



## COVID19 Pandemic Voices from Margins

### Webinar series Webinar 5

### Children with Disabilities

**Date: April 22, 2020**

**Minutes**

#### **Panelist profile:**

**Panelist 1:** Danish is in the secondary class. He performs well academically and is appearing for the National Institute of Open Schooling (NIOS) Open Basic Education (OBE) exam. He has passed levels A and B and is now appearing for level C for class 8. He is very friendly with his classmates and likes drawing, music, and dance and is good at sports. Danish's mother will support him during the webinar.

**Panelist 2:** Riddhi Halwai is 15 years old and has an auditory disability. She studies in class 8 and is good at academics, across subjects. She also has an interest in arts and crafts and is very creative. She participates in inter-school competitions for drawing, craft and language. During this lockdown period she is making articles from newspaper at home. Ridhi's older sister supports her during the webinar.

**Panelist 3:** Dr. Harish Shetty is a psychiatrist with several years of experience in the field of disaster and mental health - he has worked in Latur and Gujarat in the aftermath of the earthquakes evaluating the psycho social processes, in Kandla after the cyclone and closely with riot victims in Gujarat. He has also provided mental health interventions to seafarers (after their release from Somalian pirates) and worked extensively with children and on the issues of children with disability. He is a governing body member of the National testing agency (NTA) by appointment of the Union cabinet on behalf of the Human Resource Development ministry.

**Panelist 4:** Juber Shaikh is 19 years old and has an auditory disability. He is in class 10 and received an A grade on the elementary exam. He is very co-operative and friendly with other students. He is good at drawing and in sports. He always participates in all in-house and inter-school sports and creative activities. Juber's father will support him during the webinar.

**Panelist 5: (Couldn't be present for the webinar due to connectivity issue)** Anas Farooq Quereshi is 8 years old and he is in the Elementary Class. He is being looked after by his grandmother at home. He is very active and social and is very cheerful. He loves to learn new things and enjoys puzzles and playing new games.

**Mr. Tom Thomas, Moderator, Praxis:** Praxis is an Indian organization that focuses on various facets of participatory democracy. Praxis tries to bring the voices, concerns, and solutions of marginalized communities through several kinds of research and studies directly or through face to face meetings that happen physically or digitally between the community members, policymakers, media, activists, etc., This webinar series of COVID-19 Pandemic – Voices from Margins is a continuation of that attempt as during the lockdown days the major hope is to bring to the forefront the voices of the communities that are left unheard.

Largely, the intent of these webinars is to reach out to a wider audience and build larger solidarity from the perspective of people at the margins. This is the fifth webinar of COVID19 voices from Margins series that is being brought in collaboration with Praxis and Save the Children India. Among the previously convened webinars so far, this holds more prominence because it brings voices of children with disabilities on the impact of lockdown in their lives. So far, we have been engaging with adult voices of marginalised communities and this one is special in many ways. Save the Children India is a 32 years old organisation founded by Ms. Vipula Kadri. The organisation works to ensure children with disabilities, those vulnerable to trafficking and those in

communities where pre primary and primary learning is a challenge. The organisation works towards ensuring children's right and access to education and their skill enhancement.

There are two essential parts of this webinar- 1) A quick study conducted with a very small sample of children with disabilities mainly to understand the impact of lockdown on their lives; and 2) Listening voices of children with disabilities present in the panel representing the voices of larger section of children at the margins.

### **Sowmyaa and Nirmita, Praxis**

A **rapid assessment** of the situation of children with disabilities, a study was undertaken with 56 children from Mumbai, Maharashtra to understand the impact of COVID-19 outbreak and nation-wide lockdown. Families of 20 children with auditory disability and 36 with intellectual disability were interviewed as part of this process. The children who were interviewed aged between 7 and 15 years. Multiple set of questions were asked to them telephonically. Findings give a broader overview of the issues being faced by the children with in the period of lockdown. The findings are:

- Impact on **nutrition: 8 out of 56** children reported to have some impact in their lives. Though none of them have gone hungry yet, **three** children overall reported to have merely two meals a day. **One** of them mentioned surviving on tea and biscuits;
- Impact on **self and parental care: 8** children reported to have some impact on care;
- Impact on **behaviour: 5** children reported to have change in their behaviour (ranging from irritability to much more mischievous);
- Impact on **access to hearing aid accessories: 4** out of 20 children with **auditory disabilities are** facing problems due to **unavailability of battery and repairing issues.**

Families were consulted about the access to the various kinds of entitlements that have been announced by the central government.

- **Right to food:** It is noteworthy that only **one in four** families have received any ration for the last one month (since 17 March) when the lockdown was announced. Given that the families are dependent on daily wages for their survival; this would create implications in immediate and long term health and nutritional needs of families and especially the children.
- **Access vis-a-viz eligibility to avail schemes:** Interviewees were asked about 5 schemes- Pradhan Mantri Jan Dhan Yojana (PMJDY), Pradhan Mantri Ujjwala Yojana (PMUJ), Pradhan Mantri Kisan Samman Nidhi (PM-KISAN), Pension for Senior Citizens and Pension for the Disabled. **None of the 56** families are registered for **Ujjwala or Kisan Saman Nidhi Yojana**. Among **only 6 eligible** families having **Jan Dhan Account, 3 families** received Rs. 500. **Only 1 eligible** family entitled for **Elderly Ex gratia payment** (senior citizen pension) hasn't received any money.
- **Disability allowance:** None of the 10 children with intellectual disability entitled for disability allowance have received money from the Maharashtra government.
- **Indebtedness:** Among 56 families interviewed, 9 have already taken loan from friends, relatives and neighbour to manage household expenses. It indicates that nearly 20% families are already indebted in less than a month of nation-wide lockdown. Such loans in informal settings at times create bondage conditions.
- **Impact on lives of children:** During interactions with children they expressed their keenness to go out, play visit friends but are restricted by the parents for not going out. Children are unhappy with such restrictions.

## Farida, Save the Children India

The lives of children with disabilities have been affected severely in many ways post nationwide lockdown. Such children are going to face several disruptions in their normal lives with closure of schools and changed normal routine. Additionally, the restricted mobility has impacted their behaviour as they are confined into homes without any physical activity and not getting social interaction with peers and teachers that used to happen before. Thus, this has impacted on social emotion and functioning of such children. Also, the care givers and the parents are finding it difficult to deal with the behavioural changes of children.

Longer period of lockdown will incur major **learning loss for children with disabilities** who have been availing of speech therapy, hearing therapy and physiotherapy. Bridging the gap of this learning loss will be a big challenge for educational and health institutions which work with such children. Even, the **general health services are put at halt and difficult to be accessed by them.**

Despite of growing adaptations with virtual mediums of learning and teaching still for people at the margins, the access to online platforms is a big challenge. Among families who are experiencing severe food crisis the closure of schools has deprived the children from mid day meal resulting in the nutritional loss in them. All these need serious consideration as such situations will have more adverse impact on children with disabilities rather than children with normal conditions. It's the people at the margins who have been badly impacted and children with disabilities in such situations are bearing the burnt. Economic hardships is constantly adding the hardship experiences for caregivers in such families whose primary survival is daily wage earning.

Towards the end March, The Ministry of Social Justice and Empowerment has issued a set of guidelines which states specific guidelines for PWD. This suggested for prompt cash transfer and issue of passes as an easy process for the families having persons with disabilities to be done on a priority basis. Besides, this also emphasises the access to food, water and essential medications to them. However, this hardly happens in reality. Nonetheless, the challenges discussed so far largely depicts the situations of children who are in Mumbai and connected with the schools or some institutions and can access these. Situations with children with disabilities in rural areas are extremely worrisome. Also, the parents/ caregivers lack capacities and skills to deal with behavioural aspects of children with such condition which needs serious consideration. Few things can be helpful in such context could be as follows:

- **Targeted Direct Cash transfers** to families having persons with disabilities using the already updated data base of PWDs under UIDAI to **help the families facing situations of food crisis**;
- **Focus on the medical aid** i.e. (ease in accessing the therapies, repair of accessories, aids required by children in govt. hospitals) and **capacitation of health professionals** addressing these specific needs;
- **Redesigning of educational curriculum**, particularly the **academic calendar** for children to bridge the gap and the losses would incur in these longer lockdown days
- Viable **platforms** for participation which can be accessed by families of children with disabilities to **seek support and advice.**

## Panelists DISCUSSION

### Panelist 1: Danish

**(Danish' smother)** Earlier Danish would go to school; his time was passed very well. He would be energetic and happy. However, post lockdown he does not feel very happy as he is not going to school. These days he helps me while doing the household works. I am facing difficulty in arranging the medicines for him. He has problem of dizziness and headache which requires medication. We had fallen short of medicines. Any how we managed to arrange some medicines for him. He is preparing for getting admission into ITI.

**Danish:** I like doing activity based things. I have made some crafts bags using newspapers, also decorated them. I get bore at home. I like to play football and basket ball. I am waiting for the school to reopen to join my

studies. My mother doesn't allow me to go out. I like operating mobile. When I will grow an adult either I will buy or make a mobile. I want to do something good and big in future.

***(Danish has deep interest in craft. He was enthusiastic while showing his crafted bags, paper bags using newspaper. He showed all the participants some of the beautifully crafted bags mentioned how explained how he has decorated them using pearls, threads, etc.)***

**Panelist2: (Ridhi's sister)** She makes beautiful illustrations and has collection of sketches. After the lockdown she was happy that it's now a holiday but soon after 2-3 days started getting bore. She also spends her time on computer and in trying out new recipes to pass her time. She keeps herself busy in drawings and paintings.

**Ridhi:** Since it's lockdown so I will stay at home. I will keep drawing. Corona has come from China. It will be good if everyone stays home and stays safe at this time.

***(Ridhi is fond of painting and displayed her extensive collection of beautiful drawings and sketches on a range of subjects- cartoon creatures, portraits, scenery etc. She also showed some crafts such as wall hangings flower pots etc., None of her paintings reflected that she is amateur in the art of painting.)***

**Panelist 3:**

Juber is a 19 year old teen boy who has a hearing loss. He also has a twin brother with the similar condition. And his father is an auto rickshaw driver, at the moment all of them are at home. They are struggling with the damage in the hearing equipment aid. With two brothers, they have to share the hearing aid. Given the situation of lockdown, it's not possible for the father to get out and get it repaired. Also, this longer period that children are spending away from school will result in the learning loss in the long run.

**(Juber's father)** I ensured that my sons study at least till 10<sup>th</sup>. But now, I am in a perplexed state of mind and unable to think about any future possibilities for them. Both of my children are immensely talented and they carry out most of the designated works in the most effective manner whether its kitchen related chores or computer related skills. They are a gift of god to us. I have studied e till class 4<sup>th</sup> from Marathi medium. My sons want to become hair dresser. Juber want to become a hairdresser. Once I approached a trainer in hair cutting school regarding fees which was Rs. 25,000 out of my economic limit. My sons experiment with hair cutting. They use their own ideas and experiment with their skill. They have attempted different types of haircuts of people in neighborhood areas. On learning about Juber's passion for hair cutting, their brother has gifted them a set of equipment required for haircutting. Junaid is his brother. He has a different perspective; he wants to earn a lot of money in life. Juber is happy even to do a job for Rs 10, but Junaid would do it only for Rs 100.

Amidst lockdown, we are facing a lot of challenges. There are only 1-2 doctors near our locality and due to lockdown there is always a long queue which makes it difficult for me to take them for medication in case of general ailments also. Juber was having issues with digestion and this has been affecting his health. Due to restricted mobility both of them complain of muscle pain as there is no physical activity. They miss their school friends but we didn't let them go out considering the situation. We survive on daily wage earning and after the lockdown I am sitting idle in home for last one month. This has badly impacted our economic condition. I would like to request my fellow participants if they can think off some better avenues towards bettering their lives and helping them in achieving the goals. I am clueless and worried about how to engage them in some productive works in future. Both of my children, Juber and Junaid do paintings and are very talented.

***(Juber and his twin brother Junaid, both showed the collection of their beautiful paintings they have made to the participants. Also, they showed the walls of their room which was beautifully painted by them. Both of them showed their bald fade hairstyles attempted by themselves.)***

**Panelist 5: Dr. Harish**

Children with disabilities are the worst to be affected by this pandemic and confinements due to lockdown. While listening to the responses of the parent, I could see five conditions to be common in situations for children with disabilities:

- I. **Lack of any physical activity:** Restricted mobility of such children has brought aggression in their behavior which is creating challenges for parents/caregivers to manage irritant/angry behaviors of children.
- II. **Loss of learning to be long lasting:** The adverse impacts will be longer in the absence of no contact with school, no access to therapies and this loss of learning will have long lasting impacts upon children much beyond after the lockdown period as well.
- III. **Increase in anxiety levels of parents/caregivers:** Staying at home all the time with children has increased the frustration levels among parents and care givers. Dealing with children's situations in such times when their own livelihoods are impacted has increased the frustration and uneasiness.
- IV. **Secondary isolation:** In case of normal children, the social interactions are much higher, broader and richer. In case of children with disabilities, these confinements have pushed them into secondary level of isolation.
- V. **Loss of livelihoods of parents/caregivers:** Issues related to the financial is the biggest fears among parents. Though the parents have more time with the children instead of dealing with conditions of children the stress of livelihood and food occupies their mind.

#### **Suggestions by Dr. Harish:**

- **Advocacy with the govt is a must** and that has to be a continuous process but at the same time there several hundred NGO s working in the field. There should be creation of **opportunities of cross learning, sharing of resources in an environment of cooperative learning among all CSOs** is important in this regard. There is no need to invent the wheel all over again. The present experience with COVID 19 has made us realised that cross boundaries learning will be helpful for each.
- **Availability of an open platform/ helpline** that can be accessed by families having children with disabilities to seek support and advice within reach of all sections. Still, many children with disabilities of are out of the reach of NGOs and not linked to any of the schemes. Efforts towards identifying such children and linking them to schemes are needed. This would call for **active collaboration across all CSOs**;
- In reference with the rapid study undertaken by Praxis, a bigger sample size can be accessed later to understand whether such conditions are common in normal days too which is most likely to be true.

In response to Dr. Harish's suggestion towards NGO's taking ownership, some of the participants expressed their opinions in this regard.

**Professor Anita Ghai:** I am Professor Anita Ghai. I am a wheelchair- user. At the age of 2, I got infected with Polio. So, my research work and teaching everything revolves around disability. I am a very concerned when it's comes to disabilities with children ad as well as adults. In responding to what Dr. Harish said my question is why only NGOs? Placing the entire onus upon NGOs will not solve the problem. Attempts are needed to bring them into mainstream. For instance, if we give the responsibility of education to NGOs, children will the education is sandwiched between special education and mainstream education entitled under MHRD guidelines. There is always a buzz around inclusion of such children but largely they are addressed in a charity mode. Access to online mediums can't be availed, even by adults. Connecting these children to virtual modes of learning is an issue. Also, I have some concerns regarding the quick study undertaken by Praxis. The whole idea of emancipatory research should be something that can help the subjects rather than the participants. In further part of the research, there is a need to involve the people with disabilities in part of the research team.

**Niharika Das:** I would like to make a small comment here in reference to DR. Shetty's comment regarding active and larger collaboration of NGOs. In my opinion, the focus should not be NGOs working in the disability sector but rather it is the responsibility of the government as has been mentioned in the NDMA guidelines. There is a

clear mandate on Disability Inclusive Guidelines but however, it is as a lack of implementation on the part of the government. To summarise, we should be questioning the government more in order to ensure persons/children with disabilities are not left out in the entire process.

**Nilesh Singit:** This is Nilesh Singit disability rights activist. A group of us got together and have sent letters to Central govt and state governments {Maharashtra} on issues persons with disabilities shall face during the lockdown to get the government machinery to address the issues. We have tried to get in touch with the disability commissioner too. In fact the onus to address these issues lies on the disability commissioner. Unfortunately not much is happening from its office.

#### **Q&A SESSION:**

**QUESTION:** Ridhi, from where is she learning this skill of painting? Whether she sells her paintings?

**RESPONSE :(*Ridhi's sister* )** Ridhi has learnt the art of paintings from you tube and she loves doing it. As of now, she has no plans to sell her painting and want to keep the collection with her only.

**QUESTION: (*To Danish's mother*)** Are you following any specific schedule for Danish throughout the day, would you like to suggest how you are engaging Danish throughout the day?

**RESPONSE:(*Danish's mother*)**I don't plan anything concrete but take care of him so that he remain engaged with me in works. While doing the household chores I usually ask him help me with small works to keep him busy. He gets the homework and he does it daily. He is waiting eagerly for the school to reopen as soon as possible. He thinks his longer absence from school will impact his studies and probably make him weak.

Listening to the plight of parents related to children's future, a few of the participants gave suggestions for the support of panelists such as Shahnaz Academy and Teach Programme which provides free education to children.

#### **Closing remarks:**

A thanking note was made by Tom to all participants and panellists for their cooperation and participation in the webinar series. This webinar was an attempt in highlight the issue that children are facing in these lockdown days. To understand how the lives of children with special needs have been impacted at multiple levels resulting in learning deficiency, nutrition loss, mobility loss, absence of openness and social interaction at school. During these times, we can listen to voices at the margins and manoeuvre and how are we going to take this further. As we move forward, we hope there is a thought and hope of solidarity at an individual and at collective level.

#### **LINKS:**

**<http://www.praxisindia.org/covid19.php>**