

Unconditional Love and Support is the Magic Key for Children with Down Syndrome

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Received: February 26, 2018; **Published:** June 27, 2018

Pakistan is a developing country with a total population of 198.36 million [1] 6th most populous country in the world. In this overflowing populous country 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 Down syndrome.

Down syndrome (Trisomy 21) is most commonly occurring chromosomal disorder with an incidence of 1 in 700 births. Advance and progressive research in this area in developed countries has resulted in increasing the lifespan of these children from 25 years in 1983 to 60 years in 2012 [2]. Progressive and advanced research in developed world has also helped in improving the rehabilitation programs and strategies for these children; thus making them positive, constructive members of the society, and enables them to live independently.

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

In contrast, the scenario is quite opposite in developing countries specifically in Pakistan with regards to their health care and progressive rehabilitation system. A decade back the word Down syndrome had never received even an iota of attention from the society in a positive and constructive manner. Thus, these angelic children were left to get rehabilitated in whatever way parents could do for them. I, as a mother of a Down Syndrome child 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. In the past decade children with Down Syndrome gained some attention due to the efforts of affected parents who have been successful in making "Pakistan Down syndrome association" and few others bodies like this one. Whereas, in public sector specific Down syndrome associations are still nowhere to be found nor has the government has made any effort in making a strong cohesive working network in this regard. There are many factors that are playing a role in this context of health and rehabilitation of these children, to list few of them here:

First: Having a child with Down syndrome is a stigma for parents and family even in this day and carries lot of psychosocial stress for parents. Second: Therapeutic interventions required for these children from day one after birth are not available to all at an affordable cost. Third: constant health care facilities required for these children are again out of reach for many [3].

The pertinent question is how much these few Down syndrome specific organizations in private sector are able to help the children and parents in a constructive way that enables them to build their child into an independent, earning member of the society with due self-respect and self-esteem? Are they able to help and guide a good number of families or just a little section of the society?

In my humble opinion Down syndrome specific organizations in private sector of Pakistan should join hands and pool in their resources at various center points to cater to the children and parents under one roof. 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. Learned parents who had been successful in achieving positive rehabilitation of their child should be acting as Mentor Parents and be there as part of the training and advisory board. While working at such collaborative centers, these parents can lay down the road map for development of children with Down syndrome.

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

Bibliography

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Volume 7 Issue 7 July 2018

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