PLIGHT OF REHABILITATION FOR CHILDREN WITH DOWN SYNDROME IN PAKISTAN

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Situation related to children with DS is 180 degree opposite in developing countries as compared to developed. On account of continuous progressive research in developed countries, life expectancy for these children has increased from 25 years in 1983 to 60 years in 2012. (1) In contrast situation is different in developing countries and specifically in our country. Pakistan a developing country is the 6th most populous country in the world with a population of 198.36 million; (2) and in this big populous country plight of children with DS should be a moral burden upon the conscious of society and Government. Their inclusion in the society at all levels, constructive rehabilitation program, specialized organizational network, main stream integrated schooling, life skills training, contemporary professional skills training, customized job placement, legal rights protection in society and family; all this and so much more goes into the life planning of these lovely children. In the West advanced applied research has enabled the society to develop such children into independent, positive, and constructive members of the society with a satisfactory feeling of self-respect and self-esteem; and all human rights well in place for them. Children with DS are the best coachable children among all types of mentally challenged children; on account of their non-aggressive behavior, loving and congenial disposition.

Constructive and successful rehabilitation of DS children in Pakistan remains a sore point till this date. In this society where ever we find a child with DS well incorporated into the society at all levels; is due to sheer hard work of the parents and immediate family, plus some minimal external support system. Till date this situation remains bleak in our social setup and it definitely needs understanding by all the stake holders at its priority. Otherwise we will keep on losing our lovely children into being nothing. The objective of this commentary is to identify the factors influencing rehabilitation of children with Down syndrome in Pakistani society.

As a professional doctor/ Public Health Specialist and as mother of a 28 year old son with DS who is now independently working at Mc Donald in Lahore, after completing his High School education; my opinion in regards to improvement in this situation consists of the following facts that definitely need to be addressed:

a) Acceptance of such child is very hard and delayed by the parents/siblings/extended family/society at large in our setup; on account of the social taboos attached to it. Hence parents and immediate families stay in a state of denial for a very long time; which delays their will to act as empowered parents.

b) Lower educational level and low socio economic status in Pakistan results in lack of awareness regarding this condition. The understanding and comprehension of the fact that these children can develop into a near normal individual provided they fall in the mild to moderate category of deficiency; is totally lost to them. In this societal set up such children who need extra quality time are not at the foremost priority for majority of parents. In their concept giving time to these children is not going to result in some fruitful rewards plus their social and family activities bind them to an extent that little time is left for such child.

c) Comprehensive awareness raising programs for people from all walks of life is next to nil in our country. As a result people who can act effectively as support system are unaware of the scope of this task; and they do not actually grasp the opportunities where they can effectively play their role.

d) Children with Down syndrome (with mild to moderate category deficiency) don't need special needs schools. They do very well in mainstream inclusion program and social inclusion at all levels is the mainstay of their rehab program. On the contrary, practically children with DS in this society are accepted only in special needs schools. Special needs schools have mushroomed up in large extent in both public and private sector in Pakistan but they are not following a progressive roadmap required for children with DS. Dilemma is that in public sector
these schools are catering to all types of disabilities under one roof; and following obsolete methods of rehabilitation for DS children. The fact that children with DS are being trained and coached along with all other categories of disabilities is a gross setback for these children who are not severely challenged; and such an environment influences in a negative manner for progression of children with DS. Another important factor that researcher observed is that these special needs schools are not preparing children to move onto integration in mainstream schools at the required level. This is in contrast to developed world where integration for DS children is being done successfully. There is evidence that wide range of intellectual ability is found amongst children with DS; and published reports of their successful integration into mainstream classes are available. (3, 4)

e) Research culture is grossly deficient at all levels in Pakistan; whereas the highly educated class in academics is in the habit of doing some research. This fact particularly prevails in these special needs school's staff also; they are not doing any related research in this area and are not able to follow and apply the research done in developed countries.

f) Mainstream inclusive education is not available to these children as per policy in public or in private sector schools. There are few private sector schools that accommodate children with special needs including children with DS too but constructive end point of the rehab program or the Individualized Education Plan (IEP) for each child is not made in black and white and not followed to the hilt. It is very rare that these schools can actually tap the inner strengths of a DS child and develop it into making the child empowered and independent. This observation on part of the researcher is totally opposite to the attitudes and practices of the teachers in developed world. Studies have shown that teachers' attitudes and expectations affect the learning and development of these children to a great extent. These studies suggest that children are more prone to conform according to the expectations of their teachers. (5, 6) More importantly the way children perceive themselves when these expectations are communicated to them by the teachers. (7) Critical factor for successful integration in mainstream school is the school philosophy and attitudes of the staff that actually makes or breaks such children. (7, 8)

g) Constraint of research, lack of awareness on part of all stake holders, resources, compassionate human resource in abundance, ongoing training of the staff, volunteer learned and resourced parents, capacity building of volunteer human resource for DS rehab, mentor parent program, inter-collaboration of the expertise within and outside the country, and well trained conducive environment of mainstream school; all these factors have marked impact upon the rehab programs for DS children. A study conducted in past concluded that conducive school environment for integration must have: 1) effective leadership from a head teacher who is committed to meeting the needs of all pupils; 2) confidence among the staff that they can deal with individual children's needs; 3) a sense of optimism that all pupils can succeed; 4) arrangements for supporting individual members of staff; 5) a commitment to provide a broad and balanced range of curricula for all children; and 6) systematic procedures for monitoring and reviewing progress. (9)

h) Few organizations for DS children have come up on the horizon in private sector in the past decade, due to the efforts of groups of affected parents; that are working as a lonely planet. Their services do not span the whole scope of a good rehab program; they are out of access for majority, and are not cost effective too. All components of the required therapeutic interventions from day one after the diagnosis of the child need to be in place; both in public and private sector with due inter collaboration to enhance the network for majority parents and children with DS. This area has very less expert persons; hence the cost and access is very high for all parents to get these therapeutic interventions. What it needs is capacity building of human resource in this area.

i) Parental co-operation in this regard is also debatable. Parents in most cases don't want to make extra efforts at their end, expect too much from the support that is luckily available to them, have so many social activities and responsibilities; that they end up in delaying the rehab program of their child. Commitment and dedication in parents/families, to the rehab planning of this child is not a very frequent phenomenon in our social setup. This observation is in contrast to a previous study that stated: effective education for children with DS in an integrated mainstream school is the result of factors such as constructive two-way communication between home and school. (10, 11)

j) Under One Roof Integrated DS Rehab Program Model - should be considered for these children including all less the health care facilities. This should also include an advisory body that includes learned parents who have worked well with their children. Involvement of such parents is the only factor that can relate to other parents and can be role model and source of motivation to other parents.

k) Specialized affordable health care for children with DS at priority is minimal on part of the Government. And private sector facilities in this regard are unaffordable for majority of parents. This is actually a very sad situation. A child with DS brings high health care cost on account of the many medical and other related problems. Their need of specialized occupational therapies is also there from day one after birth. In addition to this parents need varied other resources in order to take care of such child.
l) Empowered parents acting as mentors for other parents in order to counsel, motivate and guide them; is the need of hour. It's high time that parents start acting proactively to help themselves with the help of other parents in a systematic and well planned manner.
m) Corporate Social Responsibility (CSR) places a moral responsibility upon the shoulders of corporate sector to fulfill their responsibility in this regard by opening and maintaining customized job placements for these children, supporting an authenticated parental body that is doing actual work in this area or has well placed plans to do it but operating cost is not possible for them. CSR is next to none for children with DS especially, and at the moment less few organizations that are doing it. Fields of recreation, music, arts and designing, acting, patient facilitation, health care industry, modified and specialized office work, schools, culinary craft, customized computer work, hospitality industry; all are fields where these children are working successfully. Gone are the days of teaching them carpet weaving, carpentry, needlework; though this will still fit to some but not to most children.

n) Philanthropic personalities should look towards this side and try to build and support a DS exclusive network; with committed and learned parents and expert in the operational and advisory body. Financial support and honestly committed human resource (developed from among the families of these children on volunteer basis) is the probable key point.

These are my personal views as a result of the journey through which I have passed along with my son; plus my observation of the whole system as a Public Health professional. I am so much thankful to Allah Almighty who gave me strength and perseverance throughout this journey and gave me the guidance. Alhamdulillah if I am able to help and guide few that I can, and can teach some others about the ethics related to our children, and do some efforts to raise awareness in society in this regard; though I think these still are very meager efforts.

References
2. Pakistan Demographic and House Hold Survey 2016-17.