

COVID_19

ISSUES, CHALLENGES, RESPONSES & THE SUGGESTIONS FOR THE INCLUSION OF PERSONS WITH DISABILITIES

The present document has evolved against the background of COVID-19 outbreak in India and the nationwide lockdown to prevent the spread of this disease. The lockdown has an unprecedented impact on the people especially the vulnerable section of the society. The present document based on the information provided by various organizations/individuals working with persons with disabilities, brings forth the issues, challenges, responses of the state and the civil society to cater to the needs of the persons with disabilities. This document endeavors to be a source of information for the various stake holders.

Acknowledgment

In this time of humanitarian crisis that has taken a toll on the life of millions across the globe, there is a need to work collaboratively and holistically to save mankind. In order to stop the spread of the novel Corona virus and protect the people from COVID-19, States across the world have opted for nationwide lockdown as a viable step in this endeavor. Given the rising number of cases, the Government of India too opted for the 21 days nationwide lockdown that started from the midnight of 24th March 2020. The nationwide lockdown has direct implications on the lives of the people in the territory of India especially the marginalized and the vulnerable sections of the society. Persons with disabilities are perhaps the most vulnerable social group and are more prone to contagious diseases like COVID-19 and thus it is imperative to address the issues and the challenges they are encountering due to lockdown.

As has been acknowledged before the need of the hour demands a collaborative and holistic approach, this document has been prepared to understand some of the major issues and challenges the persons with disabilities have been facing across the country and the initiatives taken by the government and the civil society organization in the various parts of the country. Thus this document acts as an important source of information for the not only for the policy-makers, but also for the civil society members and individuals working in the disability sector.

This document would have not been possible without the cooperation of the various organizations working in the area of disabilities. Thus, we extend our sincere gratitude to all the individuals and organizations for sharing the relevant information, important documents, suggestions, inputs and have contributed directly or indirectly throughout the preparation of this document and giving it a final shape.

We would also like to acknowledge that this document will be owned by all the contributors and we would request you to disseminate it far and wide and use it as and when required to cater to the needs of the persons with disabilities.

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1. Introduction

This document entitled “**COVID-19: Issues, Challenges, and the Suggestions for the Inclusion of Persons with Disabilities**” has been the outcome of the meeting initiated and organized by ASTHA against the background of pandemic COVID_19. Persons with disabilities are the most vulnerable section of the society and due to their bodily limitations are more susceptible to the deadly disease like COVID_19 that has cost the lives of millions across the globe. The document brings forth the various issues and challenges the persons with disabilities and those who require constant medical intervention have been encountering due to lockdown and COVID-19 crises. Based on the information and suggestions provided by around 20 organizations and professionals from various parts of the country and working in the field of disabilities, the document can be used as a source of information for the states and organizations to cater to the needs of persons with disabilities in this humanitarian crisis.

2. Issues faced by persons with disabilities in access to food and essentials

Food remains a basic concern of persons with disabilities and other vulnerable groups- daily wage earners, migrant workers, families living in extreme poverty. Many of the families we all work with, face dual challenges. They are living in poverty and face extreme hardships – struggling to meet even their basic needs.

Civil society organizations across the country have been instrumental in reaching out to these families and persons with disabilities. While State governments have initiated drives to reach cooked food as well as dry rations to families in need, many of these initiatives seem to be centralized to urban areas and areas bordering them. People living in remote areas seem to remain cut-off. There are many whom we still don't have complete information about. It is in this context that mapping and identifying who these people and families are and where they are based, becomes extremely important. While each organization can reach out to the people it is aware of and is in touch with, there may be many who get left out.

The lack of documents in access to their rights is reflected time and again. It comes to the fore yet again. The State governments have also reached out with rations to persons- however here again the documents like ration cards required to access these create obstacles. While there are different strategies being seen in different

states, some of the common elements that come to the fore are that it is the civil society organizations that are devising strategies to reach out to persons with disabilities. Some of these strategies that organizations across the country have shared include:-

In Delhi, Civil society organizations like Astha have been reaching out to families of children with disabilities as well as adults with disability, in the communities they work with and beyond. The organization reached out and supported many families in the Northeast of Delhi that is distressed due to violence over NRC followed by the lockdown. ASTHA has identified around 50 high risk families with children with disabilities or persons with disabilities (families that have 5 or more than five members, or single-parent families and economically downtrodden) in the areas it is operational and provided them immediate support and ensured dry rations for two months reach them as well as ensuring that the families are linked with centers where they can get cooked food. ASTHA has followed a multi-prong strategy and approached local MLAs and local organizations to support persons with disabilities in distress. The team also have been engaged in telephonic follow-ups with the families they are working with to provide relief.

In Bihar, Persons with BPL cards are being given rations, but many persons with disabilities do not have their names on the ration cards. Thus they get left out.

Commissioner Disabilities of Assam has been looped in to ensure that essential commodities reach persons with disabilities.

In CHANDIGARH, different agencies like Social Welfare department, the Chandigarh Administration and the Red Cross have come together to reach out to children and adults in need, including those with disabilities. Food is being delivered to them at home.

Additionally, in Chandigarh the Childline and the Helpline for Women are also coordinating the effort. Any call pertaining to need for food or essentials is connected with agencies; who have it delivered to the person's house. The anganwadis workers are delivering 7 packets of panjiri, per week [one for each day] to each child in their area, including children with disabilities. The ICDS Supervisors are connecting all families in their area with persons with disabilities

across all age groups, children and adults, with the government agencies and they are able to reach out with dry rations, other essentials and cooked food. This is being done for all families in need, not only families with persons with disabilities.

The state government of Gujarat has started providing free ration only to ration card-holders. People can not get rations on the basis of other documents like the disability card or widow certificate. The government has also started a helpline number 1077 for food, where if you call for food then meals for two times are provided/arranged by the local authority immediately. No ID is required for accessing this service.

However the NGOs in Gujarat are distributing essential rations for one month to persons with disabilities. Disability certificate is not mandatory nor is the physical presence of person with disabilities required for availing the ration. Any family member can avail it on her/his behalf by showing any kind of ID proof / a photograph / any document/ID of any organization issued to the person with disability.

Most of the persons with disabilities are being supported by their primary organization. For example, Sense International India has collaborated with Blind People Association and four other organizations. They have made hubs for providing support to persons with disabilities. In these hubs, happy meals are being provided but things are procured centrally. The hub also acts as a center for those who can come and collect food. They are also connecting with other disability organizations or other organizations that have community outreach.

Self-help groups of people with disability are being contacted and kits are sent to them and they are able to distribute it door to door. The major challenge is movement as there is limited vehicular movement, which impacts the number of food kits that can be transported. The Police Authority is however cooperating and issuing the necessary movement pass to them. People are also not able to come due to restriction and the onus of reaching them has been ultimately on the organization.

In Karnataka, the government is working pro-actively to provide food to the needy. The government is distributing cooked as well as raw food through Indra

Canteen. The Disability Commissioner is pro-active and reaching out to the organizations to assist persons with disabilities and their families.

Organizations linked to the Disability Network Alliance [DNA], Karnataka are reaching food to families- grocery for one month in urban areas. Apart from that DNA through its partner organizations has been reaching out to around 2000 families in northern Karnataka. Vivekananda Youth Movement in Mysore are arranging for medical assistance and shelter. Small organizations are reaching people in their vicinity to provide medical kit and food.

In TAMIL NADU the main demand of persons with disabilities in rural areas is for food. They cannot go out and dry rations need to be delivered to them. People with disabilities who tried to access food supplies from the distribution center found that by the time their turn came, the food had run out.

The organizations are using community workers to approach the persons and their families. Funding partners such as Azim Premji Foundation are allowing organizations to use the funds to provide food and immediate relief.

A Helpline run by the Disability Commissioner with the help of Civil Society Organization in Tamil Nadu has received 7000 calls from persons with disabilities across the State and most of the calls are pertaining to food, rations and medicines. In the recent days there has been a slight drop in demand for ration as the State Government scheme has started distributing Rs 1000 and some amount of ration also. However, to avail that one must have a ration card.

In WEST BENGAL The government is distributing dry rations to everyone. There are many private organizations that have come forward to distribute cooked food to people. However this is largely limited to the towns and urban areas. The people living in rural areas, especially those in remote areas are getting left out. Distances and the lack of public transport make it challenging for people to come to access food supplies themselves and also pose a challenge for others to reach them.

Civil society organizations through their community workers and volunteers have started going home- to-home reaching dry rations in the areas that remain unreachable. Besides rations, they are distributing biscuits, treats, stationery, essential medicines.

In Uttar Pradesh during the lockdown, people are allowed to go and buy food, other essentials and medicines. However, access to these pose a major challenge for persons with disabilities. They are unable to wait in long queues and the lack of transport facilities makes it worse. Daily wage earners who were earning about 300-400 rupees a day and supporting their families are the worst hit. The loss of work and wages has impacted entire families.

In Cities/ urban areas, NGOs in collaboration with the government is distributing cooked food and rations. NGOs need to seek government permission before distributing food. The permission is easy to get and NGOs working along with the government in distributing food is working well.

Suggestions and strategies for reaching out to persons with disabilities in times of need

- ✓ Mapping and identifying persons with disabilities:- In coordination with the local coordination with local ngos, the government needs to prepare a database of the location of the persons with disabilities along with all necessary information so as to enable easy and effective reaching out in times of need.
- ✓ The district administration should carve out specific time for all the centers in the community like ration shop, dairy etc. Allocating a specific time for persons with disability would facilitate them in accessing essentials.
- ✓ The ICDS supervisors are totally clued-in regarding the children and older persons with disabilities in their area of jurisdiction. They could become key stakeholders in this process of identifying families in need of support, and link them with the concerned agencies and authorities.
- ✓ Flagging the concerns related to food security of marginalized sections of the society including persons with disabilities and especially people who have migrated across States, it is suggested : There is a need to reconsider the feasibility of the model such as the one followed in Tamil Nadu and elsewhere. There should be a direct transfer of cash in the account of beneficiaries instead of people distributing it in person. The system of delivery services should be retained during the lockdown period. Since it is difficult for persons with disabilities to go out and purchase essentials given

the long queues and lack of transport facilities. Persons with disabilities should get things delivered at their doorstep.

3. Issues related to access to health care facilities and availability of medicines:-

The lockdown has had a huge impact on persons with disabilities who require regular medication, therapy, caregiver support and access to health care facilities. Families of children with Thalassemia, children undergoing treatment for cancer, children who are on medication for epilepsy are all fighting against all odds to procure the necessary medicines, blood for transfusion, chemotherapy. Many are unable to procure the medicines, many are unable to reach the hospital they access services in. no public transport facilities have added to their woes. Many states are reporting short supplies or no supply of certain medicines, of blood that persons with Thalassemia require on a regular basis. Some families are being discouraged from coming to the hospital – both as a preventive measure to minimize the exposure to infection in a hospital; and also because the hospital personnel are over-burdened with persons who have tested positive for the corona virus.

Experiences across States portray more or less the same concerns.

A) Access to Blood for Persons with Thalassemia:-

In the present scenario the major concerns for **persons with thalassemia** especially children in the **Union Territory of Delhi** is availability of blood as they require blood transfusions on a regular basis. Since blood is generally collected through blood donation camps in colleges and offices, the lockdown has meant no camps. At the present moment, children are getting blood, but it is in short supply. Some have to wait for longer periods of time. Immunity levels are already compromised in children with Thalassemia and not receiving the transfusion at regular intervals lead to a further drop in immunity levels.

The Health Department in Tamil Nadu has made arrangements for persons who require dialysis. A specific ambulance number has been dedicated for this. The same service is made available for the persons who require blood transfusion.

A group of blood donors has been identified who have volunteered to donate blood in case of a shortage of blood. However, as of now, there has been no complaint about shortage of blood or medicines for Thalassemia in Tamil Nadu.

B) Access to Medicines :-

In Delhi, medicines for thalassemia are not available with chemists or even through e-pharmacies. These are only available with hospitals or the Thalassemia Society. Families of children with Thalassemia are able to procure a curfew pass and reach the hospitals or the Thalassemia society.

Families from other States who procure the medicines from Delhi are unable to procure medicines. They are unable to come to Delhi and with courier services currently not available, sending the medicines is also not an option.

The helpline for persons with disabilities operationalised by the **Disability Commisioner and the civil society organization in Tamil Nadu** has been receiving calls pertaining to non-availability of medicines. Hydroxychloroquine (HCQ), a medicine that is being used by persons with rheumatoid arthritis and those with lupus are unable to procure it. Chemists are reporting a shortage of HCQ because of it being publicized as a drug that can be used for dealing with the corona virus. It is difficult for persons with disabilities, especially those living alone, to go to the chemist to buy medicines. Waiting in long queues is not possible. Home Delivery of medicines should be mandatory for them.

The Indian state of Odisha is an exception as there is no shortage of medicines. Persons who require medicines need to route the request for it, through their doctor. Direct purchase has been rationed.

In West Bengal, at the moment most of the medicines are available at the local chemist, which remain open, but the shortages are beginning to be felt.

In Karnataka a pharmaceutical company is the sole manufacturer of a particular medicine that is sent out to persons requiring it. However the logistics of accessing the medicine are impacted by lack of transport facilities and lack of courier services.

Suggestions with regard to medicines:-

- ✓ Home delivery of medicines should be undertaken for persons with disabilities who are unable to go to the chemist or those persons with disabilities who live alone and do not have people who can support them access the medicines.
- ✓ At the national level, there should be a registry where people can fill in information about their medical condition (eg blood disorder) and get information about how and where to access medicines or health care services, closest to them.

C) Pertaining to guidelines and access to health care and other facilities:-

While the government has issued a set of guidelines for persons with disabilities during the lockdown, the guidelines do not have any specific provisions for persons with Thalassemia and many other conditions and disabilities.

The government needs to be aware that there are persons with disabilities living in the community, in remote areas, often living in poverty. They require access to health care facilities, among other things. Systems need to be created to facilitate this access. Persons with disabilities who are living alone are more vulnerable and require more support in accessing their rights.

TAMIL NADU has some tele-health facilities available for the persons with disabilities who require regular medical interventions.

In KARNATAKA [Based on documentary evidence shared on the group] **Parents from Karnataka** have highlighted the challenges faced by children with Autism and Down Syndrome. They are more prone to infections and require routine checkups, but are unable to access hospitals given the current scenario.

Uttar Pradesh reports that, in cities, people requiring access to medical services are able to get it. It is not posing too much of a challenge.

In the rural areas, Medical and health care facilities, on an average, are 8- 10 kms away. This makes it difficult for persons with disabilities to access these in times of need, especially in case of an emergency.

Public transports are not operational so even travelling to the nearest hospital or health care transport is not operational, so even traveling to the nearest hospital or health care facility is not possible, even if it is from one village to another.

Children with disabilities who are undergoing some medical intervention /treatment process are not able to meet doctors as most appointments are being postponed.

In Bihar persons with disabilities and those who require constant access to medical and health care facilities are facing challenges in Bihar, especially at the community level.

A lot of children who are undergoing treatment for cancer in Chandigarh and travel from places like Himachal Pradesh, Punjab, Haryana, Rajasthan, Jammu, Kashmir, Uttar Pradesh, Uttarakhand and many other places, including from Nepal – on a regular basis - are finding it difficult to get there. There are no trains or buses. While a few who are at a crucial stage of their treatment struggle to find their way to Chandigarh, most are advised to seek medical treatment at the hospital in their own State. Some have reported being forced to take private taxis – which charge a huge amount to get to the government hospitals in their own State, to access chemotherapy or get injections. Thus facing the dual impact of financial burden as well as going to a different hospital and doctor.

The children are also unable to get the specific dietary recommendations [curd, fresh fruit, juice, specific vegetables etc]

ORGANIZATION OF RARE DISEASES – EXPERIENCES FROM ACROSS THE COUNTRY

Lack of access to nutritious food, supplements is being seen. Most Government and Private hospitals have shut down the OPD services so blood transfusions, therapies, immuno-therapies etc. are not being provided.

D) Therapy

In the Indian state of TAMIL NADU The Physiotherapy Association has a list of volunteers who would go and conduct the therapy sessions at home on request.

In BIHAR many children with disabilities require various kinds of therapies-physiotherapy, occupational therapy, sensory integration therapies on a regular basis. Though the parents and therapists are in touch, it is not possible for all families to carry out therapies at home.

In **West Bengal** therapy of various kinds – physiotherapy, speech therapy or any other therapeutical input, remains impossible. This will pose a challenge for many children who have been receiving and require regular physiotherapy.

Suggestions

- ✓ In Tamil Nadu it is difficult for persons with disabilities, especially those living alone, to go to the chemist to buy medicines. Waiting in long queues is not possible. Home Delivery of medicines should be mandatory for them.
- ✓ In Bihar there is a need for some systems in place for assisting parents of children with disabilities who test positive for the corona virus. There is a need for trained personnel who can provide care-giving facilities for their children with disabilities in such an eventuality.

4. Issues and challenges related to mental health Care, mobility and livelihoods

The lockdown has brought the focus on basic needs like food, access to health care facilities and medicines. Some focus has also been on children with disabilities missing out on the education programme they were following. Many organizations have ensured that worksheets, story books and other activities are sent to the children to keep them involved. Many organizations and families have also highlighted the fact that children with disabilities who were accessing therapies on a regular basis are unable to do so. However, in this process the area that has not received adequate attention is that of mental health. Persons with psycho-social disability, persons who require medication, persons who are connected with counsellors on a regular basis are impacted by the lockdown across the country. Strategies need to be devised to reach out to them. People who were meeting

counsellors face-to-face need to shift to talking on the phone. Organisations such as Sangat, in Goa are reaching out to people on the phone to ensure that the support continues. Availability of and access to medicines remain another challenge that needs to be overcome.

Several tele-counselling facilities for people with mental health issues have been announced. But the question remains: are they adequate enough to address issues of those even with pre-existing conditions?

Besides this, mobility and livelihoods are other concerns of persons with disabilities across the country. While persons with movement difficulties find it difficult to go and procure essentials – given the lack of public transport facilities, the long queues and limited monetary resources in hand. Many people with disabilities have got even more isolated due to the lockdown.

DPOs that were active and were able to touch the lives of all persons with disabilities in their area are also unable to function. The redressal of many of their issues and concerns remain unaddressed.

Their employment and income generating ventures also have taken a hit due to the lockdown.

A) Mental Health Care

In GOA the mental health care needs of persons and the challenges that families are facing during the lockdown were highlighted. During regular times, there are some organizations that focus on the mental health care needs of the children/persons with disability and their families but now there is an increased need to address their mental well-being. There is a need to reach out to them. Organizations like Sangath are reaching out to persons with disabilities and their families through phone calls, instead of the walk-in support that they were providing pre-lockdown.

In TAMIL NADU, the challenges and issues of psycho-social disorder has been pertaining to medication running out or unavailable. The District Differently Abled Welfare Office (DDAWO) has been engaged in catering to their needs. With respect to, some emotional health or support, there is a mainstream tele-counseling service available by various government organizations. There are individuals who are dependent upon substance use – there are no support systems for them in the

present scenario. There is also a rise in domestic violence. Support systems also need to be created for them.

The State of Bihar does not have any provisions to cater to the needs of children with intellectual disabilities or those with mental illness. The parents and families are left out by themselves to cope up with any such condition.

B) Mobility and livelihoods

In CHENNAI and DELHI mobility is increasingly becoming an issue for persons with disabilities, especially persons with vision impairment. Since persons with vision impairment depend totally on touch for mobility and also need to rely on touch whether it is railings or shelves and items on the shelves in a store. While other people are avoiding touching things, they have to. This puts them at more of a risk.

Due to lack of mobility and closure of shops, persons with disabilities are unable to re-charge their phone credits. This cuts them off from many things that they do using their phones- reading, working, connecting with various media, friends etc. Many people are isolated further.

In DELHI Many people who are also running their own employment ventures and businesses are also affected. Their livelihoods are impacted due to the lockdown.

In Uttar Pradesh The assessment camps and distribution of aids, appliances and devices is also affected due to other departmental priorities.

DISABLED PERSONS ORGANIZATIONS

The DPOs that were very active in the State are being hit. They used to have meetings once a month to discuss issues and find strategies.

They used to approach the District Officers for grievance redressal - that is not possible these days.

They were able to reach out to all persons with disabilities in their area. Now because of the social distancing norms in place, they are unable to meet.

They were also getting together, taking loans and starting small scale units/employment generating ventures- all that is not possible during the lockdown-impacting livelihoods.

Suggestions

- ✓ ***SYSTEMS THAT HAVE BEEN INITIATED AND THOSE THAT NEED TO BE INITIATED*** Members from the Disaster management team should be trained to understand the specific needs of persons with disability. They should be trained on how they can reach out to persons with disabilities. A model should be created that is sustainable.
- ✓ Commissioners, Persons with Disabilities must be activated in all States and engaged with, so that guidelines are adhered to and necessary steps can be initiated to reach the most vulnerable.

5. Issues related to access to social security schemes:-

Social security scheme like disability pension has been instrumental for persons with disabilities to meet their daily living expenses and the states have the liberty of fixing the amount of the pension and the eligibility criteria. The amount of pensions varies from Rs 400 to Rs 2,500 per month. In the light of the COVID-19 pandemic and the complete lockdown of the country, pensions for persons with disabilities and other forms of social security schemes become crucial for the survival of the persons with disabilities. Additionally, the Government of India announced the cash transfer of Rs 1000 under the PM Garib Kalyan Yojana for supporting the persons with disabilities to tide over difficulties during the next three months. However, the financial assistance to the persons with disabilities are not only highly inadequate to meet the daily requirements of persons with disabilities but also has been creating ambiguities and challenges to avail it. There is to clarity if the amount of Rs 1000 will be disbursed every month to the persons with disabilities or the said amount will be divided in the next three months. For availing this financial aid, possession of disability certificate is essential however this very requirement has been acting as a major impediments for persons with disabilities as large number of persons with disabilities do not possess disability

certificate. Also there are apprehensions about the effectiveness and viability of advancing a pension for persons with disabilities at this hour. The promised transfer to Jan Dhan accounts of Rs. 500 - several people have reported it be credited to their accounts. But there is no information available as yet on transfer of this ex-gratia.

The Chief minister of Bihar has announced the immediate advance disbursement of three months disability pensions into the beneficiaries' account. However, the pensions would now be issued on 21st April is problematic due to a range of issues. There are a large number of persons with disabilities who lack documents like Aadhar Card, disability certificate etc. to avail the benefits of pensions. Also the mechanism of direct transfer of amount into the bank account of the beneficiaries is problematic as many of them do not have bank account. Additionally, Rs. 1000 are being given per month to children with disabilities; how far will it go when a child requires physiotherapy regularly

The Government of Gujarat has started providing an assistance of Rs 1000 per month through direct transfer to the bank.

In Goa the monthly amount dispersed is Rs 2500 for persons with disabilities and Rs 3500 for the disability above 90%.

Kerala has put in place doorstep delivery of pensions since the last nearly four years. Earlier it used to be through the post offices, but lately it is through local cooperative banks. Kerala initially gave two months pensions in advance. They had targeted to give five months more advance during April. Though the amount is Rs. 1,100/- coverage is higher as compared to other states. Also social security measures, health care, coverage of PDS etc is far better compared to other states.

In Uttar Pradesh Persons with disability receive 500/- rupees per month as disability pension. In line with the Central Government guidelines, UP State has also announced 1000/- rupees for 3 months as additional pension. There was confusion whether the 1000/- rupees were going to be given each month for 3 months and people thought it would be deposited in their accounts as soon as the announcement was made. Not receiving the pension has been the main point of concern.

Suggestions related to social security

- ✓ Disability pension should be given in advance to meet the daily living costs of persons with disabilities during the lockdown period.
- ✓ The government should come up with some social protection package for the children with disabilities or child protection allowance for children with disabilities which would compensate for the additional cost to the family. The government should also flag a child care grant at this time.
- ✓ There should be basic income support apart from compensating disability additional costs and services.. However, asking only for basic income support may not be useful for persons with disabilities. For example, if we consider the Pension (obviously an increased value) to be the basic income support, some States have maintenance allowance, care grant, additional costs due to barriers etc., that could be considered as compensating additional costs. The government needs to come out a package for them to compensate for their basic income and additional cost.
- ✓ In the current scenario where there is a squeeze in funds for social security (much more in future) it would be better to demand for an enhanced ex-gratia. As compared to other sectors have been demanding Rs. 5000/- per month, what is being offered to persons with disabilities is highly unsustainable.
- ✓ There should be demand a doorstep delivery of pensions, as also other services. Despite orders, it is not happening in many cases.

6. Issues related to access to information and helpline:-

The Central Government of India in its guidelines “**Comprehensive Disability Inclusive Guidelines for protection and safety of persons with disabilities (Divyangjan) during COVID 19**” has provided for the dissemination of all information related to COVID-19 in the accessible format, development of on-line counseling mechanism to de-stress persons with disabilities as well as their families to cope with the quarantine period, setting up of 24X7 Helpline Number at State Level exclusively for Divyangjan with facilities of sign language interpretation and video calling. It also provides that the States/UTs may consider

involving Organisation of Persons with Disabilities in preparation and dissemination of information material on COVID 19 for use of PwDs.

24x7 Helplines and mobile-based apps for persons with disabilities at this time of humanitarian crises are instrumental to protect the rights of persons with disabilities. The Government of various states, as well as various organizations, have operationalized helplines to cater to the needs of persons with disabilities and are proactively engaged in disseminating information related to COVID-19, government guidelines, and schemes to provide relief to the persons with disabilities in this crises, providing counseling to persons with disabilities and assisting them in a wide range of issues. The calls are related to food, medicines, assistance to reach the native place, strategies to deal with the children with disabilities due to closure of schools, etc. However, most of these helplines have limited outreach, confined largely to the urban regions and have not been able to cater to the needs of the persons with disabilities in the remotest of the various geographical regions. Also, issues and the challenges that have evolved due to this crisis have been unique and most of the helplines do not have the quick and the readymade answers to these issues and challenges. For example, since most of the children with disabilities are in their home due to the closure of the schools, parents especially having children with autism remain clueless and unaware of the ways to keep the children engage at home, how to conduct therapies etc., for which many of these helplines do not have quick answers. Also, several tele-counselling facilities have been announced in various states, and there is a need to engage and explore the viability of these facilities and are adequately informed and equipped to address issues of those even with pre-existing conditions.

Project Mumbai, has been providing counseling service for parents of disabled children from across the country to cope with COVID-19 related stress. The counseling is available in eight languages and fifty counselors from across India have been volunteering in this initiative. The queries are related to a range of aspects addressing the anxiety levels of their children to the activities ideas to engage their children as the schools are shut and there has been a disruption in the daily routine of the child. There are thirty special needs therapists on board whom the organization have equipped with an idea of the questions they are likely to be asked and gave them activity ideas to share.

The National Disability Helpline of ASTHA, New Delhi has started a temporary mobile number to assist the persons with disabilities on issues related to food, medicines, schemes in this crisis.

Project Eyeway, a helpline operationalized by **the Score Foundation a New Delhi** based organization for persons with visual impairment, has been engaged in providing disseminate relevant information related to COVID-19 through their counselors. The helpline has been receiving a large number of calls from the parents of children with visual impairment and blindness who are distressed as the schools are shutting down and forcing the parents to take the children back amidst the lockdown. There has been a large number of calls by the persons with visual impairment related to the queries on recharge of the mobile phone. Also, the helpline has been operational in only some geographical locations and catering to the needs of persons with visual impairment, the urgency of the time requires the organization to enhance and to broaden the scope and services of its helpline, setting up a helpline in new geographical areas where they have remained inoperational and serve the wider audience through disseminating the information about available resources and the ways to procure them. Additionally, the documents, guidelines, and information provided by the government remain highly inaccessible and disabled unfriendly and therefore the organization has been engaging itself in converting them into accessible format (word format) through various apps and software.

The Office of State Commissioner Disability, Bihar has launched a 24x7 helpline number **8448385590** in sign language, Braille and video calling facilities to cater to the needs of persons with disabilities and information about the disease. However, there is a need to extend the services at the various district level to further broaden its scope and extent. The government should work closely with organizations working with persons with disabilities that have a complete database of persons with disabilities – disaggregated based on disability. The government should use this to check out on persons with disabilities and ensuring they have the basic requirements within their homes during the lockdown.

In Chandigarh the Childline and the Helpline for Women have been involved in coordinating the effort. Each time a call is received regarding the need for food or

essentials, they share the contact details of the family with the agencies that can do doorstep delivery of the same.

In Gujarat the government has also started a helpline number 1077 for food, where if you call for food then meals for two times are provided/arranged by the local authority immediately. You do not require any id to avail the food and the food packets will be provided.

In Tamil Nadu, the Office of Disability Commissioner has been working closely with the organizations and members of civil society to operationalize the 24x7 Helpline with sign language. The helpline has received around 7000 calls for medicines, food and other things. Unlike other helpline started by other state government caters to the needs of urban persons with disabilities, this helpline serves till the remote areas/villages of Tamil Nadu. They have received 7000 calls from persons with disabilities across the State and most of the calls are related to the food, rations and medicines. The helpline have been receiving most of the calls from Persons with visual impairment.

There are some te-lehealth facilities available for persons with disabilities that need constant medical interventions. The Physiotherapy Association in Tamil Nadu has a list of volunteers who would go and conduct the therapy sessions in a home on request.

Mobile based app called Addressing & Including Diversity in Emergency Response (AIDER) which is run by the Disability Rights Alliance has been launched in Tamil Nadu to help the people in distress. The app is available in several languages and has an easy read version for people with intellectual disabilities. The app mystifies the COVID-19 and related information.

In the Indian state of Uttar Pradesh, there is a District Welfare officer for the empowerment of persons with disabilities in each District. Their numbers are on the websites and any person in the State should call them directly for redressal of grievances.

The Handicare's National Disability Helpline, in Lucknow Uttar Pradesh, has been receiving a lot of calls about pension, gaining access to e-pass for commuting for essentials, and very few calls about food not being available. The Handicare National Disability Helpline has been able to support persons with disabilities who

really need support and through the support of ‘National Disability Network’, the police and government agencies can reach out to them. Many DPOs, NGOs, PRIVATE agencies, good Samaritans are working in collaboration to provide much needed help to the Persons with Disabilities in these extraordinary times. But the role of Department of Empowerment of Persons with Disabilities in UP is not visible. However the Director of this department issued an order on 3rd April 2020 regarding issuing e-pass to the caregivers.

Suggestions related to the access to information and helpline

- ✓ There is an urgent need to design, form and publicizing a network of helplines that would proactively disseminate information and an authorized person at a designated time to talk with the persons or families of persons with disabilities.
- ✓ Information from the public and otherwise should be always inaccessible in terms of Braille, Audio, word and text format.
- ✓ Personnel working in the disaster management department should be equipped to handle issues related to disabilities
- ✓ Mobile based apps like AIDER should be used extensively by the government and can use it for converting the information in the local language. The district collector should be aware of it and use it whenever someone approaches him for the grievances.

7. Important suggestions and recommendations:-

- ✓ **WORKING TOGETHER** As individual organizations, with limited human resources, we can reach out to own areas where we work - but maybe that is not enough at this point. We should be linking with larger networks aggressively and the State and suggest strategies. We need to work out these strategies and identify networks to work with.
Civil Society Organizations and the government need to work together to ensure that all persons with disabilities are reached, with or without a disability certificate or other documents [given the fact that a large segment of the population does not possess any documents]. Civil Society Organizations working at the community level are clued in on the number of

persons with disability living in their area of reach and they should be involved in the effort to identify and reach the people who require support.

- ✓ There is a need to revisit the food security of marginalized sections of the society and especially migrated. There is a need to reconsider the feasibility of the model followed by the government in various states. There should be a direct transfer of cash in the account of beneficiaries instead of people distributing it in person. Some amount of delivery services should be retained and for the persons with disabilities essential things should be delivered at their doorstep.
- ✓ District administration to carve out specific time for all the centers in the community like ration shop, diary etc. only to cater to the person with a disability. In the general time, there is a huge rush and allocating a specific time for the person with a disability would provide ease and assured ration.
- ✓ The government must strengthen the social security measures for the persons with disabilities, increase the amount of disability pensions or ex-gratia and there should be a special security package for children with disabilities.
- ✓ There is a need to put together a matrix with different heads such as, food, medicine, counseling....and then putting together the quantitative information.
- ✓ The Government must in coordination with local NGOs, prepare or collect a clear database map of the locations of persons with disabilities mentioning their complete details to reach out to them easily and effectively
- ✓ Helpline through the department of PWDs in every State interconnected with all panchayat levels should be either strengthened or to be initiated.
- ✓ Information from the public and otherwise should be always inaccessible in terms of Braille, Audio, word and text format.
- ✓ Mobile-based app should be used extensively by the government and be used for converting the information in the local language. The district collector should be aware of it and use it whenever someone approaches him for the grievances
- ✓ Personnel working in the disaster management department should be equipped to handle issues related to disabilities. A volunteer band like NCC / NSS should be formed and trained to physically reach out to persons with disabilities for personal support.

- ✓ At the national level, there should be a registry where people can inform their medical condition (eg blood disorder) and access the information about the various links through which they could get their demands filled.
- ✓ The lockdown is likely to continue for a long period of time and its effects will be felt longer. The Central government should set up a monitoring cell exclusively for persons with disabilities. This cell should initiate specific measures for persons with disabilities across the country and this should be monitored on a regular basis.

8. **Information shared by the NCPEDP on issues and challenges in four states:-**

J &K:

Our partner is based in South Kashmir and he shared that there has not been any emergency situation with PWDs in this lockdown. And they are able to manage smaller issues of food supply or any other requirement at the NGO level. Government authorities are helpful. One issue that needs attention is the availability of passes. They are facing difficulty in getting passes to go out to provide essential services to needy. Our partner NGO and others have an emergency response group in place.

Maharashtra:

Report from there is not very happy. The helpline numbers are landline numbers that are not accessible for deaf. Also these officials are not well equipped to answer queries of PWDs or help them in any way. Social Welfare Dept. does claim of all the support but in reality nothing much is happening. Issues of ration, pension and medicines exist. There are people who can not go to the ration shop. NGOs help such people but they can not cover everyone. The Disability Commissioner has released an online link for essential services. But every PWD does not have a smart phone, or not proficient to access this link. This information was collected from the Rashtriya Vikalanga Kalyan Sanstha. They say monitoring is very important to keep a check on the implementation of programmes.

Madhya Pradesh:

We got a positive feedback from there. People who were getting pension INR 600/m were given 2 months advance (March & April) pension in March. There is no information on the central Govt. announcement of INR 1000 pension. Gram Panchayats in every district are vigilant and issues are getting solved at their level. State has provided shelter and food for PWDs who were homeless. Ration and medical needs are being taken care of.

Rajasthan:

Nodal officers have already been appointed. There was an announcement of INR 1000 pension for PWDs. There are total 350000 PWDs in Rajasthan who receive pension and out of these only 28000 people received the new announced pension. The criteria they set was, a person has to have disability 80% or above and must have BPL card. Even the amount was reduced to INR 500. Regular pension is available. And ration is also available. Landline helpline numbers are inaccessible for dear.