	2(1.9%)	6(5.6%)	1(0.9%)	
	N(%)	Not at all	33(30.8%)	13(12.1%)	1(0.9%)	
Fear of dying	n]	Moderately	21(19.6%)	33(30.8%)	2(1.9%)	0.37
	Lockdown	A lot	1(0.9%)	0(0.0%)	3(2.8%)	
	ckd	Not at all	40(37.4%)	10(9.3%)	4(3.7%)	
Lack of support	Ľ	Moderately	11(10.3%)	29(27.1%)	5(4.7%)	0.40
	ရြ	A lot	1(0.9%)	4(3.7%)	3(2.8%)	
Candanhaaad	During	Not at all	91(86.7%)	3(2.9%)	0(0.0%)	
Gender based	Du	Moderately	7(6.7%)	0(0.0%)	0(0.0%)	0.02
violence		A lot	4(3.8%)	0(0.0%)	0(0.0%)	
		Not at all	20(19.4%)	8(7.8%)	9(8.7%)	
Loss of income		Moderately	5(4.9%)	13(12.6%)	15(14.6%)	0.32
		A lot	8(7.8%)	8(7.8%)	17(16.5%)	
Interruption of		Not at all	71(78.9%)	7(7.8%)	0(0.0%)	< 0.001*

 Table 35. Comparison of participants' feelings during lockdown and after easing of lockdown

care giver	Moderately	6(6.7%)	2(2.2%)	0(0.0%)
	A lot	3(3.3%)	1(1.1%)	0(0.0%)

Marginal homogeneity test

\*Statistically significant at 5% level of significance

Of the total, more than 50% of the persons with impairment were stressed before and also after easing of lockdown, of which 17% were feeling extremely stressed. The McNemar's test determined that there was a statistically significant reduction in the proportion of persons with stress (p value= 0.001), anxiety (p value =0.001), stigma (p value <0.001) and discrimination (p value<0.001) after the easing of lockdown (Table 36 & Table 37)

Items			After easi	ng of lockdov	wn N(%)	P value
		Categories	Not at all	Moderately	A lot	
		Not at all	2(1.9%)	7(6.6%)	1(0.9%)	
Stressed		Moderately	7(6.6%)	38(35.8%)	27(25.5%)	$0.001^{*}$
	(%)	A lot	0(0.0%)	6(5.7%)	18(17.0%)	
	H	Not at all	8(7.7%)	15(14.4%)	2(1.9%)	
Overwhelmed	UM.	Moderately	4(3.8%)	51(49.0%)	6(5.8%)	0.19
	Lockdown	A lot	1(1.0%)	10(9.6%)	7(6.7%)	
	ock	Not at all	10(9.5%)	15(14.3%)	4(3.8%)	
Anxious	Ţ	Moderately	5(4.8%)	50(47.6%)	6(5.7%)	$0.02^{*}$
	uring	A lot	1(1.0%)	5(4.8%)	9(8.6%)	0.02
	Jur	Not at all	5(4.8%)	15(14.3%)	3(2.9%)	
Uncertain	D	Moderately	4(3.8%)	36(34.3%)	12(11.4%)	0.74
		A lot	6(5.7%)	14(13.3%)	10(9.5%)	- 
Marginal homogeneity	test					

Table 36. Level of stress & anxiety among the participants

\*Statistically significant at 5% level of significance

Items			After eas N(%)	sing of lockdown	P value
		Categories	Yes	No	
Problems in	N(%)	Yes	2(1.9%)	3(2.8%)	— 0.25
relationship	_	No	0(0.0%)	102(95.3%)	-0.23
Change in family	IM	Yes	1(1.0%)	7(6.7%)	— 0.99
dynamics	cdo	No	6(5.8%)	90(86.5%)	- 0.99
Abandonment	ockdown	Yes	1(0.9%)	5(4.7%)	— 0.06
Adandonment		No	0(0.0%)	100(94.3%)	- 0.00
Isolation	ing	Yes	0(0.0%)	7(6.6%)	— 0.18
Isolation	Durin	No	2(1.9%)	97(91.5%)	- 0.18
Stiama	A	Yes	6(5.7%)	29(27.4%)	— <0.001*
Stigma		No	2(1.9%)	69(65.1%)	- <0.001
Violence		Yes	1(0.9%)	1(0.9%)	0.99

Table 37. Participants' experience during lockdown and after easing	of lockdown
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	No	0(0.0%) 104(98.1%)	
Discrimination	Yes	4(3.7%) 15(14.0%)	
	No	0(0.0%) 88(82.2%)	
16.37			

McNemars test

\*Statistically significant at 5% level of significance

## Access to mental health services and psychological impact on caregivers

There was a statistically significant increase in the proportion of persons who were able to get regular mental health counselling or therapy related services (p value= 0.03). 48.6% did not need mental health & care, psychological or emotional support and services. Less than 1% of the persons faced problem for getting regular psychiatric medicine **Table 38** displays details on the access to mental health services. There was no significant difference in relation to caregiver's mental health during lockdown and after easing of lockdown.

## Table 38. Access to information related to mental health

Items			After easing of lockdown N(%)			D	
		Categories	Yes	No	Did not need	- P value	
Access to information related to mental health & care,		Yes	8(7.5%)	1(0.9%)	2(1.9%)		
		No	10(9.3%)	6(5.6%)	18(16.8%)	- 0.63	
psychological or emotional support and services (n=107)	During Lockdown N(%)	Did not need	7(6.5%)	3(2.8%)	52(48.6%)	- 0.03	
		Yes	4(3.7%)	0(0.0%)	1(0.9%)		
Able to get regular mental health counselling or therapy		No	3(2.8%)	5(4.7%)	5(4.7%)	- - 0.03*	
related services (n=107)		Did not need	6(5.6%)	6(5.6%)	77(72.0%)	- 0.03	
Facing any problem for getting		Yes	1(0.9%)	1(0.9%)	0(0.0%)		
your regular psychiatric medicine if prescription date was old and you cannot get recent prescription (n=107)		No	1(0.9%)	3(2.8%)	6(5.6%)	- 0.60	
		Did not need	1(0.9%)	2(1.9%)	92(86.0%)		
Only for caregivers Getting enough professional support (n=67)	Du	Yes	10(14.9%)	2(3.0%)	7(10.4%)		
		No	4(6.0%)	2(3.0%)	3(4.5%)	- 0.13	
		Did not need	1(1.5%)	3(4.5%)	35(52.2%)	- 0.15	
Feeling stressed, anxious, or		Yes	0(0.0%)	6(13.6%)	2(4.5%)		
depressed with caring for children or other family members at home with impairment (n=44)		No	0(0.0%)	3(6.8%)	24(54.5%)	-	
		Did not need	0(0.0%)	1(2.3%)	8(18.2%)	- 0.16	

\*Statistically significant at 5% level of significance

## Education, Livelihood, and social empowerment

There was no statistically significant difference in education, livelihood, and social empowerment before and after easing of lockdown (**Table 39 and 40**)

Items		Categories		easing of wn N(%)	P value	
		Categories	Yes	No		
(only for respondents with children)		Yes	19(61.3%)	4(12.9%)		
On being confined to the home, the children feel distressed (n=31)		No	3(9.7%)	5(16.1%)	0.99	
Since all schools are closed, it affected the child learning (n=26)		Yes No	18(69.2%) 6(23.1%)	1(3.8%) 1(3.8%)	- 0.13	
School is providing online		Yes	8(33.3%)	2(8.3%)	- 0.99	
teaching to children (n=24)		No	3(12.5%)	11(45.8%)	0.77	
Impact on daily activities (n=98)		Yes	58(59.2%)	19(19.4%)	- 0.09	
		No	9(9.2%)	12(12.2%)		
Affected the Supply chain of material that you have developed (N=10)		Yes No	2(20.0%) 4(40.0%)	1(10.0%) 3(30.0%)	0.38	
Affected the supply of farm	%	Yes	1(11.1%)	1(11.1%)		
inputs like seeds, fertilizer, and Pesticides? (N=9)	During Lockdown N(%)	No	5(55.6%)	2(22.2%)	0.22	
Affected the transportation of	kdc	Yes	6(35.3%)	6(35.3%)		
input and output supply due to lack of transportation (N=17)	g Locl	No	2(11.8%)	3(17.6%)	0.29	
Affected the facility of water	i.	Yes	0(0.0%)	9(31.0%)		
supply	mC	No	0(0.0%)	20(69.0%)		
The current situation is affecting the Pensions / Remittance (N=74)		Yes	10(13.5%)	19(25.7%)		
		No	18(24.3%)	27(36.5%)	0.99	
Getting full wages / pay? (N=83)		Yes No	14(16.9%) 5(6.0%)	12(14.5%) 52(62.7%)	- 0.14	
Borrowing money (N=101)		Yes	33(32.7%)	12(11.9%)	- 0.99	
Catting and datas that you require		No	11(10.9%)	45(44.6%)		
Getting updates that you require for your business (such as price, suppliers)		Yes No	4(36.4%)	0(0.0%) 7(63.6%)		
I will accept any job for low pay		Yes	11(45.8%)	4(16.7%)	0.00	
because of poor income (N=24)		No	5(20.8%)	4(16.7%)	- 0.99	
Able to sell your		Yes	8(42.1%)	1(5.3%)	- 0.99	
produce/products (N=19)		No	1(5.3%)	9(47.4%)	• • • •	
Loan/funds available with inclusive Cooperatives (n=50)		Yes No	1(2.0%) 4(8.0%)	2(4.0%) 43(86.0%)	- 0.69	
McNemars test						

Table 39. Education and Livelihoo
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	Categories		After easing of lockdown N(%)		P
		8	Yes	No	value
yat Raj Institution		Yes	8(20.0%)	17(42.5%)	0.06
as Members?		No	7(17.5%)	8(20.0%)	0.00
relief work?	(%)]	Yes	13(26.5%)	15(30.6%)	0.13
Teller WOIK?		No	7(14.3%)	14(28.6%)	
nobilization with		Yes	37(66.1%)	3(5.4%)	0.06
ommunity members munity issues?	Lockdown N(%)	No	11(19.6%)	5(8.9%)	
ation in village	ocł	Yes	37(64.9%)	3(5.3%)	0.06
OVID response and g?	During L	No	11(19.3%)	6(10.5%)	
d people	)ur	Yes	48(67.6%)	9(12.7%)	
ation (DPO)	D	No	10(14.1%)	4(5.6%)	0.99
feel that after		Yes	52(66.7%)	9(11.5%)	
nity and PRIs will		No	10(12.8%)	7(9.0%)	0.99
vn, working with nity and PRIs will	evel o	No		. ,	

 Table 40. Impact of lockdown on participation and social empowerment of Persons with disability

Out of the total 107 persons with impairment during the repeat survey, 72.9% hesitated to go to hospital because of fear of getting COVID. 86% were scared to go out and meet others. 78.1% did not fear the lack of companionship.

## Phase II: Easing of lockdown/ Post lockdown (July 2020) Qualitative results:

## **Post Lockdown Findings**

As indicated in Table - 32, the 2 focus group discussions were repeated after easing of lockdown. The findings are as follows:

THEME-1: **Difficulties in daily life and management** describes problems faced by Persons with disability after easing of lockdown or post-lockdown. Most of the respondents reported that there has not been much change compared to lockdown phase. Persons with disability are trying to cope with the situation and many have accepted that it is like other diseases such as malaria or dengue.

## THEME-1: DIFFICULTIES IN DAILY LIFE & MANAGEMENT

## Personal Care Needs and Management

From field level feedback, reflection and reports not much change has happened in the last one and half months. Situation remains same but people are trying to cope up with it". (Program Manager, Male)

"We have to live with the COVID-19 like other diseases, malaria, dengue" (Program Manager, Male)

## **Psychological impact**

- "There are many challenges with respect to children with disability. They are still
   at home, and really frustrated particularly autistic children they are very much
   disturbed". (NGO In-Charge, Male)
- 'The parents are getting worried on what next? With no schools, how long we can take care of children at home?" (Caregiver, NGO In-charge, Male)

**THEME-2: ACCESS** and availability to basic necessities such as food & water, medicines, and transport. Access to food and non-food items are better as many NGOs within their capacity have provided them to Persons with disability. However, in some regions, costs of groceries and vegetables have gone up. Availability to free medicines provided by specific government programmes are still not fully functional as many health workers and staff are absorbed in COVID-19 response.

## THEME-2: ACCESS

Basic Necessities: Availability and Access to Food & Water
- "The costs of other commodities like vegetable and groceries have risen". (NGO In-Charge, Male)
- 4 "Access to items like food, grain, food and non-food items within the capacity and resources collected through various sources have been provided to Persons with disability". (Program Manager, Male)

#### **Basic Necessities: Availability and Access to Medicines**

- Fire and rescue mission are helping people who require medicines, which are not available locally. Any other essentials also are brought by the Fire and Rescue Mission". (Caregiver, NGO In-charge, Male)
- \* "One challenge pertains to availability of medicine for people with psycho-social disability or mental health issues who are regularly taking medicine. For them it is a big challenge as even the district mental health programme is not functioning well because all medical staff is engaged in COVID-19 response". (Program Manager, Male

#### Transport

"We are running a day-care centre but beneficiaries are not coming there now because no transport is there". (Caregiver, NGO In-charge, Male)

**THEME-3: SERVICES** included availability and access to general health services, COVID-19 services, mental health services, specific rehabilitation services, education and school services and the exacerbations due to lockdown. Most stakeholders indicated that access to general health services is still a problem to Persons with disability as the government is focussing on COVID-19 response. Costs for testing or admissions at hospitals have gone up. Educational services are being provided online but mostly in urban areas, reach to rural and remote areas is still difficult.

# **THEME-3: SERVICES**

#### Availability and Access to General Health Services

- "Public health machinery and complete task forces are only focusing on COVID response. No other regular business is happening. General health is a bigger concern especially for people who visit the PHC, district hospital, but they are only serving the COVID-19 cases and other emergency cases which has created bigger issues" (Program Manager, Male)
- "Any patient coming to the hospital is treated as COVID patient. First COVID test is done then the treatment starts. Initially they don't admit patient if at all they

admit, they don't attend properly. They themselves are scared of this infection". (NGO In-Charge, Male)

"They began charging huge amount for admission, testing. Even for normal test they charge a huge amount, cost of one-day treatment is around 30- 60 thousand like that. It is a huge problem. But the government is also trying to control". (NGO In-Charge, Male)

### Availability and Access to Mental health services/therapy

- "For people needing regular psychosocial support the project has stared telecounselling services" (Program Manager, Male)
- We are continuing early intervention therapy for children below 6 years of age on WhatsApp. We have found a very novel way of doing that. Our therapist, a gives instruction on phone saying you have to perform these activities". (Program Manager, Female)
- Interventions are done on one-to-one basis others have to replicate it. Those recorded videos are also circulated on WhatsApp group and others also learn from it. The therapist also writes the instruction on a paper and circulates on the WhatsApp. She gives instructions like how to feed children how they should eat on their own." (Program Manager, Female)

### Availability and Access to Specific rehabilitation services

- \* "Rehabilitation is challenging till now, as most of the people are not able to access rehabilitation services like some of the therapeutic services and assistive devices, they need. Few hospitals began early rehabilitation services through the members of the disabled people's organisation in the community who are aware about where the children with disabilities are in the villages". (Program Manager, Male)
- "Through mobile, WhatsApp group and sharing of videos or through one to one talk over the telephone with the carers, rehabilitation services to the needy is being provided". (Program Manager, Male)

# **Education & School**

- The situation continues to be challenging like it was 2 months back. (Program Manager, Female)
- Education is happening mostly in urban and peri-urban settings but in remote places in the villages it is extremely difficult. (Program Manager, Male)
- Schools are in lockdown but the services continue like it was done earlier. From providing casual services and remedial services they have now moved to some kind of academic support. Regular classes have resumed in a way; subject teaching has started. In some places resuming the services despite our willingness is difficult due to lack of internet connection or TV connection. (Program Manager, Female)

- Looking at the larger parameter, what is currently being provided is not effective as a result, because of the lack of knowledge, skills and gadgets and understanding of the whole e-learning. (Program Manager, Male)
- Currently it remains just an interaction between the teacher and students. It is not considered as an alternate to the schools as most of the government school teachers are not familiar with all these software and apps. This is seen as a bigger challenge (Program Manager, Male)

#### Exacerbations due to lockdown.

"A partner in one of the states reported that the eye care hospital turned into COVID treating centre. So, patients suffering and needing eye care after screening they cannot access and their cataracts surgery are postponed and not allowed" (Program Manager, Male)

**THEME-4: PARTICIPATION** in work and Livelihood, leisure, stress management, community activities. As observed during lockdown period, many reported losses of job and unemployment, not only among Persons with disability but among caregivers of Persons with disability and children with disabilities at home. As reported earlier, apart from government pensions, there is no other income source as most have lost small businesses such as petty shops. Participation in leisure activities have improved as many NGOs are conducting online activities such as music competitions, sports activities, etc.,

# **THEME-4: PARTICIPATION**

Work & Livelihood: Engaging in paid / self-employment / Volunteer, Work, Contingency plans, Barriers faced.

- "There is lot of unemployment, underemployment, wage cuts and job loss were reported. Example – Migrant who returned back to the community doesn't have sufficient income and business still". (Program Manager, Male)
- "For the poor and marginalised, employment is still a question, both in unorganised and organised sector which is not functional" (Program Manager, Male)
- "Apart from pension there is no other income source as most have lost their small businesses like petty shops". (Program Manager, Male)
- "At some places parents are going for daily wage work and children are left without any engagement and no means of support". (Program Manager, Female).
- # "After the Atma Nirbhar announcement by government, departments like agriculture have become active now including NABARD and some banks because they have been assigned some target. They are trying to support the migrant and

the small holder farmers. Where we have this advantage to include Persons with disability in small farmers where we work in some of the states". (Program Manager, Male)

#### Leisure

- **We have arranged online sports activities**". (NGO In-Charge, Male)
- Lot of agencies and parents' association are conducting various kinds of competition through WhatsApp and video calls, like drawing and music competition. But the reach is not very much. Only the top layer of society is being reached". (Caregiver, NGO In-charge, Male)

#### **Community activities**

**4** *"The larger NGOs played a vital role". (Program Manager, Male)* 

"Corporates supported, which came as a timely relief. There are several network and individuals voluntarily distributed food packet, grain and grocery packets to persons with disabilities on the roads and slums and vulnerable occasions". (Program Manager, Male)

**THEME-5: COMMUNICATION** included staying connected with friends and other for social support. Post lockdown many respondents reported that they are more confident of supporting Persons with disability at home as there was no external support in the last few months.

### **THEME-5: COMMUNICATION**

Staying connected: Friends and others for Social support

After spending three-month time with the family, family members know how without external support they can support Persons with disability family members and sibling. People are more supportive to such people in their own homes. (Program Manager, Female)

**THEME-6: NETWORKS** describes how the various networks of Persons with disability ensured that new activities were undertaken after easing of lockdown or post-lockdown. Respondents reported that many NGOs continue to help Persons with disability in providing basic necessities such as food kits, dry ration as well as psycho-social support. Some big corporates have come forward to support NGOs in supporting Persons with disability.

## **THEME-6: NETWORKS**

#### **Awareness Raising**

Like earlier, we give them the WASH kit, and lot of training and orientation are being given on awareness part of Covid-19

#### Contribution to support persons with disabilities

"There is no specific support from the government especially for persons with disability. Whatever support is provided to the general people we are extracting from that. We are getting support from corporate but not from the government." (NGO In-Charge, Male)

#### **Approaches and Methods of Contribution**

"The advantage of hospital's community-rehabilitation programme is that they are using Persons with disability volunteers in the community, who are identifying and referring people to the hospital. They are also helping people to come to the hospital and ensure that they are getting services". (NGO In-Charge, Male)

#### Support / Exchange of Good practice

We have been organising training for corporates and making presentations. They promised to provide support with respect to virtual meetings; We are trying for more such partnerships particularly with IT companies". (NGO In-Charge, Male)

**THEME 7: COMPASSION** included promoting well-being, inclusion and considerations provided for Persons with disability during post lockdown and plans and actions, safety and hope and self-protection. Many stakeholders reported at the village level, the attitude of panchayat officials even political leaders have become positive towards Persons with disability and it is a positive change observed in this pandemic.

# THEME-7: COMPASSION

Protect / Promote Well-being- Inclusion and Considerations provided for persons with disabilities in current COVID 19 / Lock down plans, actions and policies.

♣ At the village level when the government schemes began to be implemented, the attitude of Panchayat, PRIs members and local political leaders became positive and they wanted that Persons with disability should get all the support. A positive change that we have seen. (Program Manager, Male)

**THEME-8: FINANCES** included access to financial support and pensions, family savings at individual level and funding cuts at NGOs level. The economic difficulties continue to impact Persons with disability even after lockdown has been eased. Loss of livelihood was reported mainly among Persons with disability with small businesses and petty shops.

# **THEME-8: FINANCES**

Access to services and financial support, Pensions

- "Apart from pension there is no other income source as most have lost their small businesses like petty shops". (Program Manager, Male)
- "Project is trying to support with the available resources and build their income generating micro enterprises. But the challenge remains due to limited resources and banks are not willing to give loan to poor people". (Program Manager, Male)

#### **Funding cuts to NGOs**

"The staff of XXXX not been paid salaries for 3 months. The staff is working but that is harming children's home as well as their own home". (NGO In-Charge, Male)

**THEME-9: GOVERNMENT RESPONSE** included about any innovations, guidelines and policies in response to COVID-19 pandemic and any other specific plans and programmes to meet the needs of Persons with disability after easing of lockdown. Like earlier, stakeholders indicated that government should address the livelihoods of Persons with disability and their family so pandemics has minimal impact on Persons with disability lives. After easing of lockdown, government has taken initiatives and many circulars such as concessions to teachers, concessions given to attend offices and schools were circulated among NGO partners and Persons with disability.

## **THEME-9: GOVERNMENT RESPONSE**

#### Specific plans/programmes made to meet the needs of persons with disabilities

- "Many government circulars and SOPs have been circulated which we have shared with our members and homes and even schools though they remain closed". (NGO In-Charge, Male)
- "There are other circulars like concessions to teachers, concessions given to attend offices and schools". (NGO In-Charge, Male)

**THEME-10: POSITIVE IMPACT** included findings on positive impacts of the COVID-19 pandemic outbreak and after easing of lockdown among Persons with disability and their families. Many respondents agreed that government is more responsive compared to lockdown period. Attitudes of people have changed towards Persons with disability.

# **THEME-10: POSITIVE IMPACT**

## Positive impacts of the Covid-19 outbreak and post lockdown

- *The government in general are now more responsive. (NGO In-Charge, Male)*
- Attitude of people have definitely changed towards Persons with disability, which many project partners is acknowledging (Program Manager, Male)
- More people when they are talking of development they are talking about inclusion.
  If in a village there are Persons with disability then they are also thinking about them, which is a great and positive change. (Program Manager, Male)
- There are positives. After relaxation they are able to go out with restrictions and do some of their work. (Program Manager, Female)
- One thing appreciable is the teacher's attitude to teach despite all the difficulties. They want to do something for the children and somehow reach the children in whatever possible way, which is appreciable. (Program Manager, Female)

# **Case Studies**

(i) Program Manager describing the activities that he initiated for reducing economic impact of COVID

We worked on several fronts. We have a producer organisation; we have applied for a pass for procurement. On facing difficulty, we went to the DM and SDM sir with our board of directors and explained about producer organisation they immediately understood the concept and we got permission and further continued to do our work. First we contacted our farmers and started collecting milk and distributing consumers. This was in animal husbandry. In organic farming we started to have small stalls. We took permission and along with milk products selling points we set stall to sale vegetables purchased from small scale farmers. MSP was fixed for each vegetable, which was not very different from market value. Aiming to see that money of transportation was saved. We started collecting grains from farmers and for making wheat flour. (Program Manager, NGO)

(ii) Director of NGO describing how persons with disability beat all odds and become small entrepreneurs

I realized that the poor PERSONS WITH DISABILITIESs are facing a really difficult time in two ways in terms of livelihood. One is those doing small livelihood activities. It is a gradual journey for such PERSONS WITH DISABILITIESs. to become self-dependent. It starts from being ignored they join self-help groups, farmer producer organisation, cooperative societies, then move to discussion group, and then move to decision group/ mode. Then from decision they move to development group, then they become small entrepreneurs and then start their own small businesses. Step by step they move up. They were working in small areas as barber, beautician/sale of beauty products, tailoring, bangles shop, stationary, computer trainers, clerical work, chart corner, sweet shop, Pan shop, auto repairing, driving, electronics shops, priest, salesman, delivery boys, Tent House, hardware, shoes shop utensil shops, candle making, peon, salesman in mall showroom, delivery boys, vendors, mason, painter, home tutors, and some females work as maids at homes. Their livelihood got affected very seriously due to lockdown. But people started helping each other by selling essential items like milk, vegetables, daal etc., among themselves or on credit on repayable basis.

(iii) Description of how a community based rehabilitation effort done previously has paid off during COVID time, by a Program Manager.

Community-based rehab is very important because through community based we talk about individual rehabilitation. For instance, if we have increase a person's mobility, movement of limbs, exercises, to stop muscle wastage, so for that generally we use local resource as exercise materials. Instead of gym equipment we use normal wooden stick tied with rope for various exercises. Secondly Persons with disability having even little skill like carpentry or iron work, we engaged them in making assisted devices, adaptive agriculture tools. Through this we can depend for small repair work like bicycle etc. within the village instead of sending it outside for repair. So community-based inclusive development is very important, and we should develop it as much as possible, like seed bank within the community. The more we focus on local resource the more it will be easy for us, because local is most easily available, and can be found in our backyard. We don't need go anywhere.

For small children many toys are available for intellectual disability, but we use wet sand as clay and make clay moulds like square, rectangle, sphere to increase skill works. And paint them with colour available in the village. If it breaks we can make it again. It is easy to use for a child.

(Program Manager, NGO)

# **Key Findings and Discussion**

# Lockdown Phase

# Medical

- 42.5% reported that lockdown has made it difficult to get routine medical treatment
- More than half the respondents (53.5%) said that continuous lockdown might affect their health in future
- 12.7% who reported of pre-existing medical conditions, more than half of them (58%) reported difficulty in getting routine medical treatment.
- 28% reported that they had postponed regular medical appointments due to lockdown.
- About 35% reported the need of out-patient services at hospitals/clinics during lockdown and more than half (55.6%) had difficulty in accessing the required services.
- Similarly, 16.6% reported the need of emergency medical services during lockdown and nearly 45% had difficulty in accessing emergency services.
- About 35% of Persons with disability used assistive devices, of which the use of mobility devices was the most common (63.2%).
- Majority (73.9%) reported that they sanitize their assistive devices, 87.8% reported sanitizing at least thrice a day. Commonly with soap and water (~40%) and plain water (20%).
- Majority of the persons said that they did not need the medical services during lockdown and after easing of lockdown.

# Rehabilitation

- About 17% (n=69) reported the need of physiotherapy and rehabilitation services (Table-12). Of the people who were in need, majority (59.4%) had difficulty in accessing the required services.
- 77.9% of persons with disabilities reported that they were supported by their family for assistance with activities of daily living.
- 70.7% Persons with disability opine that the government has not given any special considerations to Persons with disability during the lock down, especially in terms of access to vital information, rehabilitation /therapy support services

- During lockdown, 75% found it difficult to access the rehabilitation services, and after easing of lockdown: the percentage reduced significantly to 41.7% (p value=0.03).
- Persons with disability did not receive any government rehabilitation services for their needs and program managers were sure that the disability getting severe given this situation. The lockdown has also restricted ambulation and transport services for accessing therapy if needed,
- After the ease of lock-down, most of the services were accessed by Persons with disability and was also provided by government through WhatsApp and tele counselling.

# **Mental Health**

- We found a significant proportion (~70-80%) of Persons with disability with feelings of stress and anxiety, many overwhelmed with the COVID-19 lockdown situation and feeling uncertain about the future.
- Majority of the respondents (>65%) were worried about fear of COVID-19 infection and about loss of income due to lockdown.
- Nearly half the participants reported of lack of support, many faced stigma (22%), discrimination (13%) and abandonment (3%).
- More than 75% of the parents and caregivers felt moderate to high level of stress in caring for children or other family members at home with impairment
- Less than 9% had any access to mental health services such as helpline or online counselling. Most (>90%) received emotional and practical support from family during the lockdown.

#### Education

- 73.3% of the respondents (parents only) felt that on being confined to home the children felt distressed.
- 65.9% of the schools were not providing online teaching to children during lockdown. Among the ones who received online teaching only 9.3% said that the teaching was not in accessible formats.

# Livelihood

• Majority (84.2%, N=320) of the participants mentioned that lockdown impacted their daily activities pertaining to livelihood.

- The supply chain of material that they had developed was affected in 57.1%.
- The supply of farm inputs like seeds, fertilizer, and pesticides were impacted in 60.3% of participants
- Movement of input and output supply due to lack of transportation was impacted for 76.2% of participants.
- Facility of water supply was affected in 34.3%
- The lockdown affected the pensions / remittance among 33.1%.
- Around (45.7%) were borrowing money because of lockdown, mainly for livelihood (65.2%).
- The main method by which they were coping with the financial crisis situation was through borrowing food/ money from relatives/ friends/ neighbours.
- Only 9.2% of participants thought they will accept any job for low pay because of poor income after lockdown ends.
- Only 18.2% thought loan/funds were available with inclusive Cooperatives

### Social empowerment

- Lockdown seems to have impacted participation in social empowerment activities: 54.2% said it impacted work as PRI members
- 52.9% of the participants agreed that it impacted village relief work
- 74.6% of the participants said it impacted working as a DPO member

# Key Findings from Qualitative Interviews and Focus Group Discussions

The findings from participant perceptions reiterated that COVID-19 itself has not impacted Persons with disability as much as the lockdown has. People want to help Persons with disability but are scared to give a hand due to fear of infection. It was reported that it is difficult to teach hygiene practices to people and to Persons with disability with assistive devices in few days. The lockdown had a critical negative impact on Persons with disability. There were instances of abandonment of Persons with disability in institutional facilities. The belief that "When time comes everyone has to die" came up during the interviews.

There was difficulty in accessing necessities such as food due to the lockdown, specifically due to the financial situation of Persons with disability. Government provided rice but only rice wouldn't suffice the needs of Persons with disability, there was no fuel among many.

There was a significant disruption in accessing medicines due to lockdown, with travel bans and no travel passes and poor understanding by police, Persons with disability faced significant difficulty in getting their daily medicines. Persons with disability with caregivers were not allowed to travel and caregivers faced difficulty to reach Persons with disability homes due to travel bans. Many NGOs helped Persons with disability in providing necessities such as food kits, dry ration as well as psycho-social support

Information about COVID-19 was not in accessible formats, not in the regional language or dialect. Awareness was given but the reasoning was poorly explained. In some regions, COVID-19 messages were translated into local languages and videos about COVID-19 were developed with subtitles and sign language.

Most of the health services was reserved for COVID-19, there was shortage of ambulances for Persons with disability and without them many Persons with disability could not go to a hospital for routine follow-up due to these restrictions. The minimum support required for Persons with disability have not been added to COVID-19 treatment plan. Most of the rehabilitation services had come to a halt due to lockdown, similarly with education and therapy services in the community. The district early intervention centre RBSK had stopped services including weekly therapies. Physiotherapists couldn't reach Persons with disability due to restrictions. With schools closed, children with disabilities were impacted the most, teachers were unable to deliver online classes, parents were equally worried as children are restless and do not know how to engage them. With no schools and children at home livelihood of parents have been affected. With regard to leisure activities, there is constant fear of infection to meet people, the close interactions between people were almost nil. Participation in leisure and community activities had drastically come down due to travel restrictions as well.

Home activities were provided by NGOs to the children and the parents, to engage the children and maintain their well-being. They also supported the local health centre and PHC, ASHA/AWW to ensure that they are protected, by distributing PPE. The Persons with disability created WhatsApp groups to distributed food, ration, and worked in close proximity with the Block Development Office, visited different villages, Panchayats etc. to ensure people are getting ration that the government had provided. The NGOs expressed happiness

that the previous investments of strengthening DPOs are finally paying off during COVID. It was reported many DPOs made significant contribution during lockdown in helping Persons with disability.

Livelihood was one of the most affected due to lockdown, which had a significant economic impact on families. The economic impact faced by Persons with disability was reported by all stakeholders during the in-depth interviews as well as focus group discussions. Pensions were affected, loss of jobs, loss of livelihood mainly among Persons with disability with small businesses and petty shops. Persons with disability had to face hardships not only through loss of income but the inability to travel to draw money from banks or to get essential groceries. Many Persons with disability working in private sector lost their jobs. With children with disabilities at home, many parents could not go to work. Fear of infection affected farming and labour work. In many regions, work and livelihood was affected not only due to COVID-19 lockdown but other natural calamities such as cyclone. Lockdown had a negative psychological impact and one of the most common reason was economic difficulty.

The biggest problem faced by Persons with disability was economic impact, with poor access to services and financial support, and social welfare and pensions being affected. There was miscommunication with regards to advance pension, where Persons with disability thought it was additional pension given by government, considering the difficult situation. By the time the clarification arrived from officials that it was only an advance, and not additional sum, they had already spent the amount. There was a mismatch of perception of difficulty: the opinion of government officials was that the main problem faced by Persons with disability was not lack of earnings or money, but an inability to go to the bank to withdraw cash. NGOs expressed serious worry about impending funding cuts. Some participants mentioned positive happenings of having a safeguard due to working on organic farming, so that food security was intact. Some people who owned petty shops took a risk and sold things surreptitiously even during lockdown, to tide over the economic compulsion presented by the lockdown.

Another biggest challenge was to reach Persons with disability and fulfil their needs. Some of the state governments have developed helpline with psychologists for counselling and guidance. Many accessed latest information related to COVID-19 on TV news channels, through mobile and from friends and neighbours.

Participants lamented that although the government released guidelines for Persons with disability after facing pressure from NGOs, they may become standalone guidelines, and may not be inclusive. With respect to inclusion and other considerations, many participants mentioned that DPOs went out of their way to provide medicines for persons with disabilities during lock down. Social-distancing and self-protection was however not being followed strictly.

Respondents suggested that the government should conduct needs assessment to know about the needs of Persons with disability. They felt that if Persons with disability are involved at all levels, many issues can be solved. Specific plans/programmes made to meet the needs of persons with disabilities were mentioned. Some described how they created support groups, connected demand with supply, and promoted exchange of good practice. The participants thought that the Government is not prepared in terms of readiness for the next wave of COVID. They suggested involving Persons with disability in District Disaster Management Authority and at every level, during planning of activities, to better tackle another wave of infection in the community.

Many indicated that government may not be prepared for the next wave and the current situation could have been better for Persons with disability if there was adequate time for Persons with disability to prepare for the lockdown and make basic arrangements to get adequate food, water and medicines. Stakeholders indicated that government should address the livelihoods of Persons with disability and their family so lockdowns such as the current one has minimal impact on Persons with disability lives.

Participants discussed some of the positive impacts of the Covid-19 outbreak and lockdown/post lockdown, including learning new skills, practising sustainable activities, bonding with the family, saving money by reducing expenditure, and so on. Some attributed the resilience to the presence of small community-based institutions, while others were happy that the availability and consumption of alcohol had dropped considerably during lockdown.

# **Key Findings and Discussion**

#### Post Lockdown/Easing of Lockdown Phase

- 60% of the persons found difficulty in accessing the emergency medical services during lockdown and after the easing of lockdown, the percentage reduced significantly to 40% (p value <0.001).</li>
- Out of the total 107 persons with impairment during the repeat survey, 72.9% hesitated to go to hospital because of fear of getting COVID. 86% were scared to go out and meet others.
- Likewise, during lockdown, 75% found it difficult to access the Physiotherapy / Paramedical services, and after easing of lockdown, the percentage reduced significantly to 41.7% (p value=0.03).
- Compared to lockdown period, there was a significant reduction in the proportion of persons experiencing stress, anxiety, stigma and discrimination after easing of lockdown.
- Similarly, with easing of lockdown significantly lesser number of participants were worried about interruption of caregivers.
- There was a statistically significant increase in the proportion of persons who were able to get regular mental health counselling or therapy related services after easing of lockdown
- There was no significant difference in relation to caregiver's mental health during lockdown and after easing of lockdown
- There was no statistically significant difference in education, livelihood, and social empowerment before and after easing of lockdown
- Composite analysis showed-The lockdown had impacted more than 80% of the persons with impairment in terms of medical (81.4%), rehabilitation (88.6%),

mental health (86.4%), education and livelihood (86.1%). However only 52.3% of the persons were impacted in the areas of Social empowerment

#### **Qualitative Findings**

There was not much change in lives of Persons with disability after lockdown was eased across regions in India. The attitude that "we have to live with COVID-19 like other diseases such as dengue or malaria" was observed. The situation continues to have negative psychological impact on Persons with disability and parents of children with disabilities. The costs of commodities like vegetables and other groceries have risen. Access to medicines have improved with lesser travel restrictions and the help of local authorities. However, free medicines which were provided through government programs are still not available to Persons with disability. In some places day care facilities have started but Persons with disability are unable to reach as there is no public transport.

Access to general health services continues to be poor, most governments are focussing on COVID-19 services and not on other health services. In some regions, people visiting general hospital are treated as COVID-19 patients. Costs for other health services have increased.

With regard to therapy and rehabilitation, in many urban regions, WhatsApp have been used to provide early intervention services online for children. Recorded videos have been circulated via WhatsApp and through one to one conversation over the telephone with the carers, rehabilitation services to the needy is being provided. Schools and educational services continue to be a challenge like earlier. Some of the urban and peri-urban regions have benefitted with online services, remote places with poor connectivity are still struggling. Employment and livelihood continue to be a significant problem for Persons with disability. For many poor and marginalised, employment is still a question in both organised and unorganised sector. Apart from pensions, there is no income sources as most have lost their small businesses like petty shops.

There is no specific financial support from the government for NGOs working with Persons with disability. Whatever support is being provided are from larger NGOs and with financial support from corporates but not from the government. There were several networks and individuals who voluntarily distributed food packets, grain and grocery packets to persons with disabilities on the roads and slums.

At the village level the attitude of Panchayat, PRIs members and local political leaders have become positive and they want to support Persons with disability. A positive change has been seen. Attitude of people have definitely changed towards persons with disability. More people when they are talking of development they are talking about inclusion. If in a village there are persons with disability then they are also thinking about them, which is a great and positive change.

#### Conclusions

This study, conducted in 14 states of India, assessed the level of disruption on the living conditions of Persons with disability due to COVID-19 and related restrictions and to generate evidence to inform actions for future pandemics or emergency preparedness. The findings of this study have highlighted the concerns of Persons with disability, their care givers and the health and developmental systems due to COVID-19. These observations should be used to prepare protocols and guidelines to tackle such emergencies in the future. Advocacy with the governments is critical so that the response to such a health or non-health emergency in the future can be quickly mounted and operationalized. An inclusive plan to mitigate the adverse impact should be in place quickly and implemented immediately rather than losing a lot of time in the response cycle.

#### **Recommendations**

The recommendations are organized in way the results were reported. These recommendations are made primarily based on the findings from the study and do not include anything out of its scope.

#### **Healthcare:**

People with disabilities had trouble in accessing general health care as well as care for COVID-19 screening and treatment. The difficulty was higher during the lockdown and it reduced while the lockdown was eased. The reason being Persons with disability and their family have tried to cope as well as decided to live with the situation over the period.

1. Access to general/specific information for Persons with disability about COVID-19 screening, treatment as well as general health care must be made available.

2. This information must be made available in accessible formats (e.g. Large prints, Alt text in webpages, Sign Language interpretation in any media broadcasts, etc.)

3. Persons with disability require assistance to access health care, especially those who are unemployed, those who depend on monthly disability pensions and those who need routine check-ups for hypertension, diabetes and other comorbidities. Hence special assistance and disabled-friendly COVID-19 protocols (e.g. which hospital is accessible, how to access medicines, can Persons with disability be assisted by an escort, will access be disabled friendly, how should one travel? etc.) must be available and accessible to them.

4. Provide supplies such as medicines, disinfectants, masks etc. for Persons with disability to protect themselves as well as others from COVID-19 infections.

#### **Rehabilitation Services:**

Close to 2/3<sup>rd</sup> of the study participants reported that the government has not given any special consideration during the lockdown, especially in terms of access to vital information related to rehabilitation, therapy support, and other services.

1. Access to general/specific information for Persons with disability in relation to rehabilitation, therapy support, and other specific services must be made available to them in accessible formats.

2. COVID-19 Secure guidelines and protocols (how should rehabilitation services be provided, when to initiate tele-rehabilitation, how to sanitise assistive devices etc.) for both accessing as well as the provision of rehabilitation and therapy services to both Persons with disability, especially children with special needs as well as rehabilitation service providers must be developed and implemented.

3. Enable secure service provision using innovative strategies such as tele-rehabilitation or with collaborations from existing private service providers to cater to the therapy and support needs of persons with disability, especially children who were receiving services through the RBSK programmes.

#### **Mental Health:**

3/4<sup>th</sup> of the study participants experienced moderate to high levels of stress, anxiety, and uncertainty about the future. They were overwhelmed because of the lock-down. These experiences were statistically significant with participant's age and employment status.

1. Consistent awareness generation in accessible formats must be the top priority, especially since close to 90% are fearful of meeting others, and may affect their mental health adversely

2. Mental health services should be made more accessible and available for Persons with disability during the lockdown. Online counselling services might help Persons with disability in the management of stress and overcoming their fear and anxiety.

#### Livelihood:

Participants expressed that the unexpected lockdown measures impacted more negatively than the COVID-19 pandemic in not just their livelihoods but also their families. Their livelihood came to a standstill because they were unable to work, earn, and economically contribute to their family. Support in terms of livelihood and employment might help in reducing the level of stress, their worry about the loss of income, and feelings of uncertainty about the future among Persons with disabilities. Drastic steps should be undertaken to mitigate this as a priority by

1. Respective State Government must ensure Relief measures, Special financial assistance, Subsidies, Furlough schemes, Access to interest-free loans for improving, or at least to maintain current livelihoods. 2. Borrowing money to run the households was seen commonly, and for this, the NGOs, DPOs, cooperatives, etc. must infuse seed money wherever possible, to break the cycle of debt among Persons with disability.

3. Loans available from cooperatives, and the obstacles to availing such loans must be quickly cleared by conducting a needs assessment of Persons with disability, especially for the economic requirements.

4. Best practices such as organic farming and dairy and the income from these initiatives being a means to sustain livelihoods among others should also be promoted for enabling the livelihood of Persons with disability.

5. Pensions were accessed by two-thirds of Persons with disability, which is a good sign. But this could reduce, with increasing funds that could be diverted to COVID related activities. Keeping in mind the programmatic and financial needs of disability welfare programs, the government should ensure that they are not negatively impacted in future.

#### **Education:**

Schools were closed and many parents of children with disabilities and special needs reported that they were unable to support their children in education and learning. Neither they were informed or provided with essential assistance in terms of access to internet, electronic gadgets etc. for continuing education amidst of the lockdown in a safe and effective way.

1. Standards for special education must be developed and implemented to provide access to education for Persons with disability, especially children with special education needs and those who were actually accessing education in specialised educational settings.

2. Online education for children in schools must be provided in accessible formats. To avoid the pressure of buying smart phones by parents, education must be provided in formats that are easy for parents to receive, both economic and technology wise. For Example, Special educators could prepare individualised education plan for children and train the parents through phone or a school website podcast to deliver this to their children at home. 3. Parent training plans must be developed and implemented through innovative strategies like special apps for parents. Provision of free internet services for Persons with disabilities who requires access to internet for education etc.

4. Every school must hold responsibility for education of Persons with disability within their capacity by providing them with essential materials, technology gadgets, training, information, and weekly/monthly plans to sustain effective learning.

#### **Social Participation:**

Persons with disability were unable to participate effectively during the lockdown. Though the context and levels of participation are diverse. In this study, we looked exclusively at engagement with the community.

1. With due considerations to precautionary measures, the participation of persons with disabilities in DPO meetings, as PRI members and in local level activities must be urgently strengthened, and the gains made over all these decades in inclusive planning must be consolidated.

2. All the gains made so far for Persons with disability should be sustained, and not lost. This can be done by inclusive planning at all levels of activities at governmental and non-governmental sectors.

#### Health systems:

- Strengthen the existing system (District Rehabilitation Centres) to respond to the rehabilitation needs (in addition to health care needs) of Persons with disability
- Develop specific programs and policies for Persons with disability especially to protect them from being more vulnerable to the pandemic situation
- Convergence between the health and social welfare department to protect the Persons with disability from additional vulnerability.
- Prioritise Persons with disability when developing a program or strategy to combat emergency situations like the pandemic.
- Include Persons with disability in the development and implementation of any plan, policies, strategies and programmes

- Plan ahead for any future emergencies of this scale with people centred and evidencebased approach to empowerment of Persons with disability.
- Invest in research and strengthening of systems for social care and empowerment of Persons with disability in India.

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#### **ANNEXURE -1**

#### **Additional Literature Review Details:**

# 1. Disability, Urban Health Equity, and the Coronavirus Pandemic: Promoting Cities for All

#### https://link.springer.com/content/pdf/10.1007/s11524-020-00437-7.pdf

Urban health equity is a key element of the urban planning. It can be achieved if legislators rely on the social model of disability that considers "urban design and policy" as fallible/culpable rather than individual impairments.

#### Recommendations:

Public Health information should be made available in audio, braille, e-pub, and easyto-understand formats; using real time captioning; relay services and text messages and ensuring digital information complies with W3C accessibility standards. Persons with disability and Disabled People's Organizations should be consulted through a participatory approach and included in 'Pandemic Response Task Forces' to ensure "Universal design and Access are mainstreamed into mitigation and response strategies." Continuum-of-care through access to nutritious diet, housing, in-home school, and community support should be provided. Paid sick leave when approved to caregivers ensures their adherence to physical distancing practices and "financial support (increased funding) is essential for developmental disability service providers to arrange back-up assistants in case of emergencies." Restriction on hiring of family members for caregiving must be eliminated as a policy response. Adopt and enforce more stricter labour protection laws to ensure Persons with disability are not dismissed from work due to unfair practices / discrimination. These all together comprise an 'urban disability justice strategy' wherein 'systemic ableism and structural exclusion' are addressed beyond the COVID-19 crisis, "providing health practitioners, researchers and policy-makers an opportunity to rebuild cities that are more inclusive and healthier for all."

# 2. COVID-19 in People with Mental Illness: Challenges and Vulnerabilities <a href="https://pubmed.ncbi.nlm.nih.gov/32298968/">https://pubmed.ncbi.nlm.nih.gov/32298968/</a>

Suggested Interventions:

Limiting exposure to media-related misinformation, promoting precautionary measures, advocating against stigmatization and marginalization. Facilitating problem-solving by enhancing self-efficacy (as per Banerjee, D., 2020). Education on stress symptoms and their management through sleep hygiene and relaxation techniques.

#### 3. COVID-19 and disabled people: Perspectives from Iran

#### https://www.tandfonline.com/doi/full/10.1080/09687599.2020.1754165

A study in Iran reported the barriers to access requisite interventions due to restricted transportation within and between cities, which has been imposed as an emergency response to COVID-19. The authors also bring forth the problems of people with visual impairment, who eventually rely on tactile perceptions which increases their risk to infection by SARS- Cov2. Similarly, people with movement disorders would not be able to independently apply preventive measures like hand-washing and hygienic maintenance of their assistive devices.

# 4. COVID-19: maintaining essential rehabilitation services across the care continuum

#### https://gh.bmj.com/content/5/5/e002670

In this commentary describing modifications made to rehabilitation services as part of national COVID-19 preparedness and response across 12 low, middle- and high-income countries, shorter duration of inpatient-rehabilitation services have been reported in India, Belgium, Tanzania and the United Kingdom. All countries have been functioning at 'reduced service capacity'. Rehab services include supporting stroke patients to develop balance techniques or fitting prosthetic limb to an amputee, all which require direct contact with patients and protection of personnel especially those redeployed from their original work environment to different settings owing to care constraints in such areas should be a strategic priority. For equitable provision of virtual health services (for ex: -telemedicine) rehabilitation should be one of the essential components of Universal Health Coverage as practiced in Germany, Guyana and the UK. Caregivers should be trained to ensure effective caregiving amidst the pandemic by experts as evident in countries like the USA, Brazil and China, through tech-enabled communication tools like live webcast sessions and chatbots. This requires adequate finances and infrastructure that prevents many countries from

implementing these measures. To ensure cybersecurity and access to high bandwidth networks, collaborative leadership of professionals, government and global community via public-private partnership is the need of the hour. Another area of importance is public health communication wherein the inputs from rehab consultants should be sought prior to dissemination with due consideration for a disabilityinclusive response.

# 5. The human rights of children with disabilities during health emergencies: the challenge of COVID-19

#### https://onlinelibrary.wiley.com/doi/pdf/10.1111/dmcn.14526

This paper recommends conquering the pandemic through a humanitarian response inclusive of children with disabilities. This implies steps to prevent issues like negligence, abuse and separation from family which are some examples of violating their human rights and forsaking their dignity. Promoting individual and collective rights instils autonomy and fosters progress of children with disabilities.

# 6. Digital triage for people with multiple sclerosis in the age of COVID-19 pandemic

#### https://link.springer.com/content/pdf/10.1007%2Fs10072-020-04391-9.pdf

For patients with multiple sclerosis, who are on immunotherapy or with other comorbidities 'remote assessment of symptoms and triaging using customized digital tools that are patient-centric' can help reduce the risk of contracting covid. This article suggests steps to be implemented prior to, during and post-encounter with the health system. This 'proactive screening process through google forms' enables patients to access healthcare services from the comfort of their homes, thus 'minimizing the economic burden' in addition to increased scope for 'individualized surveillance'

7. The experience of the COVID-19 pandemic in a UK learning disability service: lost in a sea of ever-changing variables – a perspective

#### https://www.tandfonline.com/doi/full/10.1080/20473869.2020.1773711

For inpatients with intellectual disability receiving support from NHS sponsored Learning Disability service in UK, COVID-induced lockdown implied limited access to visitors and only one telephonic conversation with family members per day. The isolation and uncertainty had mixed effects with some adults age around thirty years old, with either social anxiety, avoidance or autism spectrum disorder, finding it less demanding while others with generalized anxiety suffer lockdown. Report reveals an instance of suicidal ideation as access to therapies and social support was denied in the aftermath of lockdown leading to hospital-admission to ensure patient-safety. Some service-users who self-identified their vulnerability experienced significant increase in anxiety levels. Despite modified rules like one outing per day permitted to people with IDD, for physical activity/exercise, its benefits are minimal given the disruption of daily routines. Ensuring confidentiality during teleconsultation over virtual platforms has been a challenge to doctors, support staff and end-users.

# 8. Covid-19 and Spinal cord injuries: The viewpoint from an emergency department resident with quadriplegia

#### https://pubmed.ncbi.nlm.nih.gov/32307905/

People with SCI are at increased "risk of missing a COVID-19 diagnosis" due to altered physiology and impaired sensorimotor functioning. In this article, the author underscores the need for 'aggressive early preventive measures' to be immediately adopted by Persons with disability in general, and those with (SCI) Spinal cord injuries in particular. Neglect of ethical principles by healthcare professionals while triaging for ventilators based on unestablished stereotypic grounds elevates the vulnerability of those with SCI to be disproportionately affected. 'Social admissions' of Persons with disability to hospitals when caregivers are quarantined increases the burden on already constrained health system and rapid social arrangements should be facilitated to reunite Persons with disability with the community.

#### 9. Facing COVID-19 with a disability

### https://opinion.bdnews24.com/2020/05/29/facing-covid-19-with-a-disability/

"Even if you know where to go, there is nowhere to go." For the 16 million Persons with disability in Bangladesh amounting to 10% of the national population (in 2010), fewer resources at hand, make them completely depend on external support for food and finances. The BRAC survey identified that sign language is perceived/comprehended differently across various regions even within Bangladesh and the standardized Bangla sign language had limitations in reaching out to various sub-groups.

# 10. The COVID-19 Global Pandemic: Implications for People with Schizophrenia and Related Disorders

# https://academic.oup.com/schizophreniabulletin/advancearticle/doi/10.1093/schbul/sbaa051/5826166

People with Schizophrenia have "impaired decision-making capacities and insight which may be aggravated due to comorbid substance-use disorders known to be highly prevalent in this group." This makes them vulnerable to acquiring infection as they cannot comprehend and adhere to preventive measures and "the effects of stigma on care-seeking" compounds their ailments. Although there isn't any specific evidence between clozapine medication prescribed to patients with schizophrenia and coronavirus-related deaths, risk is not contraindicated because increased clozapine concentrations as an immune response to pneumonia (one of the covid complication), result in increased difficulty in swallowing, causing sedation, hyper salivation, and eventually death.

# 11. How Does COVID-19 impact Students with Disabilities/Health Concerns? https://arxiv.org/ftp/arxiv/papers/2005/2005.05438.pdf

In Spring, 2020 when COVID-19 has been in full bloom in Seattle, more than half of the students with disabilities (SWDs) inquired expressed concerns about receiving worse academic grades in the upcoming quarters and having to move their degree requirements in comparison to twenty percent of students without disabilities. There were also apprehensions on negative impact of courses that might not go online, prospective admissions to major being jeopardized, uncertainty of graduation timing and status of financial aid. The degree of worry/concern varied across disability types. Students with high fatigue preferred staying home as against those with hearing impairment who had to prepare for accessing audio-material through transcripts or sign language translators. However, there wasn't any statistically significant difference in concerns about online classes between university students with sensory impairments and their peers with other disabilities/health concerns. In case of mental health, there was a distinct experience of tension within households during the lockdown period for students with disability compared to their counterparts without health concerns. In addition to COVID-related worries, stressors included increased exposure to chronic discrimination (derogatory remarks) and major life adversities (interpersonal-conflict, maltreatment). Students with disability reported difficulty

concentrating, trouble sleeping and had negative feelings associated with isolation. All these suggest increased vulnerability of SWDs to multiple stressors and it is recommended that occasional absences do not affect student evaluation and online classes be designed for asynchronous learning, with instructors offering a 'connecting experience to students rather than elevating their distress'.

# 12. Impact of the COVID-19 Epidemic on Stroke-Care and Potential Solutions https://www.ahajournals.org/doi/10.1161/STROKEAHA.120.030225

According to the Big Data Observatory Platform for Stroke of China, there was a 26.7% decrease in the total number of thrombectomy cases and 25.3% drop in thrombolysis cases across 200 registered hospitals for stroke care in February, 2020 during which Covid-19 peaked in the country. Hospital admission rates declined by nearly 40% in 2020 compared to the same period in 2019. Despite a slight increase in treatment rates, the absolute number of cases dropped by approximately 25% in all hospitals. In addition to people not visiting hospitals and deficits in public awareness on stroke, the authors suggest lack of transportation and inadequate ambulance resources as the contributing factors for this reduction. COVID-19 screening process including patients' febrile illness and insufficient stroke medical staff could also be attributed to the increased door-to-needle time although currently there isn't any existing evidence.

#### Recommendations:

CT Scanners and laboratory resources should be allocated on priority to patients with myocardial infarction for prompt treatment. Also, along with awareness on covid-19, public health information on stroke-signs ought to be disseminated. Organizing national level campaigns to promote hospital evaluation for stroke and other diseases requiring specialist intervention within the golden hour is a crucial factor. Preventive measures aimed at reducing recurrent stroke rate should be executed. Alerting and directing stroke patients to designated centres would ensure fast-track-stroke-care pathways and help overcome COVID-induced challenges to a large extent. Protocols for ensuring rapid COVID-screening process for potential stroke patients should be framed and adopted.

#### 13. Disability through COVID-19 pandemic: Neurorehabilitation cannot wait

#### https://onlinelibrary.wiley.com/doi/abs/10.1111/ene.14320

Delayed hospital access for people with chronic neurodegenerative diseases like dementia, multiple sclerosis and movement disorders has an unduly impact on their neurorehabilitation needs. Telerehabilitation in the form of exergaming, robotic-based and exoskeleton interventions could help address physical, cognitive and language rehabilitation needs through digital media. However, persons with severe disability having imbalance, remote sessions on virtual platforms cannot replace physical therapies.

#### Recommendations:

Simultaneous occupancy of patients in common waiting halls should be reduced to a minimum and physical distancing measures while queuing should be properly implemented. Waiting areas and medical equipment should be sanitized multiple times each day. PPE especially masks could hinder practice of logopedic exercises, language training and other physical activities requiring simulation and so alternatives like transparent panels, face shields should be provided to Persons with disability based on their specific individual requirements. Masks also interfere with emotional communication means wherein facial expressions reflect empathy. This could affect mechanisms of neuropsychological support, ultimately slowing the healing process.

#### 14. Rehabilitation in the wake of Covid-19 - A phoenix from the ashes

# https://www.bsrm.org.uk/downloads/covid-19bsrmissue1-published-27-4-2020.pdf

COVID being a 'multisystemic condition' requires specialist rehabilitation service inputs under the directions of consultants in rehabilitation medicine. Individualized needs of each patient ought to be served through Rehabilitation Prescription system after proper assessment post-discharge from Intensive Therapy Units to reintegrate them with their communities. The same individual might present with diverse requirements at different stage of recovery, owing to secondary effects caused by the blend of personal, socio-economic, and environmental determinants. This amalgam of factors involved might further be worsened by COVID-related uncertainty, anxiety, and fear, particularly among in-patients undergoing rehabilitation who are alienated from visitors in view of executing the precautionary steps. "In the wake of the 'new normal' patients requiring aerosol-generating interventions, group therapies and hands-on treatments cannot avail them and those with disabling conditions receiving long—term support might suffer, as staff are re-deployed to COVID-wards." Close networking amongst critical care, acute medical and specialist rehabilitation professionals is recommended to ensure appropriate linkages at multiple levels of care synchronized with prior-identified recovery pathways. Multi-disciplinary rehab teams should comprise occupational, physical, speech and learning therapists, neuropsychologists, dieticians, and nurses to cater to both covid-positive and negative streams of patients. Electronic assistive technologies and orthotics should be procured in advance and facilitated through coordination between departments of health care and social protection services.

# 15. The Impact of the COVID-19 Pandemic on Disabled and Hospice Home Care Patients

https://academic.oup.com/biomedgerontology/advancearticle/doi/10.1093/gerona/glaa081/5815717

#### Recommendations:

To maximize health outcomes and minimize physical contact, home care patients with disability, should be assigned home-isolation. If family members ought to be quarantined, alternative space like quarantine hotels should be arranged. Advisory on COVID-preventive measures should be multilingual to avoid communication barriers for daily carers hired from countries like Vietnam, Philippines and Indonesia. Medical personnel performing invasive procedures like replacement of tracheostomy or nasogastric tubes as part of home-care should be self-vigilant and use protective gowns and masks to avoid potential risk from splashing of secretions.

#### 16. Covid-19 and persons living with disability

# https://www.standardmedia.co.ke/health/article/2001372918/covid-19-andpersons-with-disability

The Kenyan government's national council for Persons with disability has so far provided monetary support only to those who cannot walk, speak or feed themselves characterized as having severe disability, while many patients with neurological impairments are precluded from receiving cash-transfers.

#### 17. Covid-19: Life under lockdown for people living with disabilities

# https://www.dailymaverick.co.za/article/2020-05-21-life-under-lockdown-forpeople-living-with-disabilities/#gsc.tab=0

Mobility an elderly woman with disability affected as fellow passengers reluctant to help her reportedly due to ignorance and innate fear of contracting the virus by touching the wheelchair although it has been sanitized.

#### 18. Mental health effects of school closures during COVID-19

https://www.thelancet.com/pdfs/journals/lanchi/PIIS2352-4642(20)30109-7.pdf

"Children with ASD might become frustrated and short-tempered due to disruption of daily routines" according to Chi-Hung Au a psychiatrist in Honking. In a survey on young people under 25 years of age with pre-existing mental health issues in UK, 83% reported that the ongoing pandemic made their conditions worse.

# 19. The public health response to the COVID-19 pandemic for Persons with disability

#### https://www.sciencedirect.com/science/article/pii/S1936657420300686

#### Recommendations:

In order to provide targeted interventions, disability identifiers should be an integral part of data collection systems incorporated for surveillance and monitoring purposes. To identify mortality amongst people with different types of disability, data from vital registration systems at national, state, and local levels could be used despite limitations in accuracy and coding of death certificates. Sensitizing frontline data collectors on such issues could help improve the validity. Alternatively, where available linking data from prevailing secondary sources such as electronic health records and Medicaid service systems could be beneficial to analyze disabilityspecific impacts. Specific protective measures like limiting visitor access, temperature-screening, providing personal protective equipment (masks, gloves) within care-homes should be enforced. To overcome adverse effects of isolation, resilience building strategies like engaging Persons with disability in virtual gatherings, social chat rooms, online exercise, movie/game nights could prove useful in addition to providing exclusive hours for maintenance services like hair hygiene and dental appointments. Specialized grocery delivery services including extending curb side pickups and safe-ride-share services for accessing testing centres would be beneficial. Relaxation of no visitor policy and allowing a sign language interpreter in
ICU as a reasonable accommodation to Persons with disability who require assistance in activities of daily living should be the revised protocol to be adopted by hospitals to ensure patient-provider communication. Persons with disability should be included in the priority group to be vaccinated or provided with potential life-saving treatments, given their vulnerability. Preparedness and response measures ought to be periodically modified in concordance with the emerging situation.

## **ANNEXURE -2**

### **QUANTITATIVE QUESTIONNAIRE** (for the Person with Disability/Caregiver)

#### **GENERAL:**

Name of	f the person interviewed:						
Age:	Sex:	Sex:					
Type of	disability:						
Occupat	ion:						
Date:	Place:						
Village:	Taluka:	District:	State:				
Name of	f the staff & CBM Partner:						
a)	is your marital status? Never married b) Marrie u have children? a) Yes	· •	1) Divorced e) Wide	owed			
	If yes, How many?						
<b>3.</b> How r	nuch disability pension do	you receive per m	onth?				
Rupee	es						
4. Assist	ive Device:						
	) Do you use any assistive	· · · · · · · · · · · · · · · · · · ·					
b	Which assistive device use?	do you or person	ns with disabilities of	currently			
с	Do you/persons with d	isabilities sanitize	it while using it? a)	Yes b)			
	No, if yes, How many t		<b>e</b> ,				
d	d) How do you sanitize it (with what)?						

#### **MEDICAL**

- 5. Do you have any medical conditions?a) Yes b) No5.a. If yes \_\_\_\_\_
- **6.** Do you feel lockdown has made it difficult for you to get routine medical treatment?

a) Yes b) No

- 6A. Do you feel continuous lockdown will affect your health in future? a) yes b) No
- **7.** Did you face difficulty in accessing any of the following medical services during the lockdown?
  - A) Outpatient clinics -a) Yes b) No c) Did not need
  - B) Emergency medical services a) Yes b) No c) Did not need
  - C) Medicines -a) Yes b) No c) Did not need
  - D) Physiotherapy / Paramedical services: a) Yes b) No c) Did not need
  - E) Regular blood pressure monitoring: a) Yes b) No c) Did not need
  - F) Regular sugar monitoring: a) Yes b) No c) Did not need
  - G) Surgical procedures: a) Yes b) No c) Did not need
- 8. Are you able to get the medicines you regularly take?a) Yes b) No
- 9. Has lockdown affected your health insurance scheme?a) Yes b) No c) do not have health insurance
- 10. Is online consultation helpful for you?a) Yes b) No C) didn't use it
- **11.** Are you getting the same kind of care now, as before?a) Yes b) No
- 12. Have you postponed regular medical appointments because of lockdown?a) Yes b) No
- **13.** Have you had any medical condition where you had to postpone getting medical help because of lockdown?
  - a) Yes b) No

## **REHABILITATION:**

14. Who helps you in your daily activities?

- *a*) ASHA b) Paid caregiver c) Volunteer d) Family e) Others f) do not require help
- 15. Which of the following therapies do you receive?
  - a) Physio b) OT c) Speech d) Prosthetics e) Others f) do not require therapy
- 16. How do you receive therapy services during the lockdown?
  - a) In person at home b) In person at govt. rehab centre
    - c) Private therapy centre d) Virtual session e) Telephone session
    - f) Not receiving therapy due to lockdown
- **17.** Do you think therapy /rehabilitation support services are available for persons with disabilities during the lock down?

a) Yes b) No

**18.** Do you think that you will be capable of managing yourself in case of another lockdown?

a) Yes b) No c) not sure

- **19.** Has the government given any special considerations to Persons with disability during the lock down, especially in terms of access to vital information, rehab/therapy support services?
  - a) Yes b) no

## MENTAL HEALTH

**20.** What is bothering you the most since the lockdown

A. Fear of Infection						
a) Not at all	d) Moderately	f) A lot				
B. Fear of infecting others						
a) Not at all	d) Moderately	f) A lot				
C. <b>Fear of dying</b> a) Not at all D. <b>Lack of support</b>	d) Moderately	f) A lot				
D. Luck of Support						

a) Not at all	d) Moderately	f) A lot					
E. Gender based violence							
a) Not at all	d) Moderately	f) A lot					
F. Loss of income							
a) Not at all	d) Moderately	f) A lot					
G. Interruption of care giver							
a) Not at all	d) Moderately	f) A lot					
Any other							

**21.** Since the COVID-19 outbreak, to what extent have you felt each of the following:

A) Stressed	a) Not	at all	b) Moder	ately	c) A lot
B) Overwhelmed	a) Not	at all	b) Moder	ately	c) A lot
C) Anxious	a) Not	at all	b) Moder	ately	c) A lot
D) Uncertain	a) Not at all	b) Mo	oderately	c) A l	lot

- 22. Have you experienced any of the following during the lockdown?
- a) Problems in relationship
- b) Change in family dynamics
- c) Abandonment
- d) Isolation
- e) Stigma
- f) Violence
- e) Discrimination, Others, please specify \_\_\_\_\_-
- **23.** Do you have access to information related to mental health & care, psychological or emotional support and services? Ex: Mental health helpline, online counselling, stress management tips etc.)

a) Yes b) No c) do not need

**24.** Have you been able to get regular mental health counselling or therapy related services during the COVID-19 outbreak?

a) Yes b) No c) Did not need

- **25.** Did you face any problem for getting your regular psychiatric medicine if prescription date was old and you cannot get recent prescription?
  - a) Yes b) No c) Did not need

**26.** From whom are you getting emotional or practical support from family and friends during COVID-19 outbreak?

Please specify \_\_\_\_\_

## Question -27, 28 & 29 to be answered specifically by caregivers

**27.** As a caregiver/parent, are you getting enough professional support during this covid19 outbreak like earlier?

a) Yes b) No c) Did not need

**28.** As a caregiver, are you feeling stressed, anxious or depressed with caring for children or other family members at home with disability?

a) Not at all d) Moderately f) A lot

**29.** As a parent or caregiver, did you feel unhappy when the therapy for your child had to be stopped during lockdown?

a) Not at all d) Moderately f) A lot

### **EDUCATION AND LIVELIHOOD**

30. On being confined to the home, did the children feel distressed?a) Yes b) No

**31.** Since all schools are closed, has it affected the child learning?

a) Yes b) No

**32.** Is the school providing online teaching to children?

- a) Yes b) No
  - 32A. If yes, is it in accessible formats? Yes No
- 33. Has the lockdown impacted your daily activities pertain to livelihood?a) Yes b) No
- 34. Has the lockdown affected the following?

A. Supply chain of material that you have produced/ developed?

a) Yes b) No c) Cannot say

B. supply of farm inputs like seeds, fertilizer and Pesticides?

a) Yes b) No c) cannot say

C. transportation of input and output supply due to lack of transportation?

a) Yes b) No c) cannot say

D. facility of water supply

a) Yes b) No c) cannot say

**35.** Has the lockdown affected the Pensions / Remittance?

a) Yes b) No c) Do not know

36. Are you getting your full wages / pay during lockdown situation?

a) Yes b) No c) Not getting any wage

37. Are you borrowing money because of lockdown?a) Yes b) No

If Yes, for what: \_\_\_\_\_

**38.** Are you getting updates that you require for your business (such as price, suppliers)

a) Yes b) No c) Not applicable

**39.** Do you think you will accept any job for low pay because of poor income after lockdown ends?

a) Yes b) No c) Not applicable

**40.** Are you able to sell your produce/products?

a) Yes b) No c) Not applicable

41. Are loan/funds available with inclusive Cooperatives?

a) Yes b) No c) Not applicable

42. How are you (person with disability) coping with the financial crisis situation?

- a. By reducing size and/or number of meals eaten in a day in order that it lasts long.
- b) By changing diet to cheaper or less-preferred foods to have enough food to eat
- c) By selling off some household possessions and/or livestock in order to buy enough food to eat
- d) By borrowing food or money for food from relatives, friends, or neighbours in order to have enough to eat
- e) Not applicable

## **SOCIAL EMPOWERMENT:**

- 43. Has lockdown affected your participation in the following
  - A. Panchayat Raj Institution (PRIs) as Members?a) Yes b) No c) Cannot answer
  - B. Village relief work?a) Yes b) No c) Cannot answer
  - C. social mobilization with other community members for community issues?

a) Yes b) No c) Cannot answer

D. participation in village level covid response and planning?

a) Yes b) No c) Cannot answer

E. Disabled Peoples' Organization (DPO) meetings?

a) Yes b) No c) Cannot answer

F. Do they feel that after lockdown, working with community and PRIs will change?

a) Yes b) No c) Cannot answer

# ANNEXURE-3

# Interview Guide (PERSONS WITH DISABILITIES)

Name of the person interviewed:

Type of disability:

Age: Sex:

Designation/ Occupation:

Date: Place the person is from:

1. Please tell us about your disability, how are you managing it now during the COVID-19 outbreak and lockdown?

Probe

- What alternative arrangements have been made to meet these challenges?
- 2. Could you describe how the lockdown has impacted your daily life? Describe the biggest challenges you have faced during the lockdown. How are you dealing with this? *Compassion*

Probe

- How are you coping with the changes in your work and life due to COVID-19 outbreak?
- Have you been able to buy essential commodities related to food, clean water supply, hygiene and other essential supplies?
- Has the lockdown put extra burden on the family savings which was utilized for treatment?
- How has life changed from pre-lockdown to lockdown?

- **3.** For medical and chronic conditions for which you need medical care, how are you accessing medical services/treatment during this time?
- **4.** If you need therapy on a routine basis, have you been able to get regular therapy related services during the COVID-19 outbreak?
- **5.** Where do you get information related to symptoms of COVID-19? Is the information on COVID-19 in accessible format for you?
  - What about information related to mental health care?
- 6. How do you keep yourself away from COVID19 in terms of Self-Isolation, Social Distancing, Hand Hygiene wearing mask and Screening, especially given your disability?
- 7. Please tell us briefly about the psychological impact being isolated at home is having on you. For example, not being able to see friends or family and not being able to go out for exercise?
  - What were the measures you took to reduce the stress or take care of your mental health?
- 8. Have you suffered any form of discrimination because of the COVID-19 outbreak? Have you suffered any form of violence because of the COVID-19 outbreak? Probe
  - Do you think being a women/man/girl/boy makes it easier or more difficult in the current context? Can you explain?
- 9. As a caregiver, are you experiencing any changes or challenges with caring for children or other family members with disability at home? Probe
  - Has it impacted the health of your child/maintaining hygiene measures to be taken up for your child and family?

- As a parent or caregiver, how did you feel when the therapy for your child had to be stopped during lockdown?
- **10.** Do you think the government has done enough for Persons with disabilities during this time or could have done more, and do you have any suggestions to prevent negative experiences during future epidemics?
- 11. Are there any arrangements/specific plans/programmes been made to meet the needs of Persons with disability during this lock down by any organization/ institution? Did you receive this? Did you face any problem?
- 12. Do you think there are any positive impacts of the Covid and Lockdown?

## ANNEXURE-4

## **Interview Guide for Government officers and Project Managers**

Name of the person interviewed:

Government/ CBM Project Manager:

Age: Sex:

Designation/ Occupation:

Date: Place the person is from:

**1.** Do you think it is difficult for persons with disabilities during COVID-19 outbreak and lockdown– how and why?

Probe:

- Can persons with disabilities follow prevention techniques like Self-Isolation, Social Distancing, Hand Hygiene, wearing mask, etc
- What about the psychological impact of being isolated at home is having on Persons with disabilities? For example, not being able to see friends or family and not being able to go out for exercise

- **2.** How do you expect Persons with disability to manage their disability during the lock down, especially when services are not available and when they need it?
- **3.** What do you think are the best ways to provide therapy/rehabilitation in case a Persons with disability is confirmed positive of COVID-19 infection?
- **4.** Do you think Persons with disability will require special assistance in this kind of situation? What do you think will be there needs (Information, services-health rehab, general, Access, etc.)? Please explain.

Probe

- Do you have any suggestions for ensuring the needs of Persons with disability are considered /addressed during situations like this?
- **5.** What kind of arrangements/specific plans/programmes have been made to meet the needs of Persons with disability during this lock down in your department, organization or institution?

Probe:

- Has your department/organization done needs assessment during covid-19 outbreak?
- Where do you get the information/ data/ records regarding Persons with disability, and do you know of any other programs for persons with disabilities
- Do you think you have sufficiently addressed the needs and concerns of Persons with disability during the lock down with these arrangements/specific plans/programmes?
- **6.** If there is another lockdown in the future, what kind of arrangements/specific plans/programs you think will help Persons with disability in your locality?
- What do you think are the best ways to include persons with disability in the actions to combat COVID19 and the Lock down? Please suggest
- 8. What steps should the government have taken to avoid hardship during lockdown?

- **9.** Would you think the funds for Persons with disabilities programs/ pensions would be impacted due to the pandemic, do you think the government will be able to allocate same amount of funds like last year?
- **10.** Were there any issues related to abandonment, violence, abuse reported from beneficiaries during this lockdown?



INDIAN INSTITUTE OF PUBLIC HEALTH - HYDERABAD PLOT NO 1, ANV ARCADE, AMAR COOPERATIVE SOCIETY, KAVURI HILLS, MADHAPUR, HYDERABAD - 500033 PHONE NO. 040-49006000, FAX NO 040-49006060 WWW.PHFI.ORG

