Children with Down Syndrome and the State of Affairs for them in Pakistani Society

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Pakistan is a developing country with a total population of 198.36 million,[1] is categorized among first six most populous countries of the world, and with a high fertility rate. In this overflowing populous country census has never covered the head counting of special needs children of different categories; specifically, the learning disabilities that includes Down syndrome (DS), Autism, and Attention Deficit Hyperactivity Disorder. In the very recent National Census 2017 for the first-time head counting was done for physically disabled persons. In this scenario one has to dig too hard into the data resources to find exact numbers of our special needs children of various categories; specifically, children with DS. Pertinent question is: when data is not available regarding the number of children/persons with DS of various age categories; how is it possible to make some comprehensive planning for them? Why has the Government not been able to develop a well-coordinated network for life long rehabilitation of these children at national level?

In the past two decades a number of special needs schools have come up in all the big cities of Pakistan in public sector, less in smaller cities. Similarly, private sector has also been able to follow the tide of development of special needs schools for learning disabilities and other disabilities too. Since I am a professional doctor and a public health expert topped by the fact that I am a mother of a 28-year-old son with DS; I have observed and tried to study this disjointed system of special needs schools for DS children in both sectors:

Firstly, there is no culture of research in all these centers that improves and refreshes the rehabilitation process for DS. As a result, majority of the staff working there does not fully comprehend the fact that applied research in the developed world has strongly proven that children with DS (mild to moderate category of IQ deficiency) are not meant to be coached in special needs schools amidst all types and degrees of mentally challenged disabilities. Secondly social acceptance and inclusion for children with DS in normal mainstream integrated schooling is next to none in our country neither in public nor in private sector schools as per policy matter. Rather there is no such mainstream integrated schooling system here in our country. Very few schools in private sector do include these children but then the cost and conditions are out of reach of 99% of such parents. Thirdly, due to lack of research culture whatever rehab training is being given to DS children is on very obsolete pattern that most of the time leaves the child without getting to his/her full potential and without reaching to the logical objective of rehabilitation that is: to become an independent, productive earning member of the society; with due self-respect. Fourthly human resource that is working for DS children in these organizations in both sectors need to join hands and develop DS exclusive associations; where all the required resources are pooled in under one roof that is easily accessible and affordable to all. Large number of compassionate volunteer human resource is needed that can be trained into this expertise required to rehabilitate these children. And who else can be the best compassionate volunteer other than the family members themselves who should try finding out time for this service for their own children along with others. Lastly, health sector needs to put in its chunk as these children in most cases have numerous medical problems during their life; and there is no affordable health care structure for such children that is easily accessible and cost effective to all parents.

I, as a mother of a child with Down syndrome know very well about the numerous hurdles and non-acceptance by the society; and the herculean efforts it takes to get your child to be an independent earning member of the society.

Globally, 21st March is observed as World Down Syndrome Day.

Unconditional love and support on part of the parents and family is the magic key to turn around the society for their child.

REFERENCES


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