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WE interviewed a mother who lives in a two-room household with her husband and three children. She runs a small grocery shop out of the front room. Her husband owns and drives a rickshaw. But even with the grocery store and the earnings from driving the rickshaw, the household has barely enough to keep body and soul together. They are sending all their children to school. But their main complaint is not about the economic conditions, though there is a lot to complain about the lack of government support there too; it has to do with the poor quality of education that their children are receiving at government schools.

One of the three children, aged about 14 years, is deaf. The mother felt that she never had access to proper medical facilities during her pregnancy and in the early months after her child was born. So the diagnosis of deafness came quite late. She also felt that even when her child had been diagnosed, there was no help or information available to her as to what she should have done, where she should have gone and how she could have helped her child with access to the needed services. It took her a long time to find her way to a school for the hearing impaired.

This meant that the child had not experienced the same level of development that the other children had in the early years. But, and this was her main complaint (it was heartbreaking to hear this), she felt that though she was somehow managing to send the child to a school for the hearing impaired and had been doing that for a number of years despite all financial and other difficulties, the child could still not read and write, and though she was not sure about this as she herself had not learnt sign language, she felt the child could not communicate well through the visual gestures and expressions it entails. She felt let down, to put it mildly, by the government.

This is not atypical of the situation we keep coming across in interviews with parents and children as we research the educational experiences of children with disabilities. Diagnosis takes a long time and so early childhood development is impacted. Even post diagnosis, parents and caregivers do not know what to do and where to go for getting access to services. Again this leads to delays. Sometimes, too much time is spent on looking for medical and/or miracle cures. Again this leads to delays. Even if parents reach the right schools and the right institutions, the quality of services offered, in most places, for children with disabilities, is not very good.

Parents feel they cannot let children with disabilities interact with society.

When we talk to teachers, principals and other caregivers who work in the field of provision of services, they talk of lack of resources, lack of adequate human resources and lack of training. Visits to institutions show you this side of the picture clearly too. Where we usually decry the lack of resources in mainstream education, the resource situation for the educational and healthcare provision of children with disabilities is far worse.

We have not talked of social and societal issues as yet. These complicate the situation a lot more. A teacher at the school for the visually impaired told us that they had a child with a visual impairment being brought to school at age seven and she had not, even at that age, had bathroom training. The parents had kept her, more or less, locked up in a room till then. They did not want their larger family and social circle to know that they had a child who was visually impaired. A relative, who knew that the child suffered from such impairment, had told the family that they could not bring the child to his house. The result was a seven-year-old who had missed out on years and years of education and mental development.

Even where the attitude is not as exclusionary, parents feel they cannot have children with disabilities come into public view or interact with society as other children do. This isolates such children. Parents also feel shame in owning the fact that they have a child with disabilities. This, again, leads to isolation of the child and, oftentimes, more difficulties for the young one who is already facing an uphill task.

And it is the societal attitudes that shape much of the parents’ approach. Most of us have imbibed these attitudes and we keep propagating them. Parents say that their larger family and social circle have told them ‘why are you trying to get this child educated, he/she is never going to amount to anything’, ‘why don’t you invest more and take better care of the “normal” children’, ‘why are you sending this child to school’, and so on. These attitudes from a peer group that you care about can be very discouraging for parents. And they lead to feelings of shame as well.

The parents also find little or no support from the government in countering these societal attitudes. There are no campaigns to try and change these attitudes. Laws and policies on the rights of children with disabilities are not given much importance or implemented, even when the rights are acknowledged.

Estimates vary but a lot of survey data shows that in any population, around 10 per cent to 12pc of children may be facing challenges in one form or the other (physical, learning, cognitive etc). Are these not our children? Have we not seen how the potential of every child is important? Yet the neglect of opportunities for children with disabilities, the lack of policies and policy implementation and the negative attitude of society at large are giving our children with disabilities a very poor deal. There is a need to change this.

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*Published in Dawn, October 14th, 2022*