



COVID-19 & Issues facing Children and Persons With Disabilities and their Families in Delhi

Strategies for Future Action

(A Case Study of ASTHA's outreach, March-August 2020)



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Executive Summary

The nation-wide lockdown, to break the chain of Corona virus, that started on March 23rd 2020 and lasted for three months had short and long term socio-economic implications especially for the deprived section of India, causing reverse migration, hunger, starvation, loss of livelihood and range of other sufferings. Persons and children with disabilities cut across all social groups and are perhaps the most vulnerable ones. A large number of persons and children with disabilities reside in the urban slums and resettlement colonies of Delhi, and belong to migrant families engaged in unskilled work and are employed in the unorganized sectors. These are the vulnerable population that is often left behind during any humanitarian crisis. It is with these persons and children with disabilities residing in the urban slums and resettlement colonies of Okhla, Tughlakabad, Govindpuri etc. in Delhi that ASTHA has been working with for their rehabilitation since 27 years.

The present report brings forth the issues and challenges that persons and children with disabilities have faced during the three phases of nation-wide lockdown in Delhi and the work and learnings of ASTHA in this pandemic..It is for the first time in the history of independent India, that the country has faced a humanitarian crisis of such unprecedented nature. Like other organisations, ASTHA threw itself into the task of reaching out with a focus on children and persons with disabilities and their families. The report highlights some of the learning and some short and long terms measures that could be taken on a larger scale in the event of a crisis.

Chapter 1 of this report highlights the *geographical areas, the profile of the population that ASTHA has worked during this pandemic, and the strategies adopted to reach out to the distress families of persons and children with disabilities*. The organization decided to respond, to work through the lockdown, and provide immediate help to the distress families through referral calls from other networks and organizations. The organization followed a dual approach- support government by activating and facilitating government response' by informing people of new government efforts and to provide for urgent needs of as many children and persons with disabilities to the best of its capacity. It is important to reach across various

vulnerable sections in a crisis like this and consequently, the organization started providing dry ration to other vulnerable groups. *Lack of data with the concerned authorities on persons and children with disabilities and other vulnerable populations having spatial distribution across the city made the task of identification of distressed families difficult.* Reaching out to the bodies like Delhi Hunger Committee, Delhi Commission for Protection of Child Rights, enabled the organization to reach people beyond its geographical areas of work.

The organization *worked in a coordinated manner* with different agencies, alliances, stakeholders and such personnel who have intimate knowledge of the communities where they work and provide instant relief, proved to be useful in tough times like this. For ASTHA working in a coordinated and collaborative manner by being part of alliances and specific interest groups was beneficial as ASTHA and other partners/stakeholders acted as a source of information on various issues that individual organizations may not have speculated by working in isolation. The active involvement of disability alliances during the pandemic manifests that persons with disabilities are also actors in their own right, and in a crisis like this they and their parents act as resource persons and facilitate many families. Also, the role of helpline and technology as important channels of communication, disseminating different types of information in such distress cannot be undermined.

Chapter 2 reflects on the *status of social security entitlements like disability pensions for persons and children with disabilities during the crisis and inability of the many to avail the same as they are outside the security net.* Social security laws and schemes like pensions provide great relief to vulnerable populations like persons with disabilities, and enable them to lead an independent and dignified life. Although the amount is meager, yet, in many cases, the disability pension helps in the sustenance of their families, especially in crises like this. However, the disability pension is provided to only those who have a disability certificate..

The ex-gratia one-time amount of Rs 1000 for poor pensioners, widows, and people with disabilities for three months announced by the central government and also the double amount of the pension announced by the Delhi Government created ambiguities among the stakeholders. While the ex-grantia amount would be benefitting only 7.6% of working age persons with

disabilities who are beneficiaries of the Indira Gandhi Disability Pension (NSAP),¹ and the announcement of the double pension was actually clubbing together of two months of pension. ASTHAs National Disability Helpline received a large number of distress calls pertaining to the disability pension. *Due to lack of awareness, procedural requirements, lack of documents like disability certificate, inability to prove five years of domicile in Delhi etc. a considerable number of children and persons with disabilities that we reached out to were not under the social security net.* **This raises the question of how does the state protects its most vulnerable citizens in the face of a humanitarian crisis and disaster if the majority of them do not have access to such entitlement?**

Although, orders were given by the concerned authorities from time to time pertaining to a disability pension as well as about disability certificate during this pandemic, the information failed to percolate at the ground level. *At the time of the pandemic such orders must be publicized in accessible formats to all and proactive support is given to people to avail of these benefits.* Lack of disability pensions its pre-requisition of disability certificate affects the very young children with disabilities and also who are at the threshold of impairment and disabilities and hence left out of any specific support.

A large number of children and persons with disabilities without disability certificate and pension is not unique to the Delhi but also elsewhere in the country. *These are the silent crisis that happens all the time when societies do not make adequate provisions for citizens who have specific needs and requirements. It is important to understand the present humanitarian crisis builds upon the one silent crisis that has been ongoing for many years.*

Chapter 3 of this report highlights *the issue of food security in the pandemic and range of barriers that families of persons and children with disabilities had to face while accessing the dry ration and food during the lockdown.* Though the government at various levels announced for free ration and cooked food, yet large number of people went into starvation and hunger during this pandemic. Access to dry ration through Public Distribution System was a distant dream for many of these families as they were not covered under the food security net due to a range of bureaucratic and administrative requirements. Even for the persons with disabilities who

¹<https://kractivist.org/activists-respond-to-covid-19-guidelines-and-relief-measures-for-disabled/>

have a ration card, entitlements were still beyond their reach as they had to face barriers such as lack of public transportation, long queues at fair price shop, lack of accessible information about various mechanisms and modalities to have an access to food. It became evident that despite having disability-inclusive guidelines, it was not given due cognizance while implementation of these relief programs and the policymakers have been following the strategy of one shoe can fit all.

The State intervention in terms of providing two times cooked meals to the poor and destitute in its vast network of home shelter and schools was effective at one level but proved useful but the scheme did not have any strategies to assist a large number of people or children who could not reach the school. Each of the strategies taken by the government - providing dry ration or cooked food or even e-coupons, requires rethinking and there is a need to look into the lacunas in these schemes as the procedural requirements often rendered the policy inaccessible.

ASTHA provided immediate help to many families by giving ration kits, but over the time a more pragmatic and sustainable approach was required to support the families and to revisit whom, what and how long to provide. It is essential to recognize that people most vulnerable to food and nutrition crisis in the context of COVID-19 are those who were already exposed to critical food and dietary deprivations before the onset of the crisis. People receiving nutritional care services such as women and children in the first thousand days from conception, the sick, older people, and people with special needs;”

With the lockdown the ICDS stopped giving out nutrition supplements. Even when it was resumed, huge delays, shortage of food led to many children getting left out till the system was streamlined. The community workers saw that children with disabilities were the first ones to be left out during such a shortage. *Although there was food distribution through schools for families, the lack of targeted food for children is likely to have detrimental effects on children especially the very young children and children with disabilities.*

For the organization like ASTHA, the important learning during its intervention in food security has been the creating awareness at the local level became a very important activity to enable families and persons with disabilities to avail of the food they were entitled too.

At a legislative and policy making level, the chapter on Rights and Entitlements of the Rights of Persons with Disabilities Act should have guided our response. The inclusive guidelines passed by the Central Government were not adhered to in Delhi and elsewhere. Even though various reports including UNCRPD Committee: Concluding Observation on the Initial Report of India (2019) talked about the grim scenario of the social protection schemes and also on the absence of social protection schemes covering disability-related extra costs for persons with disabilities requiring higher levels of support².

In the coming months, it will be important to strengthen social protection systems for nutrition as it will become the mainstay for hundreds of millions of people for the duration of the current crisis and possibly beyond.

Health and health rehabilitation is the focus of **chapter 4** of this report and brings forth the problem related to access to medicine, therapies, and a range of other such issues that children and persons with disabilities faced during this pandemic. It reflects upon the issue of lack of blood for the transfusions for the children with thalassemia and other blood disorder diseases which are now recognized as a disability under the Rights to Persons with Disability Act 2016. Most of the children and persons with disabilities to whom we have reached out over the time belong from the socio-economic marginalized and they are dependent on the treatment and medicines from the government hospitals. The Ministry of Health and Family Affairs has come up with various guidelines and orders about treatment, availability, and selling of medicines through e-pharmacy, blood transfusion etc. However, all these orders and guidelines failed to cater to the needs of the population residing in the urban slums or the remote areas. The chapter brings out how the entire process of immunization of small children has been affected due to prolonged lockdown.

Chapter 5 of this document focuses on the distress that ASTHA encountered and the *educational rights of children with disabilities during the pandemic: the issues and challenges that the organization faced in providing education to the children with*

²UNCRPD ,Committee on Rights of Persons with disabilities (2019) , *Concluding observations on the initial report of India*, Section 58.
<http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6OkG1d%2FPPrICAqhKb7yhsmcRCSscUCudOHc8Goa6B5KHiDSsfFpmEa0FBET1G9nvFYoOB4XH4qm6L8Hio%2BB7gRD2dbe%2F%2Bn%2Fsta28vXfb7xSH3WI2YKoBbh%2BIOAfKMAsWr> Last Browsed on 12-6-2020.

disabilities, the core activity of the organization. It further highlights the strategies and remedies adopted to overcome these challenges. For ASTHA education has been the focal point and has conceived education holistically and its scope extends much beyond just pure academic skills. ASTHA with its professional team has been assisting the families of children with disabilities to get their child enrolled in the government school and to overcome the various barriers and challenges they face in their educational rights. The nation-wide lockdown meant a long break for the children with disabilities that ASTHA had enrolled in schools- are at home, like all other children. The team perceived the various issues that may emerge when the school would re-open including the reluctance of the parents to these children to schools, and also start educational intervention from scratch. The months of hard work may need to be re-visited as families may need to be convinced and prepared yet again regarding the benefits of school, and would require a constant push.

The team members work out the teaching-learning material that can be used for various therapies that child requires for their development depending upon what material is available. The community worker would demonstrate the activity to the parents over a phone call or if there is a smartphone, over a video-call. Parents share pictures or videos of these, with the staff members, who can further guide the parent on what to do next.

A lot of online resources especially the links provided by Pratham Publications- through their story-weavers link; Tulika Publications, animated videos of stories from the NCERT books are all being used. These links proved useful for children who can listen to a story when their parents are unable to take out time to narrate a story. As time rolls, the Astha team is innovating and responding to the changing situation. The teachers are planning the goals for the child and implementing them with and through the parents.

As the lockdown continues, the entire team ASTHA has been and continuing to work really hard, without a break in ensuring that:

- Specific need based support systems are created for each child;
- Newer strategies are evolved to reach out to the child and the family;
- All new children connected to the organization in the process of food distribution are being assessed and supported.

- Keeping the most vulnerable well within their radar and ensuring no child gets left out.

Chapter 6 deals with law and guidelines. The chapter highlights that despite the presence of disability legislation in the Country and the state commitment to the principles of various international treaties and covenants, these have been sidelined in various orders and advisories issued by the different ministries and department both at central and state level.

CHAPTER-1

COVID-19 : Issues, concerns, and problems of persons and children with disabilities and their families in urban slums of Delhi.

On 11th March 2020, the World Health Organization named the COVID 19 outbreak a Pandemic³. The Prime Minister of India on 24th March 2020, announced the three-week strict lockdown of the whole country due to the pandemic. He gave the nation just four hours to shut itself up. From 25th March to 16th May, the country went through three successive lockdowns. Phase 4 of the lockdown was from the 17th to the 31st of May 2020, in this phase some opening up had started.

As the country shut itself, distress started pouring in from many quarters. As a community-based organization working in the urban slums and resettlement colonies, ASTHA started getting news of this distress through the over 500 families it works within the slums. The organization decided to respond, to work through the lockdown from home and reach out the best it could.

As the pandemic turned into a larger humanitarian crisis, the two enduring images of the lockdown in India became the large scale exodus of migrant citizens of the country from the cities to the villages and the huge food scarcity that hit families who have little savings and cannot sustain without the daily earning. Children and people with disabilities were very much part of this group. They are also extremely vulnerable at times of disaster and humanitarian crisis.

As part of civil society, ASTHA too threw itself into the task of reaching out to children and persons with disabilities in its program areas and beyond. Apart from the groundwork of providing ration to families and people, the organization attempted to bring together an understanding of how children and persons with disabilities were being affected during the pandemic in the country. Two sets of virtual meetings were organized with representation from

³<https://www.who.int/dg/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---11-march-2020>

different parts of the country.⁴ Two reports were circulated sharing concerns and good practice so that larger levels of advocacy could be done.⁵

The RPWD Act 2016 provides for the protection and safety of persons with disabilities in situations of risk, armed conflict, humanitarian emergencies, and natural disasters.⁶ It provides for the National Disaster Management Authority and the State Disaster Management Authority to ensure the inclusion of persons with disabilities in its disaster management activities. ***It requires the District Disaster Management Authority to “maintain records of persons with disabilities in the district and to take suitable measures to inform such persons of any situations of risk to enhance disaster preparedness”.***⁷

In 2019, the National Disaster Management Authority, also came up with “National Disaster Management Guidelines on Disability Inclusive Disaster Risk Reduction” where they acknowledged that *“Persons with disabilities experience the impact of disasters and climate change disproportionately and are negatively affected due to additional exposure to risk than the general population.”*⁸

On 24th March 2020, the Department of Disability Affairs, Ministry of Social Justice and Empowerment issued “Comprehensive Disability Inclusive Guidelines for the Protection and Safety of Persons with Disabilities during COVID-19.”

However, disasters do not come in isolation. They settle on the preparedness of institutions to deal with a crisis. **The big question that needs answering is whether as a country we were ready with base of services, knowledge, and information on disability to be able to address the needs of children and persons with disabilities adequately when a crisis strikes.**

A. National Capital Territory of Delhi: A house of Millions from across the Country

4ASTHA (2020), <https://asthaindia.in/home/covid-19-response/>.

5For the reports visit ASTHA website. See <https://asthaindia.in/wp-content/uploads/2020/05/Some-emerging-challenges-for-the-inclusion-of-persons-with-disabilities-some-potential-suggestions-as-remedies-to-these-challenges.pdf>

Also see <https://asthaindia.in/wp-content/uploads/2020/05/Issues-challenges-responses-and-the-suggestions-for-the-inclusion-of-persons-with-disabilities.pdf>

6 RPWD ACT in its Chapter-II, deals with the rights and entitlements of persons with disabilities.

7Right to Persons with Disabilities Act 2016, Sec- 8, Cla-2 (India).

8 National Disaster Management Authority (2019), *National Disaster Management Guidelines on Disability Inclusive Disaster Risk Reduction*, pg:iii, GOI:New Delhi

Delhi has been a host city for the millions of migrants especially from the neighbouring states of Bihar, and Uttar Pradesh that has come and settled here in pursuit of better livelihood and income among wide ranges of other reasons. The educated and skilled migrant population can get decent employment opportunities and enhance their standard of living. However, a large proportion of the migrants' population in Delhi is engaged in unskilled employment, informal sector and have been providing support to the economy of this megacity. With their meagre income all, they could manage a rented accommodation in the urban slums of Delhi with almost no amenities of survival. This has short and long term impact on their overall well-being, making them and their children prone to malnourishment, communicable, and non –communicable disease and also impairment.

According to the CSDS data, 40% of Delhi's population comprises of migrants. Amongst the migrants, 48% are from UP, 18% from Bihar and a large proportion of these are daily wage earners engaged in unskilled work, engaged in unorganized sectors, or providing labor to the industrial units in and around Delhi and residing in the urban slums of Delhi⁹. A CSDS survey during the recent Delhi Assembly elections found that 33% of migrants from Bihar and 27% from Uttar Pradesh have monthly income less than Rs.10,000.¹⁰

B. ASTHA'S work among the urban slum communities

It is with these populations that ASTHA has been working within the *urban slums of South East Delhi in the areas of Govindpuri, Lalkuan, Tughlaquabad, Batla house, Giri Nagar (Kalkaji) and the six camps of the Okhla Industrial area for 27 years (1993-2020)*. Within these areas, the organization concentrates on working with persons and children with disabilities and their families. At any given time, the organization works intensively with over three to five hundred families and another 500 through referrals from other states. In addition, it works with communities and institutions such as education, health, and other systems to ensure the inclusion of children and persons with disabilities in all aspects of life. One of the focus areas is working with school-going and very young children with disabilities. The aim is to ensure that the child gets a good head-start in life as early as possible.

⁹<https://www.indiatoday.in/mail-today/story/coronavirus-in-india-how-reverse-migration-is-breaching-the-lockdown-1660835-2020-03-29>

¹⁰<https://indianexpress.com/article/explained/coronavirus-india-lockdown-migran-workers-mass-exodus-6348834/>

C. ASTHA’S close association with children and persons with disabilities

The families of children and persons with disabilities in these urban slums face the same vagaries of economic and social turbulence as any other family. They are part of the same ecosystem in society and their needs must be understood keeping these other factors very much in mind.

Amongst them, there are families of single parents, grandparent led families, families with more than one child or person with disabilities as well as families where one of the parents is incapacitated due to illness, accidents, tuberculosis, etc.

However, children and persons with disabilities do have their own specific requirements as well as significant out of pocket expenditure for disability-related expenses. Among other barriers, educational and other institutions often exclude them, and rehabilitation services are scant. Lack of accessibility and discriminatory attitudes are just some of the factors that make it particularly hard for the child and person during a crisis.

D. Migration: In search of a cure or rehabilitation

Apart from earning a living, many families have another reason for coming to the city: looking for rehabilitation and often a cure for their child with disabilities. For parents of Pratibha and many more, it is the primary reason to be living in the city.¹¹

Pratibha a nine-year-old girl, having low vision, has been associated with ASTHA since 2016 and belongs originally from Gorakhpore, Uttar Pradesh. The child has been receiving treatment for her vision from the Safdarjung Hospital, New Delhi and now in AIIMS. The mother shared with us “Bar bar Delhi aa kar ilaaz karana mushkil tha aur ilaaz ke liye kai kai din yahan rehna padta tha. Is liye hum yahan aa kar rehne lage aur yahi kamane lage. Lekin yahan mann nahi lagta. Gaon mein humara apna ghar hai aur ghar bhi bada hai. Yahana ane ke bad ek kamre mein rehna padta hai, koi suvidha nahi hai aur kamai bhi bahut kam hai yahan. Bachhi ka ilaz chal raha hai, who thik ho jayegi yeh soch kar hum yahan hai

E. Nuclear families, lack of support, the language barriers

The fact of migration cuts away at the support structures of a person or family with the nuclear family coming to the city, the elders of the family, and other relatives mostly staying in their

¹¹ASTHA (2020), *Process Document: Stories of Some Children with Disabilities*, ASTHA: New Delhi.

native place. While families do build communities in the city, the requirement of care giving for a child or person with disabilities largely falls on the family. Within that, for children, it falls on the mother who has to carry out all household activities and also look after the individualized needs of her child with disabilities. Single mothers who are also the breadwinners of the family often have to juggle many different duties to keep her family going.

Different languages and navigating the city, big hospitals for rehabilitation, online entitlements often push families who have migrated from rural areas into helplessness. Very often they give up. Having a child or a family member with disabilities brings with it sometimes more caretaking, exclusion from services and institutions of society, and disability-related expenditure which is other than the general expenditure a family incurs. In India and even in places like Delhi, it has meant a terrible lack of habilitation and rehabilitation services that are culturally accessible and available and very meager entitlements (if any). Migration from another city, even within the country, makes entitlements extremely difficult to access. It was in these conditions that the pandemic struck. Its effect on the lives of children and persons with disabilities cannot be studied in isolation, but on the back on what was and how prepared the country was.

F. The pandemic strikes: Responding to distress calls

In the first week of the lockdown, ASTHA started receiving distress calls. As work stopped, very soon the basic requirement of food hit the whole city. The first and most important response was to try and facilitate food security to those who earned by the day and had lost suddenly their only source of income. ASTHA works with many such families of children and persons with disabilities and they were the focus of the organization

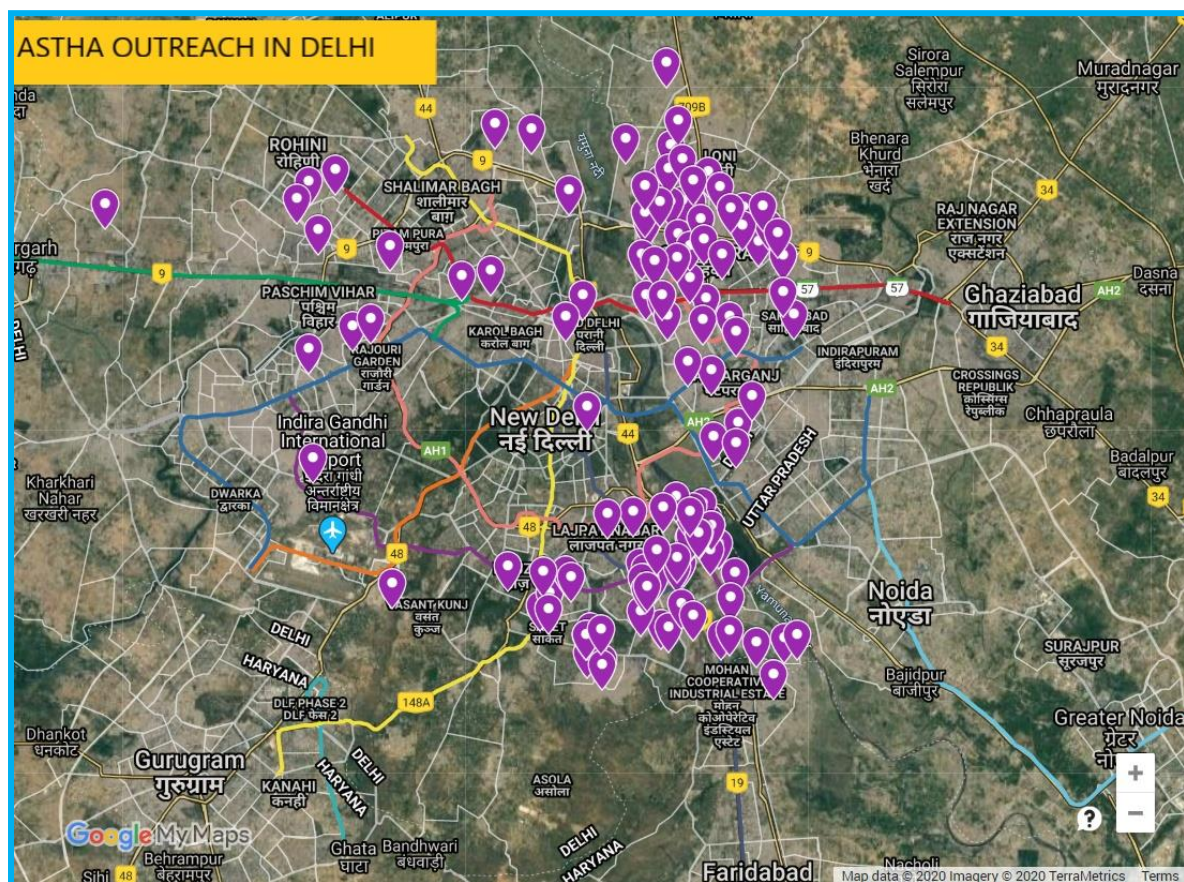
ASTHA witnessed a steep rise in the distress of the families it worked with from the start of 2nd week (30th march-5th April 2020) that there was a steep rise in distress calls. This was in geographic areas the organization works in. Soon networks and other organizations and individuals started referring distress calls from children and persons with disabilities and their families and the organization started receiving lists from areas across the city.

Apart from reaching out to the 250 families that ASTHA was already working with, the organization was able to reach out to two thousand (2000) other families through both planned and spontaneous outreach.

G. Planned reaching out to children and persons with disabilities

As distress started pouring in ASTHA realized that it must reach out to children and persons with disabilities beyond the families and areas where it works. After responding to distress for some time, *it was important to have a plan of how to reach out to people and children with disabilities as they are scattered within populations.*

ASTHA took a step back from response to a more systematic approach. *The organisation would follow a dual approach. It would support the government by activating and facilitating government response' by informing people of new government efforts. However, it would continue to provide for the urgent needs of as many children and persons with disabilities to the best of its capacity.*



ASTHA's intensive geographic areas of work are in slums and resettlement colonies of Southeast Delhi. **At any given point of time, the organization works with 200-250 families of**

children and persons with disabilities in these slums. In the lockdown period, the organization extended its arms and reached out to further around 1400 families in Delhi and some from other parts of India as well. While the reach covered nearly all districts of Delhi, there were some areas of intensive outreach. These included Northeast Delhi, East Delhi as well as South Delhi. Okhla, Batla House and Tughlakabad to Khirki, Madanpur Khadar, Sangam Vihar, Badarpur, Jaitpurin South East Delhi. Sawda colony in South West Delhi, Trilokpuri and Kayanpuri in the East. etc.

One of the focus areas of ASTHA's work, along with other disability organisations and activists has been the violence affected north-eastern parts of the city. This part of the city witnessed two disasters back to back in the form of violence and then the Covid-19 pandemic. The organizations facilitated rations distribution and initiated long term rehabilitation for families who acquired or had pre existing disabilities in the violence.

H. Where are the People and Children and with Disabilities?

Planning in a humanitarian crisis requires a double-pronged approach. It is important to reach out to all. But within all, it is important to identify people who are vulnerable and reach out to them.

According to the National Guidelines put out by the Department of Empowerment of Persons with Disabilities, the State Commissioners were declared as the Nodal authorities in respect of persons with disabilities. They are responsible to ensure that that all information about COVID 19, public restriction plans, services offered are available in the local language in accessible formats. The District officer dealing with the empowerment of PWDs is the nodal authority *“should have a list of PwDs in the District and monitor their requirements periodically and should have a separate list of persons with severe disabilities who need high support in the locality.”*¹²

¹²Government of India (2020), “Comprehensive Disability Inclusive Guidelines to States/UTs for Protection and Safety of Persons with Disabilities (Divyangjan) in light of COVID-19”, Government of India: New Delhi.

He is also “responsible for resolving the issue within the resources available and if necessary may take the help of Non-Governmental Organisations and Civil Society Organisations/Resident Welfare Associations”.¹³

Disability cuts across all the social groups including the migrant population and it is difficult to find where people with disabilities are in a city like Delhi. These are the questions that have confronted the disability community as well as planners during the pandemic.

I. What Kinds of lists are Available?

- ✓ *The Census?*
- ✓ *The school system?*
- ✓ *The ICDS system?*
- ✓ *People with Disability certificates?*
- ✓ *People availing of pensions?*
- ✓ *MNERGA lists in the rural areas?*

In Delhi, the government reached out to people with disabilities who had pensions with double the amount of pension for two months but it did not seem to have used this knowledge to reach out with any other support such as food security etc. to these families. For those who have a disability certificate too there does not seem to have been an outreach with any particular support. The Education Department of the Government of Delhi did come up with a circular about providing food to the children studying in Delhi government schools. But this number is very small and the order did not cover school run by the MCD and the NDMC.

Given the minuscule numbers of people who actually avail of these supports in the country, there have to be other ways of reaching out and targeting those vulnerable in times of crisis.

¹³ Government of India (2020), “Comprehensive Disability Inclusive Guidelines to States/UTs for Protection and Safety of Persons with Disabilities (Divyangjan) in light of COVID-19”, Government of India: New Delhi.

In the crisis ASTHA tried to reach out to those it knew would have an idea of where children with disabilities are in the NCR. It tapped the school and ICDS network.

J. Tapping the ICDS and school network: Reaching out to the Delhi Hunger Committee

The Government of Delhi set up a Hunger Committee to coordinate the serving of cooked food and rations to people in the city. Although the Central government asked states to create a policy to provide the midday meal to children, the Delhi government did not do that. Instead it designated over 500 schools in the city that provided cooked food to those who needed it twice a day.¹⁴

Seized with the question of how to reach out to children and with disabilities and other vulnerable children, *ASTHA along with members of the Delhi RTE forum wrote to the committee asking them to activate the school management committees set up under the RTE Act 2009.*¹⁵ These committees, as per the law are supposed to know about the children in their schools and who is vulnerable. Members of the committee who are parents and representatives of local bodies would also be aware of children who are out of school and needing support. This was one way of targeting our reach to the child with disabilities and others who would need support.

While the committee acknowledged the letter, it was unable to implement it as SMCs and teachers were required to serve food at schools. Almost immediately news of thousands of migrants leaving the city came out and the government's attention went to dealing with this crisis.¹⁶

The School Management Committees set up by the RTE Act 2009 are potentially powerful legally set up committees with representation from all stakeholders, parents, local authorities, teachers and other school authorities. They have a stated objective with regard to children with disabilities. Sec 6(h) of the Rules of the Act states that the SMCs are to

¹⁴Government of NCT of Delhi (2020), *Delhi Disaster Management Authority, Order dated 2-4-2020*, file no.- DDMA/COVID/2020/1/14.

¹⁵<https://drive.google.com/file/d/1eHf0TjD8PO7G1hsIe3csLcmBLIR7-tH2/view>

¹⁶*The Right of the Children to Free and Compulsory Education Act 2009, Rules, Sec. 6(h)* (India).

“Monitor the identification and enrolment of, and facilities for learning by disabled children, and ensure their participation in, and completion of elementary education”¹⁷

ASTHA then offered to the committee that if given a list of children with disabilities going to school in the South East of Delhi, it would call each child and check about the need for food etc. A list was procured by ASTHA of 300 children with disabilities who studied in Delhi government schools across the city. Then, started the task of calling every family on the list.

K. Reaching out to the ICDS system (Anganwadis)

Meanwhile, knowing that anganwadi workers are often the best source of information about children and people in their community areas, ASTHA also appealed to the Delhi Commission for Protection of Child Rights requesting them to ask anganwadi workers to identify children with disabilities and their families so that the organization could reach out to them.

On 18th April,2020, ASTHA received a formal letter from the Commission. This letter instructed the CDPOs and officials of certain areas to identify children with disabilities and their families and enable ASTHA to support them and facilitate need fulfillment.¹⁸

After some hesitation, and a lot of discussion with respective CDPOs, lists started pouring in from different areas. Surprisingly, these lists were not confined to little children but to older children and to persons with disabilities in the areas where the anganwadis operated. This gave ASTHA an understanding of the depth of information community based workers have about the vulnerabilities and the people who live in their areas.

Community workers – the backbone of any system

Sharda Rani, an Anganwadi worker with ICDS Sangam Vihar became ASTHA’s eyes and ears on ground. It seems she knew many families who were in acutely difficult circumstances. There were families which had migrated from Uttarkhand some months

¹⁷https://mhrd.gov.in/sites/upload_files/mhrd/files/upload_document/RTI_Model_Rules.pdf

¹⁸ <https://drive.google.com/file/d/1eHf0TjD8PO7G1hsIe3csLcmBLIR7-tH2/view>

ago, were living in rented cramped homes in Sangam Vihar and struggling for even food. There were persons with disabilities, families of young children with disabilities, pregnant women and other vulnerable families. It was told to the team by the families the pregnant women were forced to depend on the little nutrition they would get from the Anganwadi. The team was also informed of families where there was more than one child with disabilities, with elder people, and so on. A majority of these families were without ration cards, disability pensions etc.

This work of reaching out to ICDS enabled ASTHA to reach out to persons and families which tend to often be excluded from mainstream services and relief work as well. In the short term action, ASTHA facilitated support of dry rations and medications to families in *need but also was able to reach out to many more young children and persons with disabilities, with whom there is a huge unmet need for rehabilitation*. The team connected with many families who now are looking forward to knowing more about the work that can be done with them be it of entitlements, rehabilitation, or education for their children.

As of May 2020, the team has reached out to more than 250 families of children/persons with disabilities, elderly population, single women, etc. through the ICDS projects of Okhla, Madanpur Khadar, Gautampuri, and Sangam Vihar. The ASTHA team interacted with over 200 anganwadi workers, constantly calling, receiving lists. As lists poured in members of ASTHA spoke to each family, understood their needs, and then supported them with dry ration, information, and support for getting other entitlements such as the e-coupon, disability certificates, ration cards etc.

L. Potential Strategies in Times of Crisis

Although this strategy was tried out in a very small area, it points to many potential strategies at such times of crisis. It also informs us about the vast number of as yet unidentified children with disabilities and their lack of access to any kind of rehabilitation services. People who work closely with communities have perhaps the best knowledge about those who are vulnerable and would need support at times of crisis. The anganwadi workers, ASHA workers, CBR workers (in community-based projects), DPOs, women's groups, and other specific and other such personnel

are the people who have intimate knowledge of the communities where they work, whether it is in the urban or rural areas.

Institutions that are embedded in communities make access easy in times of humanitarian crisis. This fact comes out strongly at the time when the whole country was locked down. The government's choice of school premises to provide cooked meals is an indication of an institution that is available in nearly all areas of the city.¹⁹Because anganwadis were embedded in communities, the government was able to order that food be distributed to small children through the anganwadis and was able to cover large parts of the city.

RTE Act 2009 talked about having primary schools at a one-kilometer distance of the child.²⁰The ICDS was to have anganwadis for every 1000 families. The recent Delhi government move to merge anganwadis in an area and create hubs where large numbers of children could come have led to many children with disabilities dropping out of these services because of access issues.

It is important that these systems that are embedded in communities be strengthened and valued in India. Rather than rationalizing these systems, the country would do well to strategize in different areas and strengthen such systems and their reach in the population. These include the vast mosaic of government schools set in each community and the Panchayati Raj System. It also points to the importance of strategies that are local.

M. Where there is no institutions.

Danish is a 3 year old boy and stays with his family in Haji Colony, Okhla. His father is a labourer and mother a homemaker. Family, already with low earnings, was affected deeply by the lockdown. The government announced the distribution of nutrition to children through anganwadis but there is no anganwadi centre for residents of Haji Colony. The anganwadis that existed was merged into a large

¹⁹Government of NCT of Delhi (2020), Delhi Disaster Management Authority, Order dated 2-4-2020, file no.-DDMA/COVID/2020/1/14.

²⁰ Rights of the Children to Free and Compulsory Education Act, 2016 (India).

anganwadi to become a Hub Centre, far away from its original location. This led almost all children to drop out of Anganwadi as it is difficult for families to get their children to the centre. Children with disabilities are already left out and creating a Hub centre at a far location resulted in being left out from Government schemes. During the lockdown, there was no means for the child to get nutritional support and there was fear of malnourishment. It was then that ASTHA stepped in and decided to support the family with the supply of milk and eggs through a local vendor for children. He is not the only child affected by this lockdown, there are many similar stories from Haji Colony and other parts of Okhla.

There are geographical locations where the welfare services and systems have not been able to penetrate as in other parts of the city. These areas might be resettlement colonies, urban slums etc, pockets of migrant and refugee populations etc. The Tughlakabad village is one such area. Built on the years of conflict between state and other institutions, it is a settlement of Bengali migrants living beside the remnants of the famous Tughlakabad Fort. It is an area which has been bereft of Anganwadi network and faces a shortage of a number of such centres.

N. Reaching out to the Vulnerable amongst the Vulnerable

“Ester ki mummy ko to kothi waale ne nikal diya. Sabhi mahilao ke saath ye hua. Dheere dheere jo paisa bacha tha wo khatam hone laga aur khaane ki bhi bohot dikkat aane lagi. Jaha jaha khana mila hum waha gaye, par door paidal jaa ke bhi sirf 2-3 roti aur daal himiltithi. Mujh ko toh dar haiki is haalat mei kahi bhooke hi na mar jaye.”

As lists started pouring in from different sources, members of ASTHA called each family to understand the levels of distress and their needs. The aim was also to try and check whether the child or person with disabilities was eligible for any entitlement that the organization could

support the child to avail of? Ration cards? Disability certificates, disability pensions? Sources of income were checked and people spoke about the work they did and the situation that their family was going through at present.

The picture that emerged was an alarming one of large numbers of families stuck without work and money, without ration cards and other entitlements. Most families were out of the social security net. *It was important that we focus our first support on the family with no work, no disability certificate, pension and no ration card. While this did become a criteria to go by, very soon ASTHA realized that without any source of income even families with ration cards and pensions were in distress due to different reasons.*

The nature of state entitlements and social security support is often so small, that it is impossible for families to survive on just that. While families without any entitlements are clearly vulnerable, it cannot be assumed that those with entitlements may not come to the point of starvation during a crisis for many reasons. While there may apparently be different levels of need depending on formal indicators like having entitlements, the crisis has taught us that any family can get to the position of starvation and that it must be supported.

O. Other vulnerabilities

As an organization ASTHA has a policy to work across different vulnerabilities and disabilities. It recognizes that while there are specific requirements amongst different groups the basic nature of vulnerability with underlying poverty remains very much the same. At times of crisis, it is important to reach across sections and not rigidly stick to one's own. As the organization started getting calls from migrants, trans-people, children on railways and sex workers, single women-led families, it attempted to provide dry rations to these groups too.

Khirki Extension lies between the posh colonies of Malviya Nagar and Saket and is home to thousands of migrant workers. Sudden lockdown led to panic among workers as they are mostly daily wage workers and were left with no money and food around a week of the announcement. Around 2500 families were left in distress in the area. Among them were many with a person with disabilities, widows, and other vulnerable sections of society. ASTHA supported around 80 families with dry ration in the area.

East Delhi is a hub for trans people in the city. As ASTHA reached out for families of children and persons with disabilities, other vulnerable populations like the transgender populations and women sex workers reached out for rations from Trilokpuri and kalyanpuri.

Pallavi comes from Transgender community. She was abandoned by her family at a very young age and she started to live with the Transgender community from then. After a few years, she had to leave the community due to physical torture by a few people of the community. Then she decided to work as a beggar on the street side near Delhi Gate and she sleeps on the roadside nearby. There also she was troubled a lot by the public and even the authorities. Occasionally she was picked by Sewa kutir for punishing them for begging. They were asked to pay a fine and then released by the court. With a group of three others, she would continue begging in the day time and started to stay in a small Jhuggi. Life was already difficult, from all ends and the sudden lockdown led to loss of hope as no means of earning was possible in this situation. They did not receive any support from the Government despite the announcement of various schemes.

A few NGO's including ASTHA, stepped in this situation and supported them with Dry Ration and other essentials. This instilled a sense of hope among them and made their life easier.

P. The Building of Ecosystems Organically

As the crisis grew ASTHA let it be known that it was focusing on the provision of food and other requirements of persons for children and persons with disabilities. As the organization started to probe formally and informally individual leads started to come to us. The trickle soon turned into long lists being sent and the organization geared up to respond more while consistently energizing the system.

An ecosystem of varied organizations and individuals soon formed in the Okhla industrial area where the organization works. It was through these organizations and individuals and through small shops that were willing to accept on line payments that ASTHA was able to reach out to many families of children and persons with disabilities, now beyond its own primary stakeholders. *Working with others also helped to avoid any kind of duplicity of efforts.*

As first-time responders to such a calamity, the need to constantly verify with each other was great learning. The constant flow of information, both from the organization to the group and group to the organization helped in creating strategies and understanding how to proceed further.

Q. Responding to distress: The role of alliances and groups

At times of such a huge crisis, working together and pushing specific areas of concern such as food or education or children or disability become extremely important. Alliances and groups can easily bring together members from different regions and focus areas to be able to suggest strategies that are relevant and take into account diverse needs. They can give valuable information and suggestions to government when time is precious and when they need it the most.

For a disability organization such as ASTHA, being part of being part of alliances and specific interest groups is a strategy that has worked very well in bringing out disability concerns as well as understanding larger discussions that affect all, including children and persons with disabilities.

In times of crisis this also means that children and persons with disabilities will not be left out in planning and implementation. It also can mean that larger numbers of people are referred to specific interest organisations for their support.

In its turn, the disability organization is able to gather information about larger concerns, strategies and information to be shared with its stakeholders. It is able to reach out to other states with information and support as and when required.

ASTHA has both informed and been significantly informed by the Neev forces network, the RTE forum as well as the Right to Food alliances in this time of crisis.

R. Alliances of disability organizations

There are states in the country where alliances of disability organizations are strong and DPOs are also strong. These alliances and DPOs are extremely important as first responders in a crisis. They also proved to be extremely important in understanding the national situation of persons with disabilities in the country. It is important for organizations to be able to anticipate issues

coming up in different states as well as good practices. The process of sharing brings forward many issues that individual organizations may not have thought of.

Having consistently reached out on various issues to organizations across the country and put together national level reports of education and policies, ASTHA reached out once again as the pandemic struck. Five virtual meetings were attended by organizations and professionals from across the country. The aim of the meetings was to share the situations being faced by children and persons with disabilities during the COVID response in different states, the status of implementation of guidelines etc. The meetings and sharing and recommendations were then documented and shared with organizations to be used for advocacy in their individual states²¹.

S. The Important role of DPOs: The Viklang Ekta Manch

Nothing about Us without Us, these are some of the basic tenets of the disability world. In the 1990s as the community-based rehabilitation model gathered steam, there was a world-wide thrust on enabling groups of persons with disabilities to gather and work together in advocating for their rights. In India too, many CBR projects advocated this approach in the 1990s. However, as funding models changed in the country, the focus on enabling such groups seems to be on the wane. The attempts by the disability sector to push for CBR in mission mode did not take off and these strategies have taken a back seat to service provision.

The Viklang Ekta Manch (VEM) is a groups of young people across all disabilities who came together through ASTHA's long CBR program in the Govindpuri, and Lalkuan areas of Delhi. Over the years the VEM has become recognized as a disability advocacy group that functions on its own and is part of many different groups and alliances.²² Its strength is in its cross-disability membership of young people who live in resettlement colonies and understand firsthand the difficulties of living and coping with disability in the slums of Delhi.

²¹<https://asthaindia.in/wp-content/uploads/2020/05/Issues-challenges-responses-and-the-suggestions-for-the-inclusion-of-persons-with-disabilities.pdf>

Also see <https://asthaindia.in/wp-content/uploads/2020/05/Some-emerging-challenges-for-the-inclusion-of-persons-with-disabilities-some-potential-suggestions-as-remedies-to-these-challenges.pdf>

²²Urban village in South Delhi. ASTHA worked in CBR mode here for 17 years

During this crisis, members of VEM took the lead in advocating and negotiating at the local level. They witnessed first hand the deep distress that happened with families as the lockdown proceeded. They were able to reach out to individual families of children and persons with disabilities and negotiate with the MLAs and other officials at the district level to see that families were provided with dry ration. They were also able to apply for e coupons for many families who found on line procedures difficult and follow them up. They were able to look after their own members, some of whom faced distress because of lack of food security as well as illness. Members of VEM were easily able to understand the kinds of difficulties others in similar situations were going to face and the kinds of accommodations they needed. For young people with disabilities who were non verbal and understood by very few, the long years of friendship and understanding was very useful in their quest for food security and information on the corona virus.



For young people with disabilities having a group like this to fall back on in their community created a security net that was so required. It also strengthened the image that people with disabilities and their families do not always have to be supplicants. In their own context and milieu, they are perhaps the best to understand what is required by others with a disability as well as the community they live in. ***The strengthening of such community groups should be seen as a long-term strategy to enable communities to absorb the shocks of a humanitarian crisis.***

People with Disabilities are Not just Supplicants but Actors in their own Right: The COVID 19 crisis brought out the best in many ...

Afroz is a young man with disabilities living with his family in makeshift slums in Mazar Park near India Gate. He is part of a group of homeless families which have been living there since long and had many persons with disabilities as well. Afroz used to have a small stall of

tea on the footpath and just like him there were many more who used to do begging or had some other sources of livelihood. Post the lockdown, these families couldn't go back to their villages and stayed back. As the city moved from one lockdown to another, many of these families lost their livelihoods. Amongst them, there were single men with disabilities, families with persons with disabilities and non disabled people as well.

With information and other support from ASTHA, Afroz facilitated support for his community from the government and other civil society networks. Subsequently, he arranged basic necessities as soaps and detergents from a local NGO and reached out to the Rajya Sabha MP from Delhi, Mr. Sanjay Singh. Families from that area, with the help of Afroz received food and rations from Sanjay Singh's canteen and he later even reached out to the Sub District Magistrate of his area.

Gradually, Afroz enquired about other information from ASTHA like availability of wheelchairs, try cycles and was connected to ASTHA's helpline.

T. Parents of Children with Disability as Resource Persons in Crisis

Divyanshu is a 3 year old boy who lives in Gola Kuan in Okhla Industrial Area. He is a child with vision impairment and has recurring seizures. During the lockdown, the family found it extremely difficult to procure seizure medications of their child. The situation of Divyanshu's family was the same for many others who were not able to get these medicines. The medications weren't available in the neighbourhood mohalla clinics and going to tertiary care hospitals in lockdown was just not possible. A parent of a child with disabilities facilitated access to medication by speaking to a couple of nearby chemists. Although ASTHA paid for the medications, but it was the parent who facilitated all this, not just for his own child but for many others in the neighbourhood. Then there were many other parents who facilitated distribution of rations and milk at a time when ASTHA's community workers could not go on ground. Another parent, who lost a young child with disability recently came forward and stitched masks for families nearby.

Because of the organisation's intensive work with families in the community, parents have strong links with each other and were able to help others in this time of crisis.

U. Mapping Cities: Concentration of Persons with Disabilities

While mapping a city it becomes important to know that just like people of a cultural community band together and live together, groups of people with disabilities particularly blind people have tended to live in close proximity. In Delhi, it became clear as relief work progressed that there were other communities where people with disabilities and their families have tended to live together. The Sawda resettlement colony in North West District of Delhi is one such place.

Sawda is a resettlement colony in Northwest district of Delhi. Approximate and unofficial figures document the presence of more than 3000 persons and families with children and persons disabilities in the area. The concentration of persons with disabilities in areas of Sawda and Sunder Nagri has been because of systematic long drawn internal migration in a city like Delhi. The colony has been set up gradually in last one and a half decade with concentrated efforts to shift persons with disabilities and others who were engaged in begging etc.

It was the DCPCR and a person name Sonu which first reached out to ASTHA for support of dry rations and around 35 families were directly supported. Sonu is a person with disabilities who is a rickshaw driver and has worked for welfare and rehabilitation of children and persons with disabilities in that area. Post the deliveries of rations, more lists and requests started pouring from there every day. With another list of 100 people, ASTHA's helpline team enabled Sonu by giving him information and numbers to advocate with the government. Along with him, the team reached out to the district disability Officer and State Commissioner. Consistent reaching out and advocacy enabled Sonu to facilitate rations to more than 100 families in the second tranche.

V. Important channels of communication : The power of the phone

Information sharing has different aspects to it. As the state moves forward in tackling the crisis many different orders came out. *Much thought has to be given about how to reach this information in simple formats that are accessible to all. The dimension of accessibility is important in terms of reach of the information apart being in accessible formats.* The reach of information is an issue that concerns everyone in a city or rural area. One of the big concerns of persons with disabilities during the crisis has been lack of access to information. Information about where to go and what to do.

W. The Importance of Helplines: The Power of Information

Helplines that are already established and well known can become a very good source of information as well as outreach at times of crisis. ASTHA has been running the National Disability helpline since 2002. This cross disability helpline receives calls from all states in the country on disability issues. It connects with many other disability and specific interest helplines to ensure that callers are given the right information. Because of the sudden nature of the lockdown, ASTHA's landline could not be routed to a cell phone. Another number was immediately got for the mobile phone but the advantage of having a known number and a national reach was lost for some time.

As lists and distress started pouring in, ASTHA used its experience and resources as a functioning helpline to reach out to people rather than them reaching out to the organisation.

The helpline as a mode of provisioning has to be accompanied by a lot of information gathering about laws, schemes, rules and regulations and a connect with many different kinds of organizations. These connections, resources and referral resources become extremely useful at this time of crisis and have been used again and again.

X. Information Focused on Entitlements

Information in the time of COVID has centered around the different ways in which ration is being provided to different sets of people in Delhi. Since so many new families and persons with disabilities were contacted, information on entitlements such as disability certification, pensions, aids and appliances and other needs was also given. This is to be followed up once the crisis has abated.

Having a good online MIS enabled ASTHA to reach out to callers who had called the helpline in the last year, checking for any distress. In a short period of time, the helpline that receives calls became a help-line that makes calls and reaches out to people. Apart from calling families of children with disabilities, the helpline reached out to all the people who had called it in the last six months to check their well-being.

Over the course of the lockdown, ASTHA's helpline number received more than 500 calls from 14 states of the country. *A majority of these calls were for pensions, ration cards, disability certificates and related entitlements. From the calls received from Delhi, nearly all were*

asking for food, rations, applications to the Delhi government scheme of e coupons etc. A significant number of calls were also received from the states of Uttar Pradesh and Bihar. The focus once again has been on entitlements and how to avail of them in different states.

Even though the numbers are small in our sample, they point to the need of basic social security and protection in times of crisis. How this is to be done needs intense debate and discussion.

CHAPTER-2

The Status of Social Security Entitlements

A. Social Security Entitlements

Social Security laws and schemes like providing food to all and the financial assistance in form of pension to the old persons, persons with disabilities, widows belonging to the lower quintile of the society have acted as safety nets for the millions of people in India. However, due to the administrative requirements, the same schemes have also proved to be a bane for the migrants residing in the urban slums. Under the Constitution, the supreme law of the State, the migrants are protected under Part-III of the Indian Constitution especially Article 15,16, and 19 for their movement. However, when it comes to availing benefits of the social security schemes the constitution does not offer any advantage to the migrants and the existing administrative infrastructure for food security and disability pensions often act as an impediment for the migrants having persons and children with disabilities losing access to these social security entitlements upon moving to a different location, both within and particularly outside the state. Consequently, migrants become vulnerable to malnutrition and resultant health complications and are more profoundly pronounced among women and children with disabilities.²³

B. Disability Pensions

Persons with disabilities need financial support for independent living. Each state in India gives a different amount of financial aid in the form of disability pensions. This is given only to those children and persons who have been certified as having a disability. The disability pension ranges from Rs300 in some states to a maximum of Rs. 3,500 in Goa (in case of a person having more than 90% disability). Delhi has one of the highest amounts of disability pension at Rs2,500 a month. States also differ on the age of the persons they provide this pension to. In Delhi, pensions are given from the age of five onwards and even younger if there is a clear disabling condition the child has.

Although inadequate, ASTHA's experience shows that this financial assistance of Rs 2500/- has been important not only for the child but as for the family across the country. The amount is used

²³<http://mohua.gov.in/upload/uploadfiles/files/1566.pdf> pg. 29.

to provide essential and individualized needs of the child or person with disabilities. The same amount also often has been used by these families to make their ends meet.

Rihan is a 15 years old boy who lives in Govindpuri slums in Delhi. He lives in small rented places with his parents and a sibling. The only source of income is his father who is working on dailywages. Having two children at home and one child with special needs, the family frequently faced financial crisis. ASTHA's team of educators and social workers have been working with the Rihan and his family for his education, school enrolment and ensuring entitlements like Disability Certificate and Pension. It is during the pandemic, when there was no income that, the importance of a social security net like disability pensions becomes even more apparent. Even in pre Covid-19 times, Rihan's pension was an important support for his school expenses, medications etc. Now as the family stares at a hunger crisis and is under debt, this pension provides the much needed safety blanket for the family.

Tauqeer is a young person with multiple disabilities in his mid 20s who lives in Nehru Camp in Govindpuri slums in Delhi. He stays with his sister, Khushnuma and brother, Zameer presently. Khushnuma and Zameer, too are persons with mild intellectual disabilities but do not have any disability certificate. The family lost both the parents in a span of 12 months last year due to health issues. Mother was always stressed since in spite of her efforts, nothing would work out for the family. Being a child with Cerebral Palsy and vision impairment and living in a narrow lane in urban slums, access to education was always difficult for Tauqeer. His disability pension supported his medical surgeries, medical expenses, aids and appliances in pre Covid-19 times. During the lockdown, his disability pension is the only income for these 3 people.

Acknowledging the importance of the pensions for the old citizens, widows, and the persons with disabilities in this hour of crises, the Central government, as well as the government of Delhi, gave orders.

On 26th March the Union Finance Minister announced an ex-gratia onetime amount of Rs 1000 for poor pensioners, widows and people with disabilities. This was to be given in installments over three months.²⁴ However, as the months went by disability groups in different states realized that this announcement was not for all people with disabilities. Instead, the disbursement would be benefitting only 7.6% of working age persons with disabilities who are beneficiaries of the Indira Gandhi Disability Pension (NSAP).²⁵ Unaware of this, lakhs of disabled citizens kept on complaining of the non-transfer of the announced amount to their bank accounts. Slowly it came to light that this meager amount under NSAP is to be given only to those with 80% disability or above as in the original scheme. Under the original scheme, the Central government gives Rs 300 and State government has to give Rs 700 of the amount to be disbursed.

On 21st March 2020, the Government of Delhi announced that “all the recipients of monthly financial assistance under the government pension scheme will get an additional amount equivalent to one month’s annuity. The government has also decided to double the pension under the widow, old age, and disability pension scheme.”²⁶ The Delhi Chief Minister added that this would benefit 8.5-lakh beneficiaries. In Delhi, people with disabilities who were already getting pensions received a pension received Rs 5000, in the month of April, Rs 5000 in May. However, June and July there has been no disbursement.

In effect, it seems that the announcement of the double pension was really a clubbing together of two months of pension not really an increase in the amount. **While this was a useful strategy in the months of the lockdown, the slow pickup of the economy even as it opens up means that**

²⁴<https://www.thehindu.com/news/national/nirmala-sitharaman-announces-rs-170-lakh-crore-package-for-poor/article31170718.ece>

²⁵<https://kractivist.org/activists-respond-to-covid-19-guidelines-and-relief-measures-for-disabled/>

²⁶<https://www.newindianexpress.com/thesundaystandard/2020/mar/22/pension-doubled-free-food-for-homeless-kejriwal-announces-relief-measures-amid-covid-19-breakout-2119929.html>

<https://economictimes.indiatimes.com/news/politics-and-nation/pension-for-elderly-widows-specially-abled-being-doubled-in-view-of-covid-19-announces-arvind-kejriwal/articleshow/74747399.cms>

distress continues and is likely to continue till at least the end of the year. This was a strategy also used in some other states such as Tamil Nadu, Odisha, Himachal Pradesh and others.

C. Only a few availing of disability pension

However, only a few children and persons with disabilities could use this support:

During the months of April, May and June ASTHA reached out to a total of 1641 families of children and persons with disabilities. Out of these 229 were families which ASTHA has been working within its geographical areas. With each family and person, we asked in detail about the entitlements of disability certificates, pensions as well as ration cards.

In a random sample of 1412 people, the organisation found the following data:

Population	Numbers and details	Data
Children below 8 years	82 families <i>From urban slums of Khadar, Sangam Vihar, Aali Village, Jaitpur etc. Reached out in partnership with DCPCR</i>	3.6% of them receiving pensions (confirmed data)
Children and adults above 8 years	650 <i>350 families of school going children with disabilities across Delhi, list by the education department in Delhi</i> <i>100 families of adults with disabilities from Sawda, Delhi</i> <i>200 families of children and persons with disabilities From urban slums of Khadar, Sangam Vihar, Aali Village, Jaitpur etc. reached out in partnership with DCPCR</i>	14.7% of them receiving pensions (confirmed data)

Children and adults above 8 years	300 <i>100 families of adults with disabilities from Sunder Nagri, Okhla and Khirki</i> <i>200 families of children and persons with disabilities across Delhi referred to ASTHA from other organisations</i>	20% receiving pensions (approximate data)
Adults above 18	380 <i>People who called on ASTHA's helpline</i>	50% of them receiving pensions (confirmed data)
Total	1412 families	

Table: Random sample

The randomness of the sample and the results indicate that there would be millions of children and persons with disabilities who were bereft of this very important social protection scheme in Delhi during one of the biggest calamities that India has witnessed in the recent years.

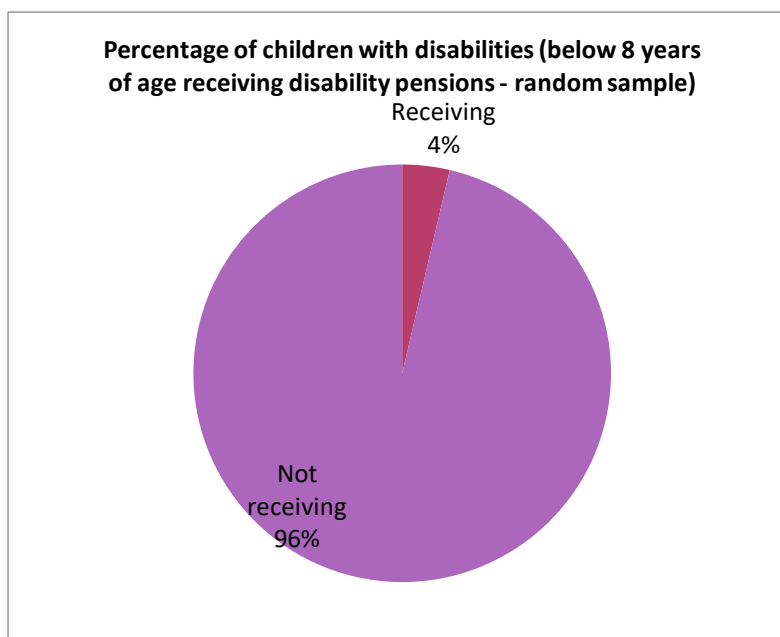
Population	Numbers and details	Data
Children below 8 years	110 <i>Families of children with disabilities in Tughlakabad village, Govindpuri, Okhla Industrial Areas, Batla House etc.</i>	10% of them receiving pensions (confirmed data)
Children between 9-18 years of age	119 <i>Families of children with disabilities</i>	28.5% of them receiving pensions (confirmed data)

	<i>in Tughlakabad village, Govindpuri, Okhla Industrial Areas, Batla House etc.</i>	
Total	229 families	

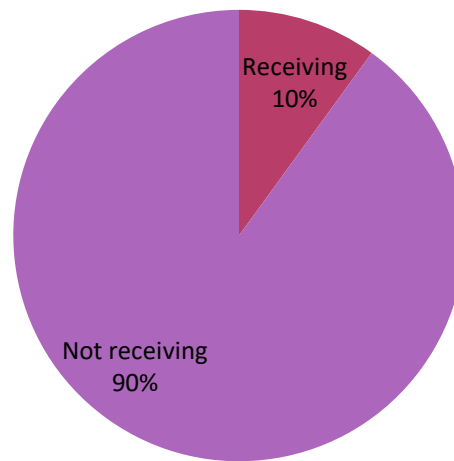
Table: ASTHA sample

If we combine all the data together, the aggregate percentage of individuals across age groups is a mere 24%.

Nearly 380 are the people who called the ASTHA National Disability helpline. It is interesting to note that amongst these 380, nearly 50% of the people were receiving pensions. For other 650 families, these corresponding figures were low as ranging from 10-15%. The age of people is also a variable which can be considered as the average age of ASTHA's helpline caller is late 20s and mid 30s. **It is probably the case as these entitlements takes years to be processed and families often miss out during early years and adolescent years of the child.**

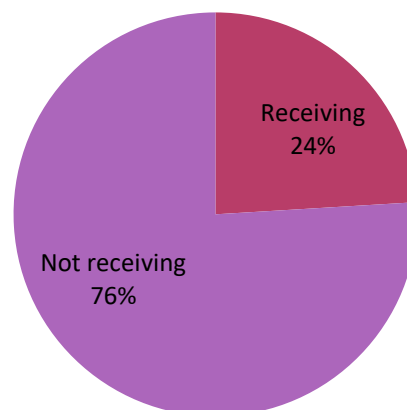


Percentage of children with disabilities (below 8 years of age) receiving disability pensions - ASTHA families sample



The lack of any social security net and entitlements for large percentages of children and persons with disabilities point to a much larger and urgent question. How does the state protect its most vulnerable citizens in the face of a humanitarian crisis and disaster if the majority of them do not have access to state given entitlement?

Percentage of individuals with disabilities receiving pensions - total data of across age groups including approximations



This becomes even more important as the COVID 19 and the consequent lockdowns have led to a severe breakdown of the economies of the majority of vulnerable households in the country.

While the debate on universalization of supports is an important one for people with disabilities too, it has to be seen whether any specific strategies are required within this universalization.

D. Reasons for Few Pensions

There are many reasons why so few people can avail of a disability pension in a state like Delhi.

- Lack of knowledge about the pension scheme,
- Difficulties in fulfilling the online processes required to avail the scheme
- Lack of documents like Aadhar card and disability certificate
- Inability to prove 5 years of domicile in Delhi

Aadhar card, disability certificate and fiveyear domicile of Delhi is a mandatory provision to avail the pension benefits. The largely migratory nature of the population staying in rented houses with often incomplete documentation or documents from another state, are big barriers to this process of acquiring support.

There are instances where the children with disabilities have been receiving the pension earlier but currently, their pension remained suspended without reason.

Some families reported that they were unable to avail the benefits of the scheme as they have submitted their application for the same but the pensions could not be processed due to the lockdown.

E. Order to Resolve Pendency of Pension Cases

With regard to the applications of pension, The Dept. of Social welfare in its order dated 3rd April 2020, directed the all the District Social Welfare Officers to resolve pendency cases on an urgent basis including all case pending at operational levels, applications under rejections and applications that are pending due to queries. It also directs these officials to ensure to process all new applications within 30 days of receiving the application and the pension to be remitted within 45 days of receipt of the application.²⁷ However, there is no information or data available about steps taken by the district social welfare officers on the same and number of new beneficiaries added under the said scheme in the aftermath of COVID_19.

²⁷<http://it.delhigovt.nic.in/writereaddata/Odr2020731397.57.45%20PM.pdf>

At the time of the pandemic it is extremely important that such orders are publicized in accessible formats to all and proactive support is given to people to avail of these benefits. Apart from non- government organisations that may support a few people, these orders have not percolated into the public domain.

Distress calls focusing on Pensions and Certificates received by the National Disability Helpline

No of Calls April	No of Calls May	No of Calls June	Total calls	Queries for DC	Queries for Pension
125	255	202	582	55	125

The large numbers of calls coming in for information on the disability pension to the National Disability Helpline run by ASTHA, are an indication of both the distress and the importance of the aid for the child and person with disabilities.

F. The Disability Certificate

Anchal is a 14-year-old who got associated with ASTHA in the year 2016. She lives in Indira Kalyan camp in Okhla, along with her family. Her father is a tempo driver and mother a housewife who takes care of the family and 4 children. Anchal is a child with Cerebral palsy and needs the support of her mother or sister to move from one place to another. She studies in a Government school in Tehkhand and is in class 9; the school is within 3 to 4 km from her house. Anchal is bright and vocal and slowly gained the confidence to speak about the barriers she faces in her studies and physical access.

In 2016, Anchal had no disability certificate and her family no information that she could apply for one. ASTHA helped and the family was taken to NIMH for her IQ testing. From there she was referred to G.B. Pant hospital for further checkups. After about 3 to 4 months the Hospital staff told the parents that the certification work will be done in AIIMS and referred them there.

Then the family visited AIIMS and again started the process of check-ups as done in G.B. Pant Hospital previously. Then at AIIMS, Anchal was given a date for an MRI, which would take many months of waiting.

The staff of AIIMS told the family if they could wait it is good or else they can go ahead in getting the MRI done privately. By now around 40 visits had already been made to hospitals, and it was difficult for the parents to keep going. It was now 2017 and multiple visits had been made by her and her mother.

The family had to take a loan of rupees five thousand, since the family is not well off and finds it difficult to save enough money. Then they did the MRI for Anchal in private and took the reports to the hospital. But once again the family was turned down, by saying that the doctor is not available or the panel of doctors are not sitting today. Her mother was getting very depressed by this situation, since she had to keep taking Anchal to the hospital and the staff was not able to guide her properly.

Finally after trying and making multiple visits to the hospital, Anchal's mother asked ASTHA to intervene. The social worker went along with Anchal and her mother to the hospital around 2 to 3 times and spoke to the hospital staff and got the accurate information and helped Anchal to get the Disability certificate.

Finally, Anchal got her Disability certificate in 2019.

The disability certificate is an essential document for getting a pension or for any other entitlement. Procuring disability certificate in itself is an exhaustive and time-consuming process, requiring the parents to make multiple visits to various departments of the hospitals for assessments and also bearing financial losses during the process.²⁸ Additionally, it also was seen that in some cases the medical authorities refused to provide the child with the disability certificate as the child does not fall under the category of bench-mark disability.²⁹ Our previous studies, reports and experience of 27 years in Delhi, indicate a great deal of variance and delay in acquiring certification. The constant change in orders and arrangements to provide the certificate and lack of information in the public domain has been a great deterrent to families and persons with disabilities. Equally difficult to fulfill are the changing requirements of documents for getting this certificate. Without a certificate, the child or person cannot avail of the entitlements. It is no wonder then that on an average about 37% of the people and children that ASTHA came in contact with during its outreach in the lockdown had their disability certificates.

²⁸ASTHA (2020), *Process Document: Stories of Some of Children with Disabilities*, ASTHA: New Delhi

²⁹Ibid.

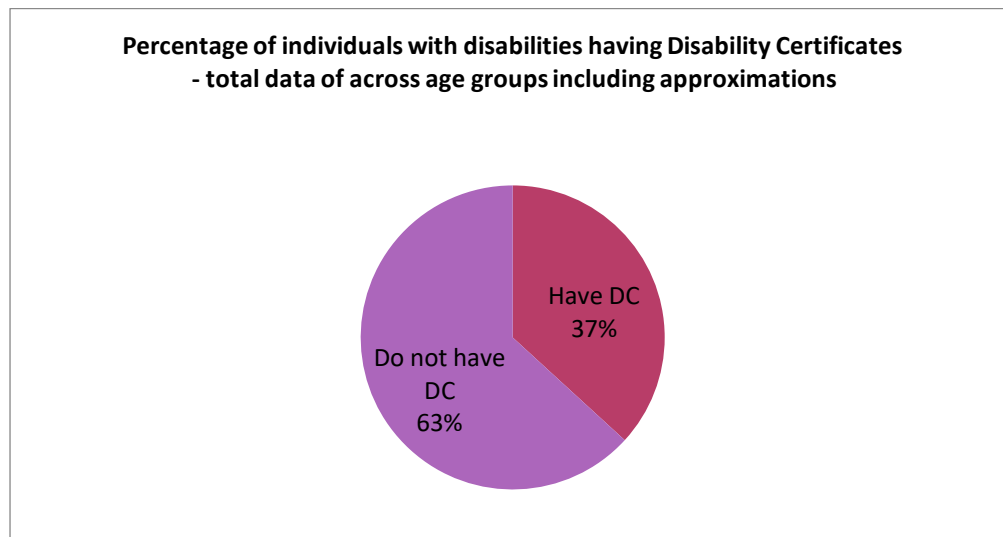
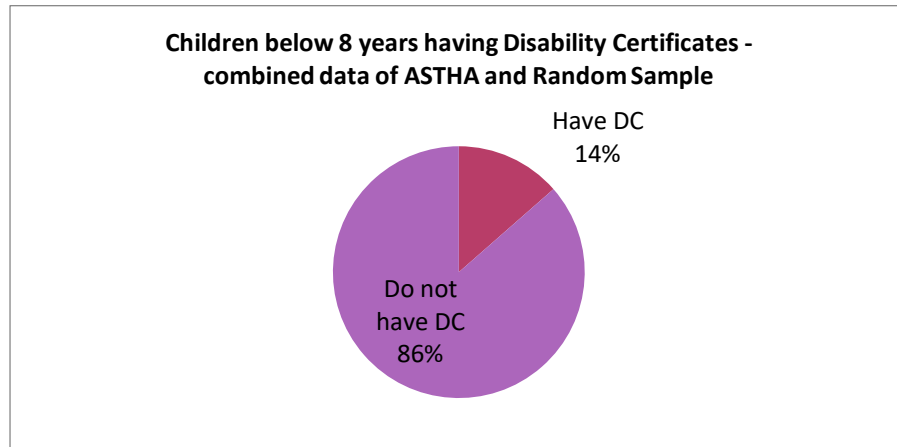
Population	Numbers and details	Data
Children below 8 years	82 families <i>From urban slums of Khadar, Sangam Vihar, Aali Village, Jaitpur etc. Reached out in partnership with DCPCR</i>	12.1% of them have Disability Certificate (confirmed data)
Children and adults above 8 years	650 <i>350 families of school going children with disabilities across Delhi, list by the education department in Delhi</i> <i>100 families of adults with disabilities from Sawda, Delhi</i> <i>200 families of children and persons with disabilities From urban slums of Khadar, Sangam Vihar, Aali Village, Jaitpur etc. reached out in partnership with DCPCR</i>	28% of them have Disability Certificate (confirmed data)
Children and adults above 8 years	300 <i>100 families of adults with disabilities from Sunder Nagri, Okhla and Khirki</i>	30% of them have Disability Certificate (approximate data)

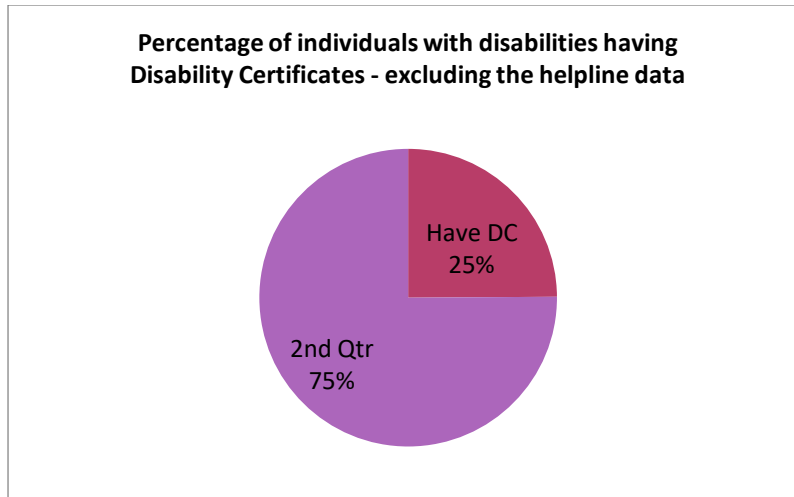
	<i>200 families of children and persons with disabilities across Delhi referred to ASTHA from other organisations</i>	
Adults above 18 (People who called on ASTHA's helpline)	380 <i>People who called on ASTHA's helpline</i>	76.3% of them have Disability Certificate (confirmed data)
Total	1412 families	

Table: Random sample

Population	Numbers and details	Data
Children below 8 years	110 <i>Families of children with disabilities in Tughlakabad village, Govindpuri, Okhla Industrial Areas, Batla House etc.</i>	14.5% of them have Disability Certificate(confirmed data)
Children between 9-18 years of age	119 <i>Families of children with disabilities in Tughlakabad village, Govindpuri, Okhla Industrial Areas, Batla House etc.</i>	38.6% of them have Disability Certificate(confirmed data)
Total	229 families	

Table: ASTHA families





G. Delhi Government Order on Certification

On 14th of July 2020, the Department of Health and Family welfare, Delhi government issued an order naming 11 hospitals in Delhi that would now be responsible for the issuing of disability certificates. The significant part of this order is that it overturns the earlier order where people could only approach designated hospitals in the area they lived in. According to the current order this no longer runs true and anyone can approach any hospital irrespective of the area they stay in for getting their certification done.

In the current situation of the pandemic and the slow unlocking that is happening in the country, an order such as this which overturns a system that has been working for sometime...needs very proactive dissemination. Till the end of July our information is that the board that is to sit to assess the eligibility for certification has not begun to sit in most hospitals.

H. The Very Young Child with Disabilities and those at Risk of Disability

The lack of social security such as certificates and pensions for the very young (0-6) child with disabilities leads to many of them not being counted as such. The concern is that when a crisis like the COVID 19 strikes, the child who requires early intervention and support and is at the beginning of their life is getting totally left out of any specific support. This is also true of children and people who are just at the threshold of impairment and disabilities and who may require supports now rather than later.

I. The National Picture: Not Much Better

Disability certification is the key to access entitlements and social protection programs across the states, however, till August 2017, only 57.98% of the disabled population have been issued disability certificates³⁰. Moreover, there is a non-uniform coverage of entitlements with a stark variation across regions in fund allocation for per-capita spending in different States and union territories. Persons with disabilities living in rural areas are ignored in coverage.

According to the NSS round 583, conducted in 2018, only 28 percent (28%) of persons with disabilities had a disability certificate. Seventy six percent (76%) of persons identified as persons with disabilities did not receive any aid from the government.³¹

For the first time the NSSO gives us an idea of the out of pocket expenditure that is often incurred by persons with disabilities and their families. According to this finding, 29.4% persons with disabilities incurred an out of pocket expenditure related to disability.³² This expenditure on an average was upto Rs two thousand four hundred and seventy seven (2477). This means that already any kind of entitlement or support related to disability, escapes the majority of people who are even identified as persons with disabilities in our country. This also means that reasonable accommodation and individualized support structures; the law touches very few people.

These are the silent crisis that happen all the time when societies do not make adequate provisions for citizens who have specific needs and requirements. It is important to understand the present humanitarian crisis builds upon the one silent crisis that has been ongoing for many years.

³⁰CRPD, Alternative Report, NPRD, pg 4 Annual Report, Department of Empowerment of Persons with disabilities 2017-18. Accessed at [http://disabilityaffairs.gov.in/upload/uploadfiles/files/Annual%20Report%202017-18%20\(E\)\(1\).pdf](http://disabilityaffairs.gov.in/upload/uploadfiles/files/Annual%20Report%202017-18%20(E)(1).pdf)

³¹Persons with Disabilities in India, Report no 583, NSS 76th round (July – December 2018), statement 32

³² Persons with Disabilities in India, Report no 583, NSS 76th round (July – December 2018)

CHAPTER -3

The Issue of Food Security

“We face an impending global food emergency of unknown, but likely very large proportions. The outbreak of the COVID-19 pandemic and the control and mitigation measures enforced worldwide, combined with the massive economic impacts of these necessary measures, are the proximate causes of this emergency”

United Nations,

Policy Brief: The Impact of COVID-19 on Food Security and Nutrition

JUNE 2020

A. Food Security for Persons and Children with Disabilities

As the lock down started one of the first distress signals amongst people in Delhi and across the country became the lack of food. In the months of April, May and June, ASTHA along with other organizations proactively reached out to distressed populations with dry rations. For ASTHA the focus remained reaching out to children and persons with disabilities and other vulnerable populations.

Recognizing the distress, the Delhi government as well as Government of India came up with a series of orders to ensure food security. These orders were focused on enhanced rations for persons who already had been counted under the NFSA 2014 and were covered under Pradhan Mantri Garib Kalyan Yojanaⁱ and later under AamAat Nirbhar Bharatⁱⁱ.

Prior to the complete lockdown and when the partial restriction was already imposed on various activities, the Chief Minister of Delhi on his first online press conference dated 21st March 2020, made an announcement. ***“We have decided to provide 50 % more quantity — 7.5 kg instead of fixed quota of five kg — free rations to 72 lakh beneficiaries attached to our ration scheme for one month. The ration will be provided free of cost,” the Chief Minister of Delhi said at his***

*first online press conference.*³³ However, just after two days the Central Government of India announced the nationwide complete lockdown for till 31st March and announced for free rations for three months under the *Pradhan Mantri Garib Kalyan Aan Yojana*. States and UTs were required to provide free ration to the beneficiaries and the entire cost to be borne by the Government of India.

B. Accessing Food Through the PDS

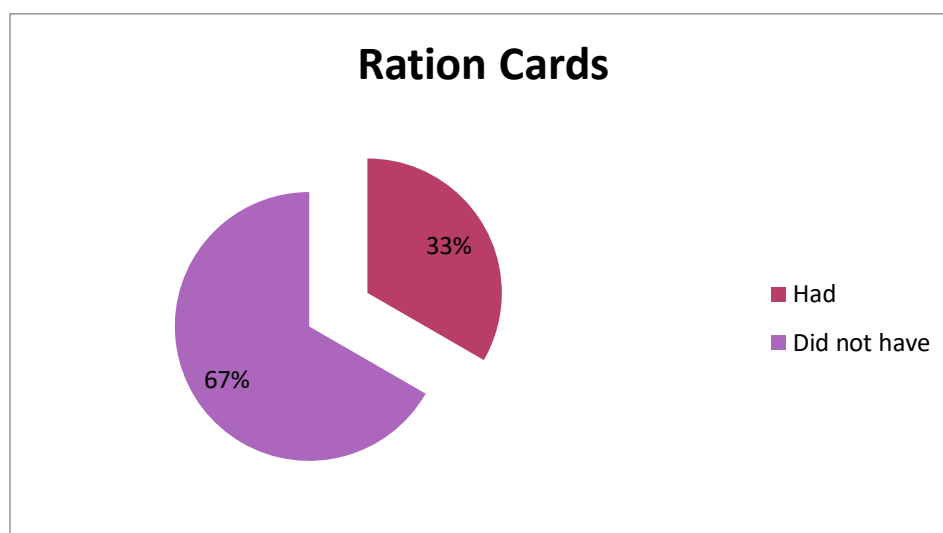


Figure: Percentage of families found with ration card during ASTHA out-reach during lockdown

As members of ASTHA called families to check on their needs, the first need that came consistently over the three months was that of food. *Of the 1440 families of children and persons with disabilities that ASTHA reached out to, around 30 percent of them had ration cards. Sixty percent of the families had no access to the PDS for one reason or the other.* Spread across various districts of the city, the earning members of these families were largely daily wage earners, rickshaw pullers, tailors, daily labourers and some with no current employment. With an average of 5 persons, no ration card or disability certificates through which they could become eligible for entitlements, these are high risk families.

The many difficulties faced by migrant families in availing benefits like the ration card in Delhi were faced by families of children with disabilities as well as persons with disabilities. These

³³<https://www.newindianexpress.com/thesundaystandard/2020/mar/22/pension-doubled-free-food-for-homeless-kejriwal-announces-relief-measures-amid-covid-19-breakout-2119929.html>.

include, lack of papers with correct names, papers from a different state, not all family members mentioned in the cards and others. The local administrative requirement of having ration cards bearing the address of Delhi once again acted as a major impediment to avail the same.

Divya is a 13 year old girl with Intellectual disability. She lives with her parents along with 2 elder brothers on rent in slums of Govindpuri, New Delhi. The father used to work in a garment export factory as a casual worker but due to lockdown he lost his job and mother is a housewife. Though mother tried many times to do several petty businesses but could not succeed. There is no other source of income except Divya's disability pension. The family has no ration card. The family was in great crisis of food during the lockdown period. Earlier the children were getting food support through mid-day meal at their school but it was also closed due to pandemic. ASTHA supported them with ration and later on e-coupon was arranged for them for ration through Delhi government. In the beginning of the lockdown period Divya's mother used to go to nearby school to get cooked food provided by the Government and it was only food support for this family. Meanwhile their landlord was also asking for the rent but after intervene of ASTHA he stopped it.

They got ration for three months by e-coupon and some from other sources. There was hope that after the lockdown was over the father will get his job and the mother can be also engaged her in a domestic servant job. But even in July they are running here and there for jobs and sources of income. They are not getting any ration from any sources. They are totally dependent on Divya's disability pension which is Rs.2500 per month. They cannot go to their native village as they have nothing there to survive. The family has tried hard to get a ration card but could not. The health of the father is not good and he frequently falls ill with weakness. The mother always keeps crying when she is speaking to someone. She says, "Kya karun, kahan jaun, kuch samajh

nahi ata. Bachho ka kaise gujara hoga kyunki ab koi bhi support karane ke liye taiyar nahi hai, koi kaam bhi nahi deta ki main use kar ke apne bachho ka gujara kar lun.

ASTHA's data show that most of the families reached out to, have more than five members. In absence of any cash, shops being closed and in absence of any help being provided from the State or the employer they are left by themselves. Children and persons with disabilities are more prone to disease like COVID-19 due to their existing medical conditions and in situation like this they require extra care and nutrition.

The lack of food security in such a small random sample, indicates the precarious situation of many who come to work in cities. *It also indicates a lack of specific and focused strategies to enable food security for the most vulnerable.*

C. Having a ration card: entitlements still beyond reach of persons with disabilities

For those who had ration cards, persons with disabilities faced big difficulties in reaching the ration shops during the lockdown. The absolute lack of public transport was very difficult for persons with mobility constraints, visual impairment and many others. The long queues at ration shops are extremely difficult to negotiate for persons with disabilities. The lack of accessible information has been another major barrier in the knowledge of where and how to get this entitlement during the lockdown. Among others, it hit deaf and hard of hearing people particularly excessively.

Sharing their anxieties over the situation some of these families informed us that the current situation has a traumatic effect on them. It is here that the disability guidelines that provided the accommodation for children and persons with disabilities would have been useful if implemented. According to the Guidelines:

“Persons with disabilities should be given access to essential food, water, medicine, and, to the extent possible, such items should be delivered at their residence or place where they have been quarantined.”³⁴

The States/UTs may consider reserving specific opening hours in retail provision stores including super markets for persons with disabilities and older persons for ensuring easy availability of their daily requirements.”³⁵

The guidelines reflect the need to understand the requirements of different groups of people while policy making in a crisis as no one shoe can fit all.

D. Food Distribution Through Schools in Delhi (Cooked meal)

A young mother called a disability helpline. What do I do? The school that is giving food is far away and I am alone with my daughter who is disabled. She cannot walk and I do not want to leave her behind. it will take a long time to go there.

Is there nobody else there with you? Your family? Asked the helpline volunteer? No, my husband died about 6 months ago and I am far away from any family. I used to work close by in a home and come every now and then to feed or look after her needs. Now there is no food in the house.

Within one week of nation-wide lockdown, the food crisis became acute and the Ministry of Home Affairs had to pass order on 29th March 2020, giving directions to all the states and the union territories to provide foods to all the poor and disadvantaged population of the country including the migrant laborers³⁶. In this pursuit, the Government of Delhi directed all its District Magistrates to provide the same.³⁷ As the Delhi administration took the steps in perusal of the said order, there was an unprecedented upsurge in the number of distress people approaching

³⁴Government of India(2020) Comprehensive Disability Inclusive Guidelines for the Protection and Safety of Persons with Disabilities (Divyangjan) during COVID-19 (2020), Point 9.

³⁵Government of India (2020), Comprehensive Disability Inclusive Guidelines for the Protection and Safety of Persons with Disabilities (Divyangjan) during COVID-19 (2020), Point 10.

³⁶Government of India (2020), Ministry of Home Affairs, Order, F.No.- 40-3/2020-DM-I (A)

³⁷ Government of NCT of Delhi (2020), Delhi Disaster Management Authority, order NO.-122-A ,dated 29-3-2020

these hunger centers for two times meals and they were forced to serve people beyond their capacity. The government also decided that two meals a day would be distributed through its vast network of schools³⁸. For the said purpose, the government arranged the food in 325 Delhi Government schools³⁹. *Through its 1961 food distribution centers (schools, shelter homes, banquet halls and other arrangements) the Government of Delhi firstly provided 22,064 day meals and 43506 night meals on 27th March 2020 and later (within a month) the number went up to 9,09,554 day meals and 9,02,784 night meal as on 27th April 2020.*⁴⁰

Even though the government of Delhi has opened many schools now giving out cooked meals, Dimpny and Bani's mother is finding it very hard to leave her two daughters, both with severe disabilities to go and get food. Feeding both the daughters takes time and it is not possible for her to carry two children to the nearby school for a hot cooked meal. Post Covid 19 lockdown, the father lost his job and the family was staring at an economic crisis. It is important that such families are prioritized and food reaches them.

Tehkhand is a slum cluster in Okhla Delhi, one of ASTHA's geographical areas of work with young children with disabilities. There are around 4-5 families of children with disabilities there. During the lockdown, all of these lost their livelihoods and gradually there was a scenario where most of them did not even have food to eat, as the rents were mounting too. It was a blessing as the government announced free meals in government schools as it helped thousands of families. However, the nearest school was around 1 km away and was only giving food in disposable plates only for one person. For these families, it became extremely difficult to carry their children with disabilities to the school. A family had three young girls with two of them being disabled. It was the mother who used to go to the schools, standing in long queues in the sweltering Delhi heat in the month of May.

As members of ASTHA spoke to family after family in distress, people spoke about going to the schools for getting a hot cooked meal. While it seemed from narrative after narrative that this was an important strategy to keep people from starvation, there were also reports of children not getting separate food plates and adults having to share their plate with the child.

³⁸Government of NCT of Delhi (2020), Delhi Disaster Management Authority, Order dated 2-4-2020, file no.-DDMA/COVID/2020/1/14.

³⁹COVID-19 Lockdown: 325 Delhi Govt schools will distribute food<https://news.careers360.com/covid-19-lockdown-325-delhi-govt-schools-will-distribute-food>.

⁴⁰<http://delhishelterboard.in/occupancy-report/food.php>

For persons with disabilities, travelling to the site of food distribution as well as knowledge of sites of food distribution is one of the biggest barriers faced.

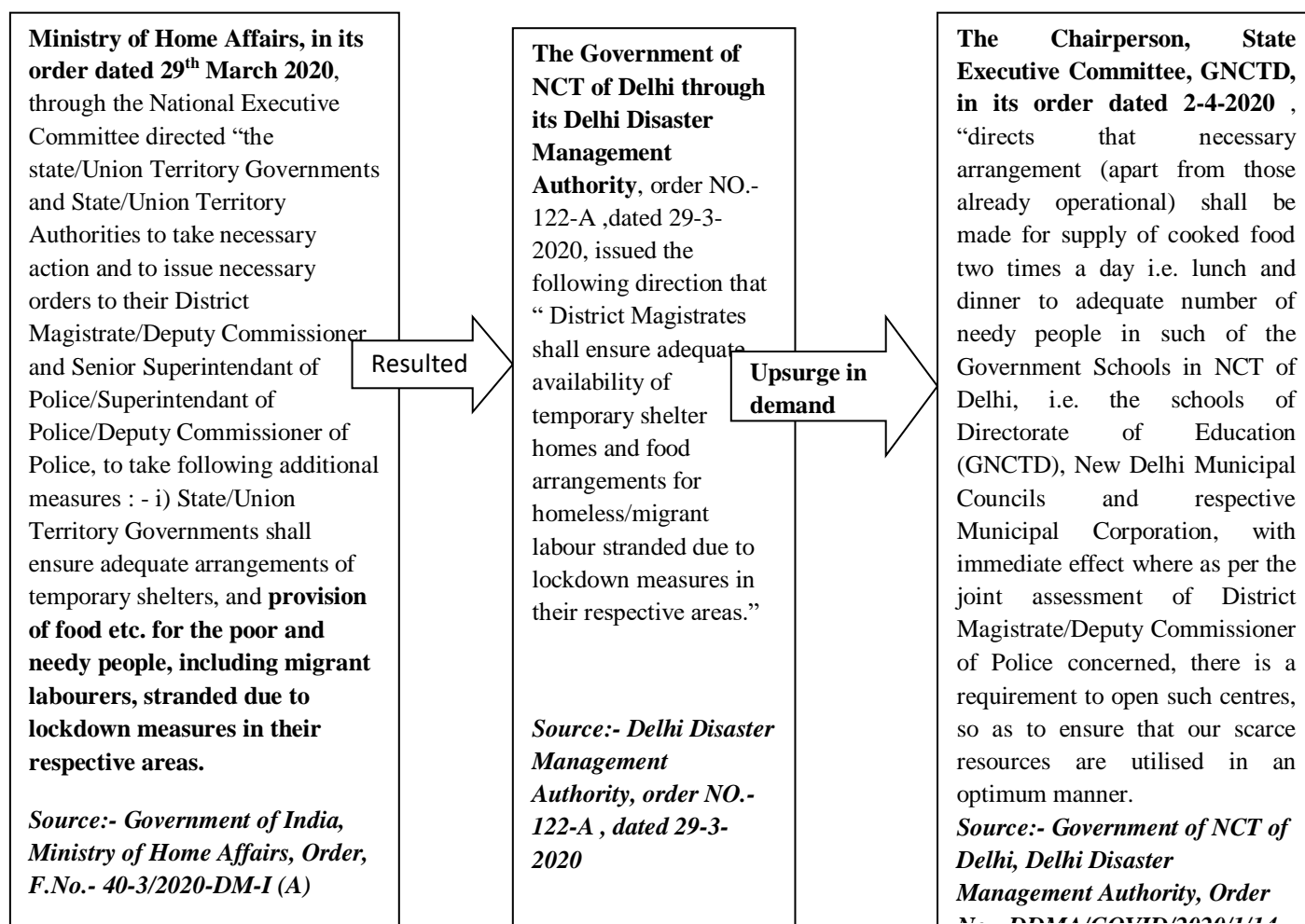


Figure: Chronology for cooked food distribution in NCT of Delhi

E. The Population of Homeless Persons with Disabilities

Delhi has a huge number of homeless people and according to the Census data 2011, Delhi has a total of 2,34,882 persons with disabilities of which 1590 persons with disabilities are identified as belonging from 1350 homeless households.⁴¹

The **Delhi Urban Shelter Improvement Board (DUSIB)** has been providing shelter to the homeless people in RCC buildings, Porta Cabins, tents, and temporary buildings, but as of now no data is available on the number of persons with disabilities occupying these shelters home during the Covid-19.⁴² Also given the capacity of these shelter homes and the present number of the people they have been providing services, thus making these shelter overcrowded, raises the very questions about the norms of social distancing being followed in these shelter homes and the effectiveness and efficiency of these norms followed.

Delhi has been providing shelter and two times meals to the homeless people and people in Distress. The order passed by the Delhi Disaster Management Authorities dated 26rd March 2020, to provide meals to the people in night shelters through the Shelter Management Agencies, authorised the district magistrates of Delhi to make necessary arrangements at appropriate locations in their respective districts to provide two time cooked **food also to all such underprivileged, poor, distressed members of the society residing in Delhi that do not resides in the shelter homes persons on regular basis** till the lockdown in Delhi continues⁴³. According to DUSIB On 10-5-2020, it has distributed cooked food to 8972 people a day meal and 10048 people night meals in these shelters.⁴⁴ However, there is no data available on any public platform on the number of persons with disabilities been able to get food in these shelters homes or the GNCTD food centers being run at 1744 locations in Delhi that claim to have distributed on 10-5-2020 day meals to around 8,59,197 individuals and 842939-night meals.⁴⁵

F. The E-coupon; A Strategy that Requires Rethinking

⁴¹Government of India (2011), Census Data 2011, New Delhi:India.

⁴² Delhi Urban Shelter Improvement Board (2020),

⁴³Delhi Disaster Management Authority (2020), Order Dated 20-3-2020.

⁴⁴ Delhi Urban Shelter Improvement Board (2020), <http://delhishelterboard.in/occupancy-report/food.php>. Last browsed on 9-6-2020.

⁴⁵ ibid.

Faaz is an 11 year old, living with his 3 siblings and family in a small rented house in Okhla. The father was the sole breadwinner of the family and lost his job just before the lockdown. The family was from Uttar Pradesh and hence had no ration card in Delhi. ASTHA's community worker worked closely with the family and applied for their online e coupon for ration. Unfortunately, due to some address issues, their collection centre was 30 kms away from their residence in Batla house. With great difficulty, Faaz's mother travelled during the peak of the lockdown only to find out ration was over in that distribution centre. Lack of public information, transportation etc. made matters worse for many such families.

In order to cater to the needs of millions who do not have ration cards, the Delhi Government initiated the provision of getting the free food grains by filling e-coupons. However, an online process, lack of smartphones and long delays in approval of the process rendered the policy inaccessible. The large number of families of children with disabilities in the urban slums and those that ASTHA called were unaware of such a service. Those who knew, were finding the online procedure extremely difficult. The very process of filling the coupon online has acted as a barrier for them to avail of the free ration. Another aspect that emerged was the reluctance of many to apply for e-coupons as they fear that the documents to be attached could be misused by the government authorities. The pandemic has come on the heels of the anti CAA protest and communal violence in Delhi leading to great insecurity among people in general. Further, the Delhi govt order of asking people to produce hard copies of their e coupons to get ration created huge difficulties at the time of the lockdown.

Arshad is a 2 year old child with delayed development. He lives with his parents in Noor Nagar in Okhla. During the lockdown, the father lost his job and there was a financial crisis. It was during this time ASTHA's community worker reached out to the family for enquiring about e coupon. The family did not have a phone and hence was difficult for them to apply online. The community worker filled up the form somehow. Finally, with a disabled child in her arm, the mother stood in the queue for nearly 4 hours to get her share of 10kgs of grain for the family.

From April till the 30th of June, ASTHA's community workers and helpline counsellors had made 63 applications for E coupons on behalf of families of children with disabilities as well

as adults. The process was often tedious and long with community workers and helpline counsellors having to get documents from people and upload these documents from their homes. After the application of the process, a hard copy of the form was demanded, which was extremely difficult for families to procure in lockdown. However, after constant trying many families, albeit after wait, acquired rations

An analysis of data shows that on an average it took 14-20 days from application to getting an approval. This delay was not tenable for many families who then had to rely on the kindness of others and NGOs like ASTHA for food to get by.

G. Learnings on Reaching out with Dry Ration Kits for all

While initially the organization was just giving kits of food, over time there was need to rethink what was being given in these kits and for how long! In the days of the lock down with very few volunteers going out, the quantity of food given could not have lasted for more than 10 to 15 days. **However, as the lockdown extended, the questions of further supporting the same family, for how long and how came up again and again. Other questions that came up were the adequacy of the kits for the needs of children, particularly the very young children.** The need for milk for young children came up again and again and ASTHA was not always successful in accessing milk or even milk powder for children. The question of availability of vegetables and fruits for children hardly came up as organizations tried hard to provide the basics for families.

These are questions to debate and understand for organizations and the State in future during such calamities. These are also some of the factors that can lead to further malnutrition among children. More planned and coordinated efforts with state and civil society would have enabled a better and qualitative outreach.

H. Enduring Malnutrition: A Recurring Theme for Children with Disabilities

“Even in the absence of a global threat, children living with disabilities are among the world’s most vulnerable, marginalized and stigmatized populations. The current coronavirus disease 2019 (COVID-19) context has disrupted life in every corner of the world and will likely

disproportionally affect those children with pre-existing vulnerabilities. The greater burden faced by children living with disabilities means that additional efforts will be required to ensure their needs are being met when transitioning to the different pandemic phases.”

- UNICEF

Malnutrition of children with disabilities has been a recurring theme and concern amongst the families that ASTHA has worked with over the years in urban slums. Just before the pandemic ASTHA had estimated that about 2/3rd of children with disabilities were malnourished in its projects. Strategies such as supplementary feeding, nutrition days and focused work on children with feeding difficulties were already part of the organization's work. There are strong links between malnutrition and disability in children. Children who are born with low birth weight or premature, children with feeding difficulties, children who cannot get to their food on their own are all often very vulnerable to malnutrition.

Bitiya is a four year old with cerebral palsy. Because she has difficulties in feeding, even at the age of four Bitiya's mother was feeding her with milk and biscuits leading to severe malnutrition. It took a long time for ASTHA's community worker to convince Bitiya's mother that Bitiya needed to eat solid food and that she needed to introduce these gradually in the correct manner.. The process was just beginning as the pandemic came upon the country. The community workers have been sending video clippings the mothers' to demonstrate the various method to feed the child and also to follow up if the parents have been carrying out the instructions.

In Delhi both the ICDS midday meal as well as the midday meal through schools were discontinued as the pandemic took place. However, the Department of Women and Child Development, Government of NCT of Delhi in its orders on 24-3-2020 provided that the angawadi workers/helpers would provide the Supplementary Nutritional Food (Panjri or laddo)

at the doorstep of all the beneficiaries.⁴⁶ Although there was food distribution through schools for families, the lack of targeted food for children is likely to have detrimental effects on children. Amongst these, some of the most vulnerable are very young children and children with disabilities.

I. Focused Strategies for Children with Disabilities

Sumit is a 3 year old bright child living in slums of resettlement colonies on the foothills of the famous Tughlakabad Fort in Delhi. Sumit has a condition known as microcephaly, lives with his elder brother, 4 sisters and parents. His elder brother is just below 8 and is a child with multiple disabilities. The family situation was precarious even pre Covid-19 but the lockdown really broke the back of the family.

Sumit's family is a case in point where the lockdown has created havoc in the lives of young children. Already vulnerable families have been pushed to the brink with loss of livelihoods, depleted savings and looming poverty. All this has severely compromised the health of already acutely malnourished children like Sumit.

There are many families like Sumit's in Churia Mohalla in Tughlakabad. The community workers had started advocating for inclusion of these children in nearby Anganwadis. With the lockdown the ICDS stopped giving out nutrition supplements. Even when it was resumed, huge delays, shortage of food led to many children getting left out till the system was streamlined. The community workers saw that children with disabilities were the first ones to be left out during such a shortage. *One of the reasons for this could be that children with disabilities have remained at the periphery of the ICDS system. At the time of crisis, they are not on the radar of the worker as other children are and are therefore missed out in the information giving and food distribution etc.* The below table saw how the number of children with disabilities in a specific geographical location started getting nutrition after ASTHA's push, although it's a smaller number.

⁴⁶Government of NCT of Delhi, Department of Women and Child welfare, Circular, F.no. 76(133)Misc.matter/DWCD/ICDS/19-20/814-824. Dated 24-3-2020

Weeks	No. of Children Received SNF
Week 1	2
Week 2	7
Week 3	13
Week 4	14
Week 5	22

It is for these reasons that when the food distribution (panjiri and laddoo) through the anganwadis started, ASTHA had to work hard to facilitate food distribution to the children with disabilities it worked with. This meant working with the ICDS system, understanding when the food was being distributed as well as informing families in advance so that they could make arrangements to get the food for the child.

Awareness creation at the local level became a very important activity to enable families and persons with disabilities to avail of the food they were entitled too. In order to build pressure on the concerned authorities and to get the status on the distribution of nutritional supplement regular follow up were done with the CPDO of the concerned areas.

Additionally, the team have also had constant follow up with the ASHA workers about the distribution of nutritional supplement in their respective areas. Ironically, it was seen there has been lack of awareness among the ASHA workers on any such scheme or provisions. Thus, the organization also engaged in creating awareness among the ASHA workers on such provisions.

J. The legal Framework; No Clear Provisioning

Unfortunately, Children and people with disabilities do not have any specific legal entitlements as far as food security is concerned.

The National Food Security Act 2013, provides for the right to food to the economically marginalized sections of society through the Public Distribution System. However, it failed to take into account the specific requirements of the child and person with disabilities.

The other formal mechanisms of providing some kind of food security to children are the midday meals provided in schools and in anganwadis in the ICDS system. Being the largest group of out of school children, in India and often excluded from the ICDS, a large percentage of children with disabilities are out of this security net.

K. PIL on Food Security for Persons with Disabilities

The Delhi High Court on Tuesday issued a notice to the Central government on public interest litigation (PIL) seeking directions to provide free ration to all persons with disabilities under the Pradhan Mantri Garib Anna Kalyan Yojana after it was informed that the persons with disabilities are struggling to survive during the pandemic.

The PIL sought the inclusion of persons with disabilities under the category of priority households to ensure that they can reap the benefits of the National Food Security Act.

Senior advocate Santosh Kumar Rungta, submitted that persons with disabilities have lost their livelihood during the pandemic and that it is the responsibility of the Centre to identify beneficiaries of each state for food security act, which has not happened.

"The National Food Security Act is aimed at providing subsidised food grains to identified priority households and the ones included in the Antodaya Anna Yojana," Rungta stated.

The PIL sought directions to the Central government to direct all States and Union Territories under Section 38 of the National Food Security

Act to provide food grains free of cost to poor persons with disabilities as was done for migrant labourers and others.

It also sought directions to give free ration to all persons with disabilities without ration cards on the basis of their disability certificates and or Unique Disability ID under the Pradhan Mantri Garib Anna Kalyan Yojana.

*The plea, filed by National Federation of the Blind through advocates Santosh Kumar Rungta and Pratiti Rungta, sought the issuance of directions for the purpose of implementation of the food security scheme and also to ensure that at least 5 percent beneficiaries of food security scheme are persons with disabilities as defined in the Rights of Persons With Disabilities Act, Right of Persons with Disabilities Act 2016, which mandates 5 percent reservation for persons with disabilities in all poverty alleviation programmes.*⁴⁷

"As the persons with disabilities belong to the most marginalised group in the society with very little opportunities for earning a livelihood and therefore their exclusion from the category of eligible persons under Antyodaya Anna Yojana and priority household for the purpose of implementation of the food security scheme guaranteed under National Food Security Act, 2013, is against the spirit and object of National Food Security Act, 2013," the plea said.

L. Provision for Adequate Standard of Living

RPWD Act 2016 under sub-section (1) shall provide for,—(a) community centres with good living conditions in terms of safety, sanitation, health care and counselling;

⁴⁷<http://www.businessworld.in/article/PIL-Seeks-Distribution-Of-Free-Ration-To-Persons-With-Disabilities-Delhi-HC-Issues-Notice/07-07-2020-294835/>

- (b) facilities for persons including children with disabilities who have no family or have been abandoned, or are without shelter or livelihood;
- (c) support during natural or man-made disasters and in areas of conflict;
- (d) support to women with disability for livelihood and for upbringing of their children;
- (e) access to safe drinking water and appropriate and accessible sanitation facilities especially in urban slums and rural areas;”⁴⁸

M. Reasonable accommodation

Chapter-II titled “Rights and Entitlements” of the Act under Section-3 subsection (1) obliges the state to “*ensure the persons with disabilities enjoy the right to equality, life with dignity, and respect for his or her integrity equally with others*”. The same section under sub-section (5) states that “*the appropriate Government shall take necessary steps to ensure reasonable accommodation for persons with disabilities.*” Reasonable accommodation has been defined in the legislature as a “*necessary and appropriate modification and adjustments, without imposing a disproportionate or undue burden in a particular case, to ensure to persons with disabilities the enjoyment or exercise of rights equally with others.*”

The two provisions are important for the persons with disabilities in this hour of crisis as persons with disabilities often fail to avail their rights, are denied their due, experience exclusion and are treated as burden to the society especially in time of crisis.

N. Comprehensive Disability Guidelines

The Comprehensive Disability Inclusive Guidelines for the Protection and Safety of Persons with Disabilities during COVID-19, did recognise the importance of having specific measures for the food security of children and persons with disabilities.

- “*Persons with disabilities should be given access to essential food, water, medicine, and, to the extent possible, such items should be delivered at their residence or place where they have been quarantined.*”⁴⁹

⁴⁸Right to Persons with Disabilities Act 2016, Sec- 24 (India)

⁴⁹Government of India, (2020), *The Comprehensive Disability Inclusive Guidelines for the Protection and Safety of Persons with Disabilities during COVID-19*, Point 9 of General Action Point.

- *“The States/UTs may consider reserving specific opening hours in retail provision stores including super markets for persons with disabilities and older persons for ensuring easy availability of their daily requirements.”⁵⁰*

Equally important were the points in the guidelines on all information about COVID 19, services offered and precautions to be taken should be available in simple and local language in accessible formats; i.e. in Braille and audible tapes for persons with visual impairment, video-graphic material with sub-titles and sign language interpretation for persons with hearing impairment and through accessible web sites.⁵¹

Unfortunately in Delhi, these guidelines were not adhered to, causing grave difficulties to children and people with disabilities in accessing their food rights.

O. UNCRPD Committee: Concluding Observations for India

Even before the outbreak of the epidemic, the UNCRPD Committee on the Rights of Persons with Disabilities in its Concluding observations on the initial report of India in 2019, has already raised their anxieties on “the lack of measures to ensure that all persons with disabilities are registered and covered by national social protection schemes and also on the absence of social protection schemes covering disability-related extra costs for persons with disabilities requiring higher levels of support”⁵².

P. Food and Nutrition Assistance Needs to be at the Heart of Social Protection Programmes

According to the Policy Brief on the impact of COVID-19 on food security and Nutrition “In the coming months, it will be important to strengthen social protection systems for nutrition: Given the socioeconomic effects of the pandemic, social protection systems will become the mainstay for hundreds of millions of people for the duration of the current crisis and possibly beyond.

⁵⁰Government of India, (2020), *The Comprehensive Disability Inclusive Guidelines for the Protection and Safety of Persons with Disabilities during COVID-19*, Point 10 of General Action Point.

⁵¹Government of India, (2020), *The Comprehensive Disability Inclusive Guidelines for the Protection and Safety of Persons with Disabilities during COVID-19*, Point 1 General Action Points.

⁵²UNCRPD ,Committee on Rights of Persons with disabilities (2019) , *Concluding observations on the initial report of India*, Section 58.

<http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPrICAqhKb7yhsmcRCSUCudOHc8Goa6B5KHIDSSfFpmEa0FBET1G9nvFYOB4XH4qm6L8Hio%2BB7gRD2dbe%2F%2Bn%2Fsta28vXfb7xSH3WI2YKoBbh%2BIOAfKMAsWr> Last Browsed on 12-6-2020.

It will become “important to protect food access for the most vulnerable by increasing their purchasing power and, where necessary, by directly providing food through government or community-based programmes.”

It will become important to ensure the continuity of nutrition services, particularly the early detection and community-based management of acute malnutrition and infant and young child feeding, as well as related maternal nutrition programmes.

Understanding who is suffering from hunger and malnourishment is essential to build momentum for action, to guide decision-making and to engage and empower the vulnerable as agents.⁵³

⁵³United Nations (2020) ,*Policy Brief: The Impact of COVID-19 on Food Security and Nutrition*.

CHAPTER-4

Rehabilitation and Primary Healthcare

A. Issues related to rehabilitation and health care.

“Jab se lockdown hua hai ye centre (ASTHA’s ECCD centre) nahi jaa paya hai. Abhiraj ko CP hai, aur lagatar therapy aur exercise chahiye. Waha centre bada tha, baaki bccho ke saath khelkhel mei therapy hota that aur khush rehta tha. Is chote se kamre mei main kitna karwau. Poora din pareshaan bhi rehta hai, ise kaun bataye ki hum sab ekdumek hi kamre mei kaid ho gaye hai. Lockdown se ghar mei bilkul paisa aana band ho gaya hai”

Abhiraj is a bright 4 year old boy with Cerebral Palsy. He lives with his parents and a younger sibling in his small rented room in Okhla. It has been seen historically that children with disabilities are isolated, neglected and often confined to their homes, this holds more for children with severe disabilities in small homes of narrow lanes in urban slums of the city. It is the responsibilities of primary health and rehabilitation systems to take these children into their fold. The flagship healthcare scheme in India for early intervention of children is *Rashtriya Bal Swasthya Karyakram* (RBSK). The scheme document comprehends the epidemic proportions we have to address as a nation when it documents that nearly 10% of all children are born with developmental delays. A lancet report puts up a figure of more than 1 crore children in India with developmental disabilities. The RBSK, through its District Early Intervention Centres (DEIC) is supposed to reach out to children from birth to 18 years to cover 4 ‘D’s viz. Defects at birth, Deficiencies, Diseases, Development delays including disability. Delhi, despite of being the National Capital, does not have a single DEIC yet.

The current Covid-19 pandemic has brought the attention on healthcare services, infrastructure and service delivery in the country. It was more than 40 years ago that the Alma Ata

declaration⁵⁴ on “Health for All” set out a broad set of principles of providing promotive, preventive, curative and rehabilitative services to all those who need it. A WHO report⁵⁵ on rehabilitation and primary healthcare documents “several misconceptions have undermined the prominence of rehabilitation in primary health care (and in the health system more broadly). **The report further documents “a misconception is that rehabilitation is a disability specific service, when in fact it is a core service for population-wide health”**

It is now after more than 4 decades of the declaration, we are witnessing that marginalised and vulnerable disabled populations have huge unmet healthcare needs. ASTHA’s previous report documents the experiences of families of children with disabilities while accessing healthcare services and found out that a majority of rehabilitation services were concentrated in tertiary and super speciality hospitals (2017)⁵⁶. Lack of information among families, huge out of pocket expenditures, incessant referrals, knowledge among healthcare service providers are some of the barriers.

B. Access to Health and Medicines

Subhishta is a young 18 year old girl, living with her mother and two siblings in Tughlakabad Village in Delhi. She is having seizures when she was as young as 15 days and it has been a regular occurrence till now. The child was born in Muzaffarpur district of Bihar and migrated to Delhi especially for her ‘cure’. She is a girl with Cerebral Palsy. In addition to seizures, Subhishta always has had many healthcare complications. When she was in her teens, her kidneys started deteriorating and the prolonged illness made her extremely weak. During the lockdown, she was supposed to go for a test and consultation for her kidneys in Safdarjung hospital but the mother says:

“Iska sharer bhi to control mein nahi hai, kaise pak denge. Waha aspatal mein pata nahi kaha kaha haath lagega, ek bimari se bachne ke chakkar mein doosri bimari ho jaaegi. Hum darr ki wajah se nahi gaye ”

Children who have Cerebral Palsy especially those having severe disability, might need assistance in mobility depending on what kind of support and adaptation is required. Although

⁵⁴https://www.who.int/publications/almaata_declaration_en.pdf

⁵⁵ Access to rehabilitation in primary health care: an ongoing challenge

⁵⁶ ASTHA (2017), *A Much Needed Headstart: Ensuring ECCD for Children with Disabilities*, ASTHA: India.

Subhishta's mother is the primary caregiver for the child but like all others, there was a fear in accessing hospitals. This further was further exacerbated with a child who needs mobility support and would touch surfaces, thus espousing the fear of Covid-19 infection.

Badal is a 15-year young boy, living with his parents in Janta Jeevan Camp in Okhla Industrial Area. He was born in Madhubani district of Bihar and is on seizure medications since childhood. The family tried many hospitals across Madhubani and Darbhanga districts trying to understand his situation but was always left disappointed. They finally decided to come to Delhi for his treatment at AIIMS when he was just seven years old and gradually settled in Delhi. Badal is a person with Intellectual Disability. His father is a Rickshaw driver and supplies water door to door by using his rickshaw. As Okhla is an industrial belt, his mother used to work with a nearby company for thread cutting. During the lockdown, both of the family members lost their respective jobs. The economic status of the family was staring at a crisis. As it was a complete lockdown, the family neither had money for buying Badal's medication nor any source of going to the far away tertiary care hospital. The primary healthcare system of *mohalla clinics* and dispensaries usually do not keep seizure medications.

The sudden burden on healthcare delivery system has led to negligence of non-Covid health care issues. Badal and Subhishta's stories are common to many more such families. As in every disaster, it has been the marginalized and vulnerable which has borne the brunt most. One of these is populations of children and persons with disabilities. The WHO acknowledges this by documenting that around 43% of children and persons with disabilities are likely to have poor health due to Covid-19 in comparison to 6% amongst non disabled peers. There have been now various reports highlighting a range of compromised services including maternal health, immunisation, Tuberculosis etc. Multiple research studies and reports highlighted the huge undetected TB cases during the lockdown period⁵⁷. The onset of Covid-19 lockdown brought about major disruptions on functioning of ICDS with pre schooling activities, nutrition distribution and other activities. There were reports of states completely shutting down the immunization programmes^{58,59}. This is a time when international organizations are predicting

⁵⁷<https://theprint.in/health/covid-lockdown-could-lead-to-over-1-8-lakh-new-tb-cases-88000-additional-deaths-study-says/473294/>

⁵⁸<https://scroll.in/latest/957552/covid-19-rajasthan-suspends-immunisation-outreach-programme>

huge morbidity and mortality of young children and estimates alone in India are of 1.5 million children missing routine vaccines. Lack of community based rehabilitation services, immunization, malnutrition and compromised primary healthcare services have severely impacted lives of thousands of children. Vulnerable populations like persons with disabilities and their families, amidst a vicious cycle of poverty, malnutrition and isolation are further at risk.

The guidelines issued by the government of India dated 24th March 2020, initially talked about the delivery of essential goods including food, pharmaceuticals, and medical equipment through e-commerce. This provision would have proved advantageous for those who have access to technology and have the knowledge to access it, however, such provisions have been futile for a large number of the children and persons with disabilities that resides in these urban slums and require regular medical interventions. These children with disabilities are dependent upon the services and medicines from the government hospitals are unable to have access to the medicines. This is an issue that affects many people and children who live with chronic conditions and need regular medications. However, this need was not addressed in the lockdown.

Also, there are a range of medicines especially those needed by the children with thalassemia that remain unavailable with these e-commerce platforms. Access to such medicines was the major concern for these families.

The norms related to main social distancing, movement restrictions, fear among the donors, created a shortage of blood and making the transfusion difficult for these children not only in Delhi but also at a pan India level. The various stakeholders raised their apprehensions on the same and subsequently, the Ministry of Health and Family welfare, passed the “National Guidance to blood transfusion services in India in Light of COVID_19 Pandemic” dated 25th March 2020. Also in order to ensure the supply of sufficient blood for the children and people needing regular blood transfusion, the Ministry of Health and Family Welfare wrote to the Honourable Chief Ministers of all State for the same.

Article 25 of the RPWD Act speaks about health care facilities and the preference to be given to the persons with disabilities especially during the time of crisis. However, the government

⁵⁹<https://www.businessinsider.in/india/news/covid-19-impact-concern-over-possible-resurgence-of-vaccine-preventable-diseases-among-children/articleshow/75942866.cms>

hospital denial to provide services to the patients with any other forms of condition is gross violation of the RPWD ACT as well as human rights.

C. Immunization

All children who are to get routine immunization may become vulnerable, as their immunization schedules will be delayed. Children with disabilities may become even more vulnerable. Several news reports have raised the red flag regarding the re-surfacing of polio and a measles out-break.

Immunization against deadly diseases is beyond the scope of telemedicine. And healthcare experts caution that countries like India must not let down their guards, lest there be an outbreak of preventable diseases like measles....Back-of-the-envelope calculations show that an estimated 5 million children might have missed out on vaccination in March, and those numbers are swelling in April. The accredited social health activist (ASHA) workers or community health workers under the Ministry of Health and Family Welfare (MoHFW) basically drive the immunization campaigns in the hinterland. ...”

"These are outreach programmes and villagers seldom turn up with their kids at the public health centres (PHCs) to get vaccinated. Now, with the ASHA workers busy with surveillance and other work during the Covid-19 outbreak, this infrastructure has collapsed."....The website of GAVI, the Vaccine Alliance, a global public-private health partnership, says delays in vaccination campaigns and routine introductions will mean at least 13.5 million people in 13 of the world's least-developed countries will be at risk of not being protected against diseases like measles, polio and human papillomavirus (HPV), with millions more likely to follow.⁶⁰

⁶⁰https://www.business-standard.com/article/economy-policy/india-s-infant-immunisation-drive-comes-to-a-halt-over-covid-19-fear-120042201411_1.html

CHAPTER-5

Children with Disabilities and their Families in Crisis: The State of Education

A. The Status of Children with Disabilities in Education

As the pandemic struck and schools and colleges were shut throughout the country almost indefinitely, the question of how to continue to provide education to our children in the face of this uncertainty and with families in such distress looms large. While this uncertainty has hit all children in the country, its impact on children who are vulnerable within the education system and who participate less in these institutions will be the greatest as many hard earned opportunities are lost.

When the pandemic struck, children with disabilities were at a juncture where their legal right to education has been upheld by two major laws, the Right of Children to Free and Compulsory Education Act 2009 as well as the Rights of Persons with Disabilities Act 2016.

Unfortunately, the implementation of these rights outlined in the law has been so slow and tardy that children with disabilities continue to be one of the largest groups of out of school children in India. With the RPWD Act recognizing 21 impairment groups as persons with disabilities in India, education systems are still to work out how to provide for the specific requirements of these children and to ensure that they get reasonable accommodationⁱⁱⁱ individualized support^{iv} physically accessible schools^v, teachers who know how to teach children with disabilities^{vi} as promised by the law⁶¹.

Education systems are still struggling with ensuring enrollment and retention of children with disabilities in elementary education as promised by both laws. Ten years after the enactment of the RTE Act as well as four years after the enactment of the RPWD Act, the NSSO 2018 gives stark reminder of the lack of participation of children with disabilities in schools. While only 62.9% children were ever enrolled, in schools only 23.1% were actually attending schools

⁶¹*Right to Persons with Disability Act 2016, Sec.16-18 (Ind.)*

at the time of the survey.⁶² This tells the story of an education system still unable to cater to the requirements of children with disabilities.

The low enrollment of the in the government system is not further bolstered greatly by enrollment in special schools or home-based education, the other two acknowledged sites for the education of children with disabilities. While the NSSO gives us an idea of the very low participation of children with disabilities in special schools (less than 10 percent), there are no national level official estimates or analysis in reports of the number of children in home-based education and the quality of their education

B. Home based education: The Great Irony

The great irony of the pandemic is that the one provisioning that was reserved by society, (law and public opinion) to be used solely for children with severe and multiple disabilities is now the fate of all children in the country. Educationists, parents and civil society is for the first time understanding the strains and stresses of educating children at home and huge debates are now taking place on whether on line education can ever take place of children coming together and in groups, playing and learning together in school.

It is said that we have lost a whole generation of children is lost in education terms and that the effects of this will be seen many years later.

C. Families in Distress

The extreme challenges they were facing, each passing week, increased the stress levels of families of children with disabilities. Suddenly, with ASTHA centers, anganwadis and schools all shut, the education of the child too fell on the shoulders of parents who were already in deep distress.

As money for both food and rental dried up for families who were leading a hand to mouth existence even before, it became difficult to focus on the education of their child.

At different points in the lockdown the organization had to be sensitive to the great distress facing many different families and deal with the irritation or often anger coming from the family. Education does not remain a priority when basic needs are hard to come by. For children

⁶²Statement 7, NSS Report No. 583: Persons with Disabilities in India pg 50

with disabilities who have other needs of therapies etc, getting the child educated is a challenge that is difficult for families and children. **In the near future, education planning must take into account the grave economic and other threats that are facing vulnerable families.**

The threats in situations like for very young children with disabilities as well as children at risk of disability are many. ASTHA's field of work can be seen as a microcosm of what is likely to happen in varying degrees all across the country.

The focus of the organization's work is on children with disabilities and their families.

D. The Very Young Child

For many children with developmental delays, those at risk of disabilities and children born with an impairment, the early years are fraught with different kinds of challenges. This is the time when the family is beginning to understand what has happened to their child, the challenges she faces and trying to come to terms with the disability of the child. The lack of readily available and affordable rehabilitation services, information and counselling is another major barrier for the family and the child. At the best of times, education, early learning and exposure to world around can get compromised for this child. It needs dedicated policy , planning and intervention to ensure that the child with disabilities gets her due in education

Families are in the process of accepting and understanding what has happened to their child.. This often requires great re adjustment in the family. Some families are caught in the process... and suddenly another crisis has overtaken them.

E. Children Just Being Born

Children with developmental disabilities often have a very traumatic birth history. They often have a history of having been put into incubators, kept in hospitals for some time, getting fits that need immediate monitoring etc.

The risks of being kept in incubators and other medical interventions can become manifold at a time like this causing a grave threat to the child and the mother. Further the regular monitoring that is required once the child goes home can get compromised at a time when there are no

For other children who are born with an impairment, there is no place where parents can find any answers or support.

F. Children with Disabilities in Schools

For the 100 children with disabilities that ASTHA supports in school, the pandemic and the resultant closure of schools is a big threat. Many children, going to school today have faced many obstacles in getting enrolled at school in the first place., their access and attendance in school being precarious at best. Children with disabilities continue to need outside agencies like ASTHA to continue

Many continue to find it difficult to attend school everyday and many are asked by teachers to come in only on certain days when the special educator comes in. In such situation when a crisis strikes, the child who is already at the periphery, can quite easily be lost to the institution and not get any support.

There are also children who have settled in the school and are steadily working their way up from class to class. The online mode needs to take their individual requirements.

As of the time of writing this report, children with disabilities enrolled in government schools are only being attended to by special educators. The children are not in the online classes being held for all children. There is very little contact with the special educator and the child and worksheets are being

What the children are missing is the contact with the teacher and explanations of what to do and how to do.

G. Strategies for Education Used by the Organization

In anticipation of a lockdown, educators put together small packets for each child. Activity kits with worksheets, some colours, puzzles, books, Lego blocks etc were put together for each child to take home. No one had any idea of this lockdown stretching so long. The feeling was that we would be back to work in a few days and that the children needed something to do till then.

However, as it turned out, the months of the lockdown stretched from April to June, schools and anganwadis shut down and it was impossible for any teacher to meet with any child. New strategies had to be thought of.

H. New Challenges, New Strategies

Unprecedented times call for exploring different avenues to not only maintain current levels of functioning but also to build on abilities. Once the three-week lockdown was announced, the staff members started sending assignments over whatsapp. This posed difficulties for parents who were unable to read and write. Verbal explanations along with the written text helped clarify things to an extent. Then there were others who did not possess a smartphone.

The staff members took on the responsibility of calling the families. Activities for the week that the parents could do with their child were discussed and explained in detail, over the phone. They would then call the families after a few days and check what had been done and whether the child was able to manage the activity independently.

With lost jobs, no income, no food, parents started saying that they do not have time to sit and work with the child. New strategies had to be evolved. It was important to send things to children that did not require a lot of support from the parent.

Links to stories, songs and work-based activities were then sent. These were identified for children, according to their individual goals. Parents were able to give the smartphone to the child to access the story independently. Teachers spoke to the child and introducing the story – talking about the title, the story line is and the main characters in the story. Then after two days checking back with the child whether she/he liked the story? What did she/he find interesting? Asking some questions around the story to gauge whether the child has understood the story.

I. Identifying New Resources

A lot of online resources especially the links provided by Pratham Publications- through their story-weavers link; Tulika Publications, animated videos of stories from the NCERT books were all identified by staff members to suit individual and age appropriate needs. Many publications with worksheets are also being sent to parents to use with their children.

Tulika Publishers have started a service wherein a person just gives a missed call and they receive a call from them. The computerized system provides a language option [Hindi or English] and asks for an age group [Below 5 years and Above 5 years]. Then the story can be heard. This is a useful tool for children who can listen to a story when their parents are unable to take out time to narrate a story. The added

advantage is that it does not impose any cost on the family for this. This is being shared with families who do not have smartphones.

J. Using Material at Home

Since the families do not have the range of material that the centre has, the team members worked out the teaching-learning material that is available and worked out with parents how to use it to carry-out the activity.

Small videos were now made by staff members, videos of children whose families have used material at home to create things for working with the children. One family for instance has now used a cardboard box and lined it with pillows to create a corner seat. Another has used a small plastic tub and lined it with pillows to create a seat for their daughter. Parents share pictures or videos of these, with the staff members, who can further guide the parent on what to do next.

K. The Parent as Resource Person

One strategy that is being tried in the community is that of putting parents in touch with each other. In the past too, ASTHA has succeeded in creating *parent mentors*. These are parents who have been empowered with information on a range of aspects connected with disability. They have also been supported to work with their own child- be it education or therapy. Over time, they have grown in confidence and advocated for the rights of their child and gradually for other children as well. Many have supported younger and newer families to walk through the maze of hospital procedures to get disability certificates. These parents who have grown in experience and happen to live in the community, close to other parents with younger children can support them with information and ideas.

L. Craft Activities: Opening Children's Minds and Hearts

As the pandemic raged in Delhi and elsewhere, there was an increasing sense of fear and doom. It was important to give activities to children that they would enjoy and enable them to create. It was then decided that a range of interesting craft activities to children so that they could use their hands and their imaginations. Several craft ideas were worked on and children were given packets with all the materials to work on. As days have gone by ASTHA has got reports from many parents about how the child their siblings and often even the parents worked together to create and learn.

M. Constant and Individualized Support

The staff members attempt to be in touch with families twice or thrice a week to check on both the child as well as the family. In regular times too, Astha focuses on the family as a whole, while the child remains the central focus. Now too, whenever calls are made to families, the staff members enquire about the well-being of the parent first and then check on the child. In unusual times, with high levels of stress, individualized support focusing also on the mental health of the family must be thought of.

N. Children with High Support Needs

Children with high support needs are the ones who tend to become more vulnerable at times like this. Sometimes there is intensive work necessary to just look after basic needs of the child. It can become physically taxing for the parents/ principle care provider to focus on the child all the time. With limited or no support from others due to restrictions on movement outside homes, this can become extremely difficult.

There is a tendency of the most vulnerable- be it the child with multiple disability, the child from a single parent family, the child whose family is living on the edge, to become more marginalized in situations such as the humanitarian crisis. The danger of this child being neglected, abused, ignored or not provided for- is high.

Aware of this, the ASTHA team ensures that children and families that are most marginalized- are the ones they reach out to the most. Families who have high stress levels require the maximum support.

O. Out of Sight- Out of Mind

Children with disability have long remained isolated and cut-off from the mainstream. Successive systems that exist for all children, like the ICDS, School education, higher education, sports, leisure, vocational training and skill development courses, avenues for employment, professional courses ... have tried to evade responsibility and sought shelter in loopholes in their mandates to avoid taking in children with disability. Parallel systems have been created within the larger system. The parallel system is not real education.

Given these facts, once schools re-open, there may once again be the need to convince children with disabilities to go back to school. In the face of dissatisfaction with the education system and the feeling among parents that children are not really learning, it requires a constant push to keep motivation levels going. With the added fears of the pandemic, getting children with disabilities into school may require well thought out strategies, involving all key stakeholders including families and teachers.

Specific measures and strategies for support will need to focus on bringing girls with disabilities and those with multiple disabilities or those requiring high support into schools. Astha's research studies and data are both witness to the fact that these are two groups of children who tend to get further marginalized.

For those who have gone back to their natal villages, the big question now is whether the schools there will be able to give any priority to the child with disabilities.

Chapter-6

Law, Disability and the Humanitarian Crisis

A. International Treaties and Conventions, Covenants for the Persons with Disabilities

The recognition of the vulnerability and specific requirements of children and persons with disabilities during humanitarian emergencies is built clearly into international law and guidelines.

Article 11 of UN Convention on the Rights of Persons with Disabilities says “States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.”⁶³

The Sendai Framework for Disaster Risk Reduction emphasizes a multi stakeholder approach to disasters risk reduction.⁶⁴ In its ‘Principles’, it requires “all-of-society engagement and partnership. It also requires empowerment and inclusive, accessible and non discriminatory participation, paying special attention to people disproportionately affected by disasters, especially the poorest. It recognizes that people with disabilities are also disproportionately affected by disasters and requires a gender, age, disability and cultural perspective to be integrated in all policies and practices.

*“Disaster risk reduction requires a multi-hazard approach and inclusive risk-informed decision-making based on the open exchange and dissemination of disaggregated data, including by sex, age and disability, as well as on easily accessible, up-to-date, comprehensible, science-based, non-sensitive risk information, complemented by traditional knowledge”*⁶⁵.

B. The Rights of Persons with Disabilities Act 2016 : The need to Audit

The Rights of Persons with Disability Act, 2016 is as an influential law for protecting the rights of the persons with disabilities. The various provisions in the law obliges the state to provide a

⁶³United Nations (2006), *United Nations Conventions on the Rights of Persons with Disabilities*,

⁶⁴<https://www.undrr.org/publication/sendai-framework-disaster-risk-reduction-2015-2030>The Framework was adopted at the Third UN World Conference on Disaster Risk Reduction in Sendai, Japan, on March 18, 2015.

⁶⁵ *ibid*.

range of supports, accommodations, amenities both at the time of normalcy and the humanitarian crises like the spread of pandemic of COVID_19.

The RPWD Act, 2016, acknowledges 21 forms of disabilities, some of the conditions like blood-disorder and acid attack being acknowledged as disabilities for the first time. The law for the first time defines persons with high support needs.⁶⁶ There are many new concepts in the law and new groups of children and persons with disabilities added to the law. *These new groups and concepts were yet to be integrated in policy and rules and regulations when the pandemic struck.*

However, of immediate relevance in the pandemic are the sections of the law that directly deal with disaster management.

i. Disability and Disaster Management

The RPWD Act 2016 provides for the protection and safety of the persons with disabilities in situation of risk, armed conflict, humanitarian emergencies and natural disaster.⁶⁷ It provides for the National Disaster Management Authority and the State Disaster Management Authority to ensure the inclusion of persons with disabilities in its disaster management activities. *It requires the District Disaster Management Authority to maintain records of persons with disabilities in the district and to take suitable measures to inform such persons of any situations of risk so as to enhance disaster preparedness.*⁶⁸

The Act further **says** *“The authorities engaged in reconstruction activities subsequent to any situation of risk, armed conflict or natural disasters shall undertake such activities, in consultation with the concerned State Commissioner, in accordance with the accessibility requirements of persons with disabilities”.*⁶⁹

These are just some of the commitments that the law makes for children and persons with disabilities during and after a humanitarian crisis.

Building Back Better

⁶⁶Rights of Persons with Disabilities Act 2016, Sec.- 2 (j), Sec.-38 (India)

⁶⁷Right to Persons with Disability Act 2016, Sec 8 (India).

⁶⁸ibid

⁶⁹ibid

The other sections of the RPWD Act that are important not only when a crisis happens but also in the phase where the country will hopefully build back better must be audited now to ensure better implementation in coming years.

ii. Right to Equality and Reasonable Accommodation

Chapter-II titled “Rights and Entitlements” of the Act under Section-3 subsection (1) obliges the state to “*ensure the persons with disabilities enjoy the right to equality, life with dignity, and respect for his or her integrity equally with others*”. The same section under sub-section (5) states that “*the appropriate Government shall take necessary steps to ensure reasonable accommodation for persons with disabilities.*” Reasonable accommodation has been defined in the legislature as a “*necessary and appropriate modification and adjustments, without imposing a disproportionate or undue burden in a particular case, to ensure to persons with disabilities the enjoyment or exercise of rights equally with others.*”⁷⁰

The concepts of reasonable accommodation and others in the law are important for policy and practice. They point to the fact that one size does not fit all and that individual variations and requirements must be graded into the state’s response.

iii. Right to Community life and Adequate Standard of Living

Section-5 of the RPWD Act 2016 details the right to live and receive services within the community. “The appropriate Government shall endeavor that the persons with disabilities are,— (a) *not obliged to live in any particular living arrangement*; and (b) *given access to a range of in-house, residential and other community support services, including personal assistance necessary to support living with due regard to age and gender.*”⁷¹

The RPWD Act 2017 also talks about social security, health and rehabilitation of persons with disabilities. While talking about the schemes and programs it says that “*the quantum of assistance to the persons with disabilities under such schemes and programs shall be at least twenty-five percent, higher than the similar schemes applicable to others.*”⁷²

⁷⁰<http://www.deoc.in/the-rights-of-persons-with-disabilitiesrpwd-act/>

⁷¹*The Rights to Persons with Disabilities Act 2016*, Sec.-5 (India).

⁷²*Rights of the Persons with Disabilities Act 2016*, Sec.- 24 (India).

It is now well documented that children and persons with disabilities and their families have faced many difficulties in accessing essential support such as both food security and medication and medical intervention during the lockdown and pandemic. The quantum of assistance to children and persons with disabilities at a time like this has not been commensurate to the requirements of the law.

iv. Health Care During Disasters

The law in section 25 does talk about local authorities taking *necessary measures for the persons with disabilities to provide,— (a) free healthcare in the vicinity especially in rural area subject to such family income as may be notified; (b) barrier-free access in all parts of Government and private hospitals and other healthcare institutions and centres; (c) priority in attendance and treatment.*⁷³

Among other commitments **section 25 of the RPWD Act 2016** also talks about “*local authorities taking measures or making schemes for healthcare during the time of natural disasters and other situations of risk*”.⁷⁴

v. Information Dissemination

According to Sec 42 of the law all the information and services should be made available to persons with disabilities in the accessible format.

“*The appropriate Government shall take measures to ensure that,— (i) all contents available in audio, print and electronic media are in accessible format; (ii) persons with disabilities have access to electronic media by providing audio description, sign language interpretation and close captioning; (iii) electronic goods and equipment which are meant for every day use are available in universal design.*”⁷⁵

Unfortunately, the guidelines, schemes, announcements, and the online process to avail the benefits of schemes have been inaccessible for a range of persons with disabilities. For people with vision impairment These guidelines, scheme etc. are not present in audio format, the soft copies being uploaded are in pdf format, often unclear and hazy to read, thus making it difficult for the persons having low vision, or visual impairment to have access to these information. The

⁷³Rights of the Persons with Disabilities Act 2016, Sec.- 25 (India).

⁷⁴ibid.

⁷⁵Rights of the Persons with Disabilities Act 2016, Sec.- 42 (India).

online mode to apply for these benefits are also problematic as the instructions and procedures are not in audible format and highly inaccessible. **With so many important orders coming out in quick succession during the pandemic, it becomes extremely important to have information available in accessible formats for all.**

vi. National and State Funds for Persons with Disabilities

The RPWD Act 2016 under Chapter XIV and XV, Section 86-90 provides for National and State Funds for the persons with disabilities for the welfare of persons with disabilities and to empower them and to provide them opportunities for their inclusion in mainstream society.⁷⁶ However, in this time of crisis wherein the persons with disabilities require support of unprecedented nature, there is need to audit whether the funds received are adequately utilized or not by the concerned persons. The need of the hour demands to audit these funds and ask the concerned authorities on the status of these funds.

C. Social audits mandated by Law

In sec 48, the RPWD Act itself mandates a social audit of all general schemes and programmes involving the persons with disabilities to ensure that the scheme and programmes do not have an adverse impact upon the persons with disabilities and need the requirements and concerns of persons with disabilities. It would be important to put this into practice at this time when the reach and implementation of any scheme is most important.

D. Comprehensive Disability Inclusive Guidelines for Protection And Safety of Persons with Disabilities (Divyangjan) During COVID 19

As the pandemic struck, the Dept of Disability Affairs in the Ministry of Social Justice and Empowerment too issued guidelines for people with disabilities. “Comprehensive Disability Inclusive Guidelines for protection and safety of persons with disabilities (Divyangjan) during COVID 19.” and in its letter to the secretaries of various states and UTs have acknowledged that persons with disabilities are amongst the most vulnerable group in situations of risk and many of them require continuous care and support.⁷⁷ The Comprehensive guidelines provided range of provisions to cater to the needs of the persons with disabilities.

⁷⁶Rights to Persons with Disabilities Act 2016, Sec. 86-90 (India).

⁷⁷Secretary Government of India (2020), “Letter to the Chief Secretaries of States and UTs” Dated 26-3-2020

Some of the important aspects of the advisory include having information dissemination in accessible formats through helplines, training of all persons responsible for handling emergency response on the rights of persons with disabilities, and on risks associated with additional problems for persons having specific impairments. The guidelines advised that “Persons with disabilities should be given access to essential food, water, medicine, and, to the extent possible, such items should be delivered at their residence or place where they have been quarantined. Further, States/UTs may consider reserving specific opening hours in retail provision stores including super markets for persons with disabilities and older persons for ensuring easy availability of their daily requirements.”⁷⁸

The Disability Inclusive Guidelines under its general action points details that training to be given to the personnel involved in emergency response services about the rights of persons with disability.⁷⁹ There is an urgent need to ask the question *whether the system has equipped itself with the requisite knowledge about the needs and rights of persons with disabilities especially the new disabilities that have been recognised? Have these personnel received any such training and have they been able to utilize the learning of these trainings to cater to the needs of persons with disabilities.*

What the guidelines did not do was to advise on the specific needs of children or women with disabilities. The RPWD Act, 2016, acknowledges 21 forms of disabilities some of the conditions like blood-disorder and acid attack being acknowledged as disabilities for the first time. The RPWD Act 2016 for the first time defines persons with high support needs⁸⁰. The Disability Inclusive Guidelines issued during the COVID-19 crisis has missed out to address the special needs of the new forms of disabilities and also the persons with high support needs.

Our experience working at the community level and our previous studies reflect lack of awareness in the system, and among the various stakeholders including the persons and their families, about the new forms of disabilities. It is for this reason perhaps that people with blood

⁷⁸Government of India (2020), “*Comprehensive Disability Inclusive Guidelines to States/UTs for Protection and Safety of Persons with Disabilities (Divyangjan) in light of COVID-19*”, Government of India: New Delhi.

⁷⁹Government of India (2020), “*Comprehensive Disability Inclusive Guidelines for protection and safety of persons with disabilities (Divyangjan) during COVID 19*”,

⁸⁰Right to Persons with Disability Act (2016), Chapter-I Section 2 (j), Chapter- VII, Section-38. <http://www.deoc.in/the-rights-of-persons-with-disabilities-rpwd-act/>

disorders such as Thalassemia had to advocate a lot before any advisories were issued to make blood transfusion and medication more easily available even in a city like Delhi.

E. Disability Commissioners: The Nodal Authority

The Comprehensive Disability Inclusive Guidelines for protection and safety of persons with disabilities (Divyangjan) during COVID 19 further stated that the State Disability Commissioner for Persons with Disabilities, of the state “be declared as the Nodal Authority in respect to Persons with Disabilities. They are to coordinate with all line departments and ensure that information, restriction plans and services are available in local languages and accessible formats for persons with disabilities is available”. Meanwhile district officers for persons with disabilities are to be in-charge of the district and monitor the requirement of persons with disabilities including persons with high support needs. This officer is to have lists of persons with disabilities and to resolve all issues relating to them.

However, there seemed to be a lack of data and records about persons with disabilities at the district level both in Delhi and elsewhere in the country, thus reaching out to persons with disabilities have been challenging process in this pandemic.

Unfortunately, Delhi has functioned without a regular Disability Commissioner through the whole crisis. At the Central level too, the Secretary of the Department for Rights of Persons with Disabilities holds additional charge of the Office of the Chief Commissioner for Persons with Disabilities for the whole country. Despite guidelines and good practices in some states, it has been difficult for persons with disabilities to know where to go and how access their nodal officers and Disability Commissioners⁸¹.

F. NDMA Guidelines on Disability Inclusive Disaster reduction

In September 2019, National Disaster Management Authority, issued National Disaster Management Guidelines on Disability Inclusive Disaster Risk Reduction (DIDRR) in line with the provisions of the law.⁸²

Among other things, these detailed guidelines talk:

⁸¹ ASTHA (2020), *Process Document: Stories of Some Children with Disabilities* ASTHA:INDIA

⁸²https://gidm.gujarat.gov.in/sites/default/files/educate_your_self_document/Guidelines%20on%20Disability%20Inclusive%20Disaster%20Risk%20Reduction.pdf

- ✓ Institutionalization of Inclusion of persons with disabilities and their organizations in DDR activities as per the 2016 RPWD law.
- ✓ Universalization of awareness of DDR planning amongst persons with disabilities
- ✓ Having a two track system on mainstreaming and providing specialized services
- ✓ In-depth consultation with persons with disabilities and their organizations

G. During Women and Children with Disabilities in the Guidelines issued by Various

Departments: Where are we?

In this pandemic, the Central government passed various guidelines to be followed during the lockdown dated 23rd March 2020, 15th April 2020, 5th May, 18th May 2020. Additionally, the policymakers at the central and state level came up with various guidelines and advisories for various social groups to be followed like- advisory for the needs of “*Internal Women Migrants India during the COVID-19 Lockdown*”, and *Coping Strategy for Children and Caregiver*⁸³. However, all these advisories and guidelines have missed out to accommodate the special needs and individualized needs of women and children with disabilities. The RPWD Act, 2016 has made a special reference to the Women and children with disabilities under Section 4. It annunciate that “*The appropriate Government and the local authorities shall take measures to ensure that the women and children with disabilities enjoy their rights equally with others. It further says that the appropriate government and local authorities shall ensure that all children with disabilities shall have right on an equal basis to freely express their views on all matters affecting them and provide them appropriate support keeping in view their age and disabilities.*”⁸⁴ are perhaps the most vulnerable group of people at risk during this pandemic. While the advisory issued by the National Commission of Women advisory on Migrant women mentions and *acknowledges the needs of pregnant women and lactating women and women from the north-eastern states of India, but does not provides special clause for women with disabilities*⁸⁵. This advisory acknowledges the need of food, shelter/accommodation, safety and security (from gender based violence), health, mental health, hygiene for the migrant women. Women and girls with disabilities, cut across all social categories including migrants and

⁸³ Ministry of Women and Child Development (2020), *Coping Strategy for Children and Caregiver*

⁸⁴ *The Rights of Persons with Disabilities Act, 2016 Sec.-4* (India)

⁸⁵ National Commission of Women (2020), *Advisory Internal Women Migrants India during the COVID-19 Lockdown*

homeless, and experience multi-level disadvantages. They have specific and individualised needs and require support in terms of nutrition health, hygiene, safety etc. due to their bodily impairment which has often remained unaddressed especially those women with disabilities that belong from migrant families, refugees, and or homeless etc.

Similarly, the advisory given by the Ministry of Women and Child Development on “**Coping Strategy for Children and Caregiver**” also fails to acknowledge that children with disabilities have specific and individual needs and are more vulnerable to psychological stress. *Most of the mothers/parents are unaware of working with their children with disabilities and to keep them engaged. There must be some resource materials available in a public domain to create awareness among the parents and caregivers about the strategies to cope up with the children with disabilities who are now spending most of their time at home, devoid of any education, therapies and other functionalities.*

The COVID-19 crisis has triggered the need to look and address the various forms of vulnerabilities especially women and children with disabilities

CHAPTER-7

RECOMMENDATIONS FOR BUILDING BACK BETTER

A. Cognizance of Existing laws

The existing law on the rights of persons with disabilities, must be the guiding force while formulating policies and guidelines by various other ministries and departments during a crisis. Persons with disabilities or the organizations that represents them must be part of the formulating stage of the schemes, legislations and policies so that the system develops the knowledge about their issues and challenges and accordingly formulates provisions. The system must develop an understanding that People with Disabilities and their families are not just Supplicants but Actors in their own Right.

The slow implementation of the rights of Persons with Disabilities Act of 2016, and general lack of understanding about new terms and concepts and people that it includes, has come out sharply during the pandemic. **As India builds back better, it is important that here is a growing momentum to implement the law in its true spirit in all the States. This will ensure better preparedness for any further or future crisis.**

B. Reaching Out to Individuals in Distress and the Vulnerable Group

In a situation of crisis, it is important to have a plan of how to reach out to the vulnerable section of the society particularly people and children with disabilities as they are scattered within populations. **The planning requires a multiple pronged approach and in absence of data in aggregated or disaggregated, one can use the data or lists of children in the school system, the ICDS system, people with disability certificates, people availing of pensions and panchayat and MNERGA lists in the rural areas. A more focussed local approach can be useful in the mapping process as many children and persons with disabilities are outside these lists.**

C. Developing and Strengthening of various institutions, agencies, and bodies.

Institutions like the Anganwadi system and the public school system that are embedded in communities make access easy in times of humanitarian crisis. It is important that these

systems that are embedded in communities be strengthened and rather than rationalizing these systems and their knowledge of children and people used by the authorities during a crisis.

Strengthening of DPOs and community groups should be seen as a long-term strategy to enable communities to absorb the shocks of a humanitarian crisis. They also proved to be extremely important in understanding the national situation of persons with disabilities in the country.

There is a need to **develop an ecosystem of varied stakeholders** that comprise of people at the community levels, various DPOs, self-help groups, alliances and groups that work in different regions and focus areas as working with others also helped to avoid any kind of duplicity of efforts. The constant flow of information, between them, helps in creating strategies and understanding how to proceed further and suggest strategies that are relevant and take into account diverse needs. They can give valuable information and suggestions to the government when time is precious and when they need it the most.

D. Schemes and Policies

- ✓ The existing schemes and policies that come up during the time of humanitarian or any risk situation must adopt a **flexible, accommodative, and inclusive approach** so that the benefits reach out to all and no one should be left behind.
- ✓ Social security schemes like pensions and ration/food under the public distribution system are instrumental for the survival and independent living of the vulnerable groups including persons and children with disabilities. **During times of crisis, the system must be more sensitive towards the needs of people and allocate additional benefits in real values so that not only cost of survival but the associated expenditure related to disabilities are also covered. The supports given should be in relation to immediate needs during the crisis, rather than amounts that have been pre- determined in normal times.**
- ✓ The lack of any social security net and exclusion from large countrywide schemes, entitlements for large percentages of children and persons with disabilities point to a much larger and urgent question. **What are the strategies and ways to reach out to all during a crisis? While the discussion on universalization is an important one for**

people with disabilities too, it has to be seen whether any specific strategies are required within this universalization.

- ✓ The lack of food security in such a small random sample, indicates the precarious situation of many who come to work in cities. **It also indicates a lack of specific and focused strategies to enable food security for the most vulnerable.**

E. Data on Persons with Disabilities

Data of persons with disabilities in aggregated or disaggregated form must be prepared for the identification of children and persons with disabilities in times of crisis like this. **The systems must take lessons from the present crisis and take proactive measures to streamline and bring its various bodies and agencies into place.** As said earlier to identify and map the persons and children with disabilities, the system must reach out to the personnel that work directly with the people at the grass-root levels like anganwadi workers, ASHA workers etc. who can act as an important source of information in the geographical regions

F. Pro-active Role of the District Disaster Management Authority

The District Disaster Management Authority must become pro-active at the administrative level to maintain records of persons with disabilities in the district and to take suitable measures to inform such persons of any situations of risk to enhance disaster preparedness.

G. Coordinated, Collaborative and Inclusive Approach

- ✓ There should be proper coordination and convergence among various ministries and departments to cater to the needs of various disadvantaged groups in general and the persons with disabilities in specific.
- ✓ Collaborative, coordinated, inclusive, and multipronged approaches must be adopted by various stakeholders including the State and Civil Society while catering to the needs of the vulnerable so that no one is left behind. Working collaboratively and cooperatively enables and widens the horizon of strategies to be adopted and helps in extending the rehabilitation services to the vulnerable.
- ✓ The persons with disabilities and their families should not only be considered as beneficiaries but also as agents of change and important actors and resource persons in the time of crisis when any civil society organization or system could make themselves physically present immediately.

H. Special Emphasis on Women and Children with Disabilities

- ✓ Women and children with disabilities cut across all section and are the most vulnerable amongst the vulnerable groups. The specific and individualized needs and the support that children and women with disabilities require should be taken into cognizance and specific provisioning should be incorporated in the guidelines, schemes and policies of for children and women.
- ✓ It is important to **ensure that all children with disabilities are now part of all national and state level schemes as well as the education system and that strong attempts are made to include them and audit their participation in early childhood and education systems** along with any standalone schemes. This will ensure that they are counted and are part of disaster relief among other implementation of rights.
- ✓ The closure and diversion of all health facilities towards COVID has led to a detrimental pause in the medical habilitation and rehabilitation of many young children with impairments, with disabilities and those at risk of disabilities. **Given the importance of the first 1000 days for the child, there is an urgent need for a countrywide plan on how to ensure that young children access the habilitation and rehabilitation services they require.**
- ✓ The same holds true for older children who maybe on long term medications and require medical rehabilitation services.
- ✓ During the crisis situation, basics ration becomes the priority of the family and the other nutritional requirements of the child come to back foot. The system must debate and understand the issues of nutritional requirements of the persons with disabilities and more specifically of the pregnant women, children with or without disabilities. The system must probewhom to support, how long to support and question the adequacy of food kits for the needs of children, particularly, very young children. More planned and coordinated efforts with state and civil society can enable a better and qualitative outreach.

I. Disseminating Information to Empower

- ✓ All the information pertaining to the catastrophe must be made available in the public domain in accessible format.

- ✓ Information campaigns that highlight the many different executive orders must be undertaken using audio and visual formats.
- ✓ People and children with disabilities must be empowered with information so that they are able to demand their rights- with respect to education, food, health care and all areas that connect with them.
- ✓ Strong networks of helplines can also be of great use during a crisis when people are unable to come out of their homes. **Disability helplines should be encouraged and strengthened to disseminate information. Helpline networks with many different focus helplines intersecting are extremely useful. A helpline dealing with women's issues or old age is equally important to the person with disability.** With many more technological options today, it is important that an attempt is made to reach out to all. The helpline as a mode of provisioning has to be accompanied by a lot of information gathering about laws, schemes, rules, and regulations and a connect with many different kinds of organizations. These connections, resources, and referral resources become extremely useful at this time of crisis and can be used again and again.

J. Education to all Even in Crises Situations

- ✓ In the sphere of education, there is a need to broaden the scope and meaning of education and go beyond just the concepts of reading, writing and arithmetic. Goals for children need to be more holistic for it to be more meaningful. During the pandemic or any situation that poses a risk, wherein schools are first to close, the system must adopt multiple pronged, alternative strategies to impart education to children.
- ✓ Education does not remain a priority when basic needs are hard to come by. For children with disabilities who have other needs of therapies etc, getting the child educated is a challenge that is difficult for families and children in any case. **In the near future, education planning must take into account the grave economic and other threats that are facing vulnerable families and not plan in isolation.**
- ✓ Though online method of transaction has proved to be an important mode to transact classes, it cannot be a one size fits all. Some children with disabilities will require accommodations and changes in both content and technology and these must be factored in by schools and teachers.

- ✓ **Children with disabilities must be included in all online classes** with the whole class with clearly worked out individual support where required.
 - ✓ Children with disabilities who have migrated back to their villages along with their families are likely to face additional barriers in getting back to schools. This needs to be a factor in education planning, particularly in states which have seen large scale reverse migration.
 - ✓ The education system needs to devise strategies to keep an eye out for children with disability, especially those with high support needs, to keep them within schools. They are more likely to drop out. They will require that extra push to go back, once schools re-open. The most vulnerable need to be kept well within their radar to ensure that no child gets left out.
-