

Rare Lives: The pandemic unravels India's weak disability support system

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Avantika Shrivastava (Host): In India, 50% of new rare disease cases are in children. Imagine this - the feeling that you are losing control over your body. But, as a child, you cannot communicate what you are experiencing well to your parents, and are unable to express what is going wrong. They see your discomfort and decide to consult a doctor. Hospital visits, tests, therapy and treatment become routine activities in your life.

The previous three episodes of Rare Lives have dealt with the immense difficulties that rare individuals face in securing proper medical attention, diagnosis and treatment of their rare illnesses. But there's another complication. Since rare illnesses are chronic, these often leave a person with one or the other physical disability.

Hi, I am Avantika Shrivastava, the host of Rare Lives. Rare Lives is the second season of the 1 in 20,000 podcast series which shines a light on the experiences of people with rare diseases, and their families.

Diagnosed at any age, rare diseases make people vulnerable, and not just because of failing health. Whether it be in homes or in the government system, physical disabilities or how a person's body is different from others, is more visible than their rare illnesses which causes the disability in the first place. This, many times leads to awkward conversations over the unfortunate events that have led the person--as people say--to "become this way". But a more alarming truth is that not many people in India know about rare diseases, and that is why, even as physical disabilities are seen as undesirable, they are more understood than rare illnesses causing the disability.

This has many consequences which I will explore in this episode. What will it take to protect rare individuals be it children or adults who also might have a disability? The disability rights movements puts a lot of these questions in perspective, especially for those with rare diseases.

I spoke to two people who helped explain the interface of the state with the disability rights movement. The first of them is Smitha Sadasivan, who has been a disability rights activist for the last 15 years. Smitha has multiple sclerosis which impacts the central nervous system- brain and spinal cord- leading to severe challenges.

Smitha Sadasivan (Guest): Hello everyone. My name is Smitha Sadashivan. I'm a person with multiple sclerosis and also a Disability Rights Activist based in Chennai. I'm also associated with different organizations on the advocacy aspect, and I'm also the accessibility consultant for the Election Commission of India. With regard to my disability as such, you know, multiple sclerosis is a neurological condition. It's a chronic condition and an autoimmune disorder that affects the nervous system and leads to relapses anytime. So, it's a chronic condition we don't know when we get a relapse and the treatments may vary the issues that we face in our lapse may vary, it may affect the limbs it may affect any other organ of the body or the sensory aspects can be vision can be speech can be hearing, it can also affect cognition, it can affect the balance of a person. So, different aspects get affected at different periods of time depending on which part of the brain or spinal cord is affected the most during that relapse. And we have to carry on with the medication at that particular point of time.

Host: She explained the core of disability rights: the person comes first, not the disability.

Smitha Sadasivan (Guest): You know, according to me and many disability rights activists, these flowery language like differently abled, or specially abled or positively able, these are not required. Actually, these don't define persons with disabilities. If you look at a legal terminology, it is persons with disabilities and it is being acknowledged by the Convention on the Rights of Persons with Disabilities also. The reason for acknowledging it, at the International plot platform is because it says persons with disabilities where persons come first. So it's always person first, and then the disability. And when you mentioned disability, it does not point to a person's inability Whereas the disability points out to the barriers in the society, which don't allow the person to function to his or her optimal level, so that is what disability you know, points out.

Host: Over the last couple of years, the government has pushed for the use of Divyangjan which loosely translates to divine body, as the official terminology to address persons with disabilities. This has been done to shift the larger society's attitudes and perceptions of their abilities and increase the acceptance of disability.

Smitha Sadasivan (Guest): We don't want to be considered as divine beings, we want equality, we want to be considered as equal human beings and equal citizens. When you call somebody as the Divyang And you are just elevating them as you know, being able to do something or being

able to overcome all the obstacles, you are stepping back from your responsibility as a state to enable a barrier free environment. So, the first duty is to bring in accessibility and inclusion for persons with disabilities as a state which you are not committing, whereas, you are just elevating somebody as being able to overcome all the obstacles This is not right this is not a human rights approach right. Different government departments are not sensitized on the Rights of Persons with disabilities and what they have to do under their programs for persons with disabilities and they are not coming up with the programs to have inclusion whereas they are just sending us to the Disability department. So this is a major lack of sensitization in the government machinery. And there is one more attitude prevailing in the government or even in the public's saying that why persons with disabilities want everything. For example, when we spoke about the need to make a beach accessible? You know, the government officials read the first initial response was, Why do you ask for a beach to be made accessible? You need accessibility in a public building because you want to access the public benefits or public programs. That is okay. But why do you want a beach to be made accessible? And similarly when we spoke about the Voting Rights of Persons with Disabilities, even a few disability commissioners or the few chief electoral officers themselves said like disabled people have a lot of basic issues, why are you talking about voting rights for a person with disability. So, this is the attitude that is settled in the government machinery with different departments, which need to be broken. Right now, the Rights of Persons with Disabilities Act is talking about various entitlements including voting rights and access to justice or you know, right to legal capacity and the right to property and many different things. Whereas, it all needs to be implemented until implantation happens. It is again, it will just remain in the document and act as just a piece of paper.

Host: The Rights of Persons with Disabilities Act, 2016 defines various disabilities and the rights it offers including reservation of seats in educational institutions and government jobs. It also mandates accessibility in public institutions.. It identifies 21 types of disabilities such as visual impairment, mental illness, disability caused by neurological conditions such Multiple Sclerosis, and others. Importantly, 8 rare diseases including muscular dystrophy which was covered in Season 1 of Rare Lives and Thalassemia, a blood disorder, These are the only diseases included out of about 450 odd rare illnesses reported in the country. The law allows for reservation in government jobs and educational institutions on the basis of disability among other things. But as Smitha pointed out, this is not as easy to get because of a difficult government system.

Ankit, the father of two children with Spinal Muscular Atrophy who we covered in earlier, speaks about his ordeal in getting a disability certificate issued by the government for his children. It requires a medical assessment and to prove to the government that they are 40% disabled.

Ankit (Guest): Aaj bhi madam kisi office mein jao bachche ka viklang certificate banwane ke liye, to koi jo hai itni asaani se deta nhi, milta nahi. Har jagah yahi hai ki aaj nahi kal aaiye, ye kagaz laiye, madam agar maan lijiye agar ham 30 din ki chutti leke jate hain to baaki 20-25 din isi mein nikal jata hai aur kaam hota nhi hai. Wo certificate hone se madam kya hai, bachchon ko kafi help milta hai, har jagah choot milti hai, to bachche agar is type ke bachche hain to aagey badhne ki koshish karenge.

Translation- Even today, it is very difficult to get a disability certificate. They just tell you to come tomorrow, bring this document, and even in my 30 days of holidays, I spend 20-25 days in the process of getting the disability certificate. This certificate helps the kids with additional benefits.

Host: The invisibility of the people with rare diseases in the government agenda is more fundamental. As per Census 2011, persons with disability constitute 2.68 crore or over 2.21 percent of the total population. Persons with disability, perhaps some with rare conditions, are at least counted in a population. But if one were to ask how many people live with rare diseases, we only have estimates of 70-90 million rare individuals to go by.

With so little information, how does one begin to ensure rights for medical, economic, social resources? Since rare illnesses are typically lifelong and mostly incurable, the physical deterioration of a rare individual's body or physical symptoms due to weaknesses will most likely take place. Given their medical complexity, the needs of a rare individual are not the same as that of a person with a disability who does not have a rare disease.

During the COVID-19 lockdown in April, the Government of India announced the PM Garib Kalyan Yojana economic package to financially give a boost to the most vulnerable, including persons with disabilities, among other attempts. An amount of Rs 1,000 was to be deposited in the accounts of those who had valid disability certificates [issued](#) by the government. But, Smitha says, this will not be enough.

Smitha Sadasivan (Guest): We lack budgeting, we get very meager budget for disability departments expenses, the schemes and programs for persons with disabilities and there are some namesake announcements or namesake schemes even for example, the recently announced scheme by the finance minister or during the COVID assistance, which was thousand rupees for a person with disability was not clear. You know, it did not, she did not say under which scheme it will be provided and who are all the beneficiaries. We found out that it was not catering to all persons with disabilities in the country, whereas it was catering only to some people with disabilities who got enrolled under this specific national program for persons with disabilities and also were considered as people from below poverty line families. So during COVID situation, everybody, or most people lost their livelihood and everybody became poor. And

whereas the poor, who were already enrolled as BPL families, were only interested in this to be part of this team, whereas all the other people were left out.

Host: But for Smitha, during the pandemic, the struggle to put together basic resources for people with disabilities was evidence of where the government system lacked.

Smitha Sadasivan (Guest): So the COVID-19 was literally a disaster and more than COVID-19, the lockdown and, you know, the government's approach on dealing with vulnerable groups was really pathetic, and many people suffered. I won't say that the government did not do anything. The Department of Empowerment of persons with disabilities came up with guidelines on how people with disabilities so, you know, employees with disabilities to be treated or the helplines to be set up in different states and all that. And whereas the guidelines were not informed to the public, you know, information about the guidelines did not reach the public number one. And number two, the implementation in the guidelines did not reach people with disabilities. And third is the government missionary did not have knowledge on how to implement these, you know, different aspects.

Host: The guidelines that Smitha speaks about relate to the prevention and treatment of COVID-19. Persons with rare illnesses are more prone to the virus, how to communicate and reach out to people with disabilities became a real challenge.

Smitha Sadasivan (Guest): So how to reach out to people with disabilities on the ground was actually an issue for the government. And yes, of course the civil societies could reach a lot of people and, and we also served as a bridge between people with disabilities in the ground and the government department, because many people was not we're not able to connect with the helpline. And so, we had to provide a list about the people who were not reaching the helpline and facilitated their assistance and with regard to rations or in with regard to medicines, again, there was a lot of issue in India like specific medications are not available in stock. And many children with disability suffered without that medication or even people with psychosocial disabilities could not avail their required medication.

Host: In episode one of Rare Lives, I spoke with Dr Dipanjana Dutta, a genetic counsellor based in Kolkata. In our conversation, she spoke of an instance that echoes with what Smitha says. The lockdown was imposed to curb the spread of the coronavirus, but it also led to severe disruptions in medication reaching patients who had little time to stock up their prescribed medications or prepare. The basic act of seeking permission from local authorities so that their caregivers could travel to their homes became overbearing. The elderly person she mentions has a rare genetic condition that leads to loss of vision.

Dr Dipanjana Dutta (Guest): There was an old man who had several comorbidities with diabetes etc also had something which is known as RP (retinitis pigmentosa) he's completely blind. And his maids couldn't come. His maids were stuck in the lockdown and he was absolutely alone and all his neighbors thought of, you know, helped him out but then they also applied to the local Thana and there the police again helped to bring those people back because the maid was ready to come. She said that she was ready to come, but she didn't have the means to come. So that was also arranged that way so maybe, you know, it looks like the troubles are very small and very insignificant, but the troubles were very real.

Host: In order to understand some steps that were being taken to protect rare children as well as those with disabilities I spoke with Ananya Chakraborty, the chairperson of the West Bengal Commission for Protection of Child Rights during the peak of the country-wide lockdown in July. She mentioned severe disruption in their day to day functioning with their routine activities now having to be made virtual. But, in a country like ours, even access to phones or the internet can be a privilege. Which begs the question- can rare children really be protected?

Ananya Chakraborty (Guest): Well, during the lockdown we have been functioning virtually. so, what we have done is, you know, children who are on the other side of the digital divide, we have spread the news. This means of all our activities, through our district Child protection officer through CWC, or NGOs, who have been frequenting the Who has been frequenting offices who have been frequenting the shelter homes or slums and ask them to collect things from there, you know, photographs or poems or somebody wants to write something, etc. and for children with these kinds of diseases, we, in fact, interviewed some of them for our mother's day program, where, because for them, the mother is a world and for the mother, she not only loves that child with the rare disease dearly, but the mother always worries that what really happened to the child once she is not she's gone.

Host: The pandemic has shown exactly where the loopholes in India's public system lie. As a disability rights advocate who has studied international protocols, Smitha offers some suggestions.

Smitha Sadasivan (Guest): What I would suggest, as a definite measure for the government is that the government should consult CSO Civil Society Organizations, whether it is DPO, NGOs, or associations or people with disabilities themselves, or any other marginalized groups. And it has to work in collaboration only then we can actually You know, tackle any situation and the community support system should be strengthened. The community support system can be strengthened only when the government works in collaboration with the, with the peoples groups, the citizens groups on the ground level. Otherwise, you know, the local authorities were

not able to perform, though they had the will to perform, they didn't know whom to reach and where to reach and how to support. So all these things need to be worked collaboratively. Lots of sensitization should go into the government machinery and a lot of collaboration with the civil societies and and the people on the ground should be done so that we can build stronger communities with stronger community support networks.

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Thank you for listening to this episode of Rare Lives. You can listen to 1 in 20000 which is the first season and covers many more interesting stories and discussions into the lives of rare disease patients. You can listen to this podcast on www.sunoindia.in or any podcast app of your choice.