

SPECIAL COMMUNICATION

JOURNEY OF A WORKING MOM AND HER SON WITH DOWN SYNDROME

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Trisomy 21, chromosomal disorder related with Down syndrome (DS), is the most common cause leading to learning disability among all races and all human population. Having a child with Down syndrome in developed world has now become less of an unfortunate incidence in the lives of the parents; not because they do not realize the tough road ahead for their child as compared to other siblings but due to the fact that they have got a comprehensive and cohesive support system running for these children at every stage of life that builds up the child to his/her full potential. The present special communication is about personal experience of a working mother with her son with Down syndrome.

Keywords: Down syndrome, Experience, Mother

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Trisomy 21, chromosomal disorder related with Down syndrome (DS), is the most common cause leading to learning disability among all races and all human population. Majority of research on this topic has been done in west. In majority of the countries including Pakistan, most of the service provision for mentally challenged people is based upon 'charity model'; which sustains itself on local benefactors and charity foundations.¹ Ground reality is that for most of the parents, responsibility of rehabilitation, education, support and caring for a DS child solely lies upon the shoulders of parents and immediate family. Such situation in turn leads to financial stress and enormous psychological stress for parents.² A study conducted in Pakistan explored experiences of parents with DS child. Mothers interviewed in the study had described social encounters as a source of great stress, particularly those who had experienced negative behaviour of others towards their child. Some parents were of the opinion that their child was accepted by their family e.g. they helped with child care in a supportive manner and were not ashamed to be seen in public along with a DS child.³ Prevalence rate of DS in one thousand women of Karachi were evaluated. Results confirmed that 0.2% of patients delivered babies with DS.⁴

Having a child with Down syndrome in developed world has now become less of an unfortunate incidence in the lives of the parents; not because they do not realize the tough road ahead for their child as compared to other siblings but due to the fact that they have got a comprehensive and cohesive support system running for these children at every stage of life that builds up the child to his/her full potential. Many Down Syndrome associations are working all over the first world countries in co-operation with the affected parents; to develop their children into leading an independent life, be a

constructive and positive part of the community and have productive job placements. Naming a few, like National Down Syndrome Association (NDSS) USA and Down Syndrome Association- UK. Such associations have occupational therapy program running for children and parents from day one, building them into main stream integration and then transition to independent life program; developing an individual who is capable to lead a normal independent life like any one.

It's exactly opposite to this picture in Pakistan- there is no cohesive support or main stream integration program working under some laid down policy throughout the country even at this age and time; what to say of having it 25 years back when I was blessed with my eldest son Raza Ahmed Shahzad on 7th Nov 1989. It was a cold winter early morning time in Combined Military Hospital (CMH) Rawalpindi when Fajar prayer could be heard from the nearby mosque. Bathed and dressed in turquoise blue woollen suit he looked like an angel, rosy complexion and jet black hair.

Being a doctor I who had graduated two years back I was unable to pick up any sign of his being a Down syndrome child. Although the paediatrician in charge had penned it down as provisional diagnosis. I was a bit shaken and amazed as to why he has written such a diagnosis. I tried to look for those positive signs but they were invisible to the eyes of a young mother. The diagnosis was confirmed within a month's time by chromosomal analysis that showed Trisomy -21. I cried and cried silently for few days but things couldn't be changed.

What do I do now and how to proceed in life? A big question, that loomed up in my mind once I got hold of myself after few days. I actually had no idea what should be my plan of action and my medical studies had not prepared me for this

experience in any manner. One spontaneous thought that came to my mind was: I have to take care, nurture, teach, and groom my child as any normal child that I would have after him. For me he is as normal as we ourselves are. That day I promised to my son and myself that I will never leave any stone unturned, any effort purposeless, and any moment gone wasted without giving quality time to my son. My resolve to rehabilitate my son strengthened day by day and specifically with the unshaken support of my parents throughout his life time. He had become first priority in my life and rest of my responsibilities was fulfilled at due priority listing. Now I had to balance my life as mother of a Down Syndrome child, a serving Captain doctor in Army Medical Corps, a wife, daughter and daughter-in-law; out of which my parents had fully and truly relinquished me from any duty as a daughter, I am indebted to them. Still too much to juggle!

I had to leave my son with my parents for the first year of life because I had started my Army career recently with all its requirement of frequent night duties, making a new home with hubby who had to be away most of the time on account of his duty as serving Army Aviation Pilot. Amongst all this it was overwhelming to look after Raza specifically when we had noticed his precarious health state within the span of my maternity leave. I used to rush to Lahore whenever I could get leave from my work place and I must admit here that my Commandant and immediate boss both were truly supportive and took care of me in this regard. After one year my father got posted to Rawalpindi and so Raza came back to me. Now the routine I had developed was to drop him off at my parent's place on the way to my work and pick him up on way back after work. When it was my night duty roster he used to stay with my parents from 7:30 am one morning till 2:30 pm other day. At that period in my life in 1990 I had an interaction with one parent who happened to be my immediate senior colleague at my work station and had a grown up daughter with Down syndrome. He actually forced into the small retiring area next to my office where Raza with my mom some time used to wait for their pick up; and after inquiring twice, thrice and being quite senior to me he had his way. It was instant revelation to him and he then very rightly made certain facts very clear to us. Actually he was the first person who broke my feeling of hesitation and fear of what others would say about Raza. The couple was serving Army doctors in CMH and I visited them frequently for counseling. From there I learnt that these lovely children are fond of music and can actually learn to play an instrument quite well if instructed well. I am thankful to him for breaking my fear of people.

I started reading whatever material upon how to educate special needs children and specifically Down syndrome children. Reading made my resolve more firm to take a hard stance upon Raza's positive acceptance by family, friends and community and believe me in our social set up it was an uphill task. I visited a number of special needs institutions in Rawalpindi (as I was posted there) to get an idea upon how they were rehabilitating Down syndrome children and if they had main stream integration plans working on ground, but to no avail. They were unaware of the idea of mainstream integration for Down syndrome children. Still they were helpful to me in lending me reading material upon different aspects of special education. I read voraciously in those days and collected reading material from all such institutions. It helped me a lot in developing a concept about my individual rehab program for Raza. My road map kept on refining with passage of time with short term targets to reach the long term targets. It was clear to me that my targets had to be placed in accordance with the normal development of a child, give more time to Raza to achieve those mile stones as compared to a normal child of his age and will have to put in extra repetitive efforts to achieve a target without any lapse. The journey had begun for me and my son!

Raza's initial mile stones were delayed but he did have them except crawling. When he was 1 year old I started reaching out to physiotherapy departments in special needs institutions and received some good advice upon development of his motor system. I tried to get same facility in the physiotherapy department of CMH where it was easier for me to follow the time schedule. I started doing same set of exercises with Raza at home in evening. For regular morning sessions my mom chipped in her help to commute with Raza when I could not due to my official commitment. From the age of 1 year till 5 years of age these sessions were a part of our daily routine. By 2 years of age Raza had started babbling sounds and it was a signal to look for a speech therapist. Another hunt!

Eventually after tracking a lot I managed to get hold of a female speech therapist. She had taken training from a British speech therapist but had no formal degree in the discipline. She was too good and used to take sessions at her home. Formal session was for one hour but it stretched to almost two hours due to Raza's own lack of concentration after a short time. These sessions were interspersed with some resting and eating breaks too. For me now a set of speech therapy exercises were added to the evening time table; and I was adamant never to miss a single session of Raza. Speech development was quite slow and

addition of a new word to his vocabulary list took quite long till it came out in right pronunciation. From her I learnt that environment at large was an informal teaching aid for Raza. Not a single moment of the day went by when I and my mom were not involved with the effort to make him learn the normal day to day identification around him as any normal child would do. Learning names, words, understanding, identification, doing small activities, learning to play small games, eating by himself, responding to verbal instructions and so much more; the list is endless. Simultaneously his medical history kept on going. Due to his associated cardiac problem and low immunity resistance he used to get acute infections very easily which took longer than usual to subside. Every such illness meant hospitalization most of the time attended by me and my mom with partial support from my husband and father. With passage of time and diligent care his health started improving but actually by that time he had reached in his teens. When he was near to 4 year old I wanted to put him in a normal mainstream school. My search started for a small scale school, near to home with a good congenial environment. Process of convincing the school administration and teachers about the capabilities of these children with evidences from researches started. By the help of God Almighty I did find a school that were willing to take on Raza with the commitment that I will be there to guide and help them. Things worked out well between us and Raza had his first school. For a long time it was my routine to come in school break time so that I could be of help to teachers and see how he was pulling up. I learnt how to teach Raza with the help of different teaching aids and some of my own custom made techniques that helped to make him learn. His concentration span was very less initially, had difficulty in speech, learning by the book took long, flash picture technique helped, I had to move at his pace; the way he learned and responded. Slowly and steadily I kept on placing the foundation stone and then building upon it. My strategy was to make him learn one thing then move on to the other and keep every learnt idea in our list of revision each day.

Do not misunderstand the idea of learning an idea and moving on to another was a quick process; certainly not. You cannot imagine the amount of patience and perseverance that went into it. Schooling went on at various army stations where we got posted but with every passing day it became difficult to find understanding on part of the school staff. I used to plan the syllabus for him myself based on the routine class syllabus but in

modified form. I used to hammer his strengths and build his deficiencies step by step. Fortunately small scale schools co-operated more as compared to the big names which suited me well. Raza's oral skills developed at a better pace than his written skills, but both kept on improving slowly with persistent effort from my side. His English reading improved ahead of Urdu and numbers came in between. He learnt to be good at spellings with phonics, English reading better than Urdu reading, English writing better than Urdu writing, sentence formation difficult in both, oral counting and tables were better than written form initially. Afternoon time was religiously allocated for studying with Raza at the table with copy and pencil. Rest all day long I kept on doing oral learning with him. I remember in those days I used to have very little social life and my time was divided between Raza, work place, home and family. Side by side his behavioural grooming was being dealt with help of my mom. These children have great urge to eat and can imitate the actions of their elders and peers. We kept a strict check upon his eating pattern as well as all other behavioural development with persistent due correction all the time. Discipline was my second nature always and I learnt that this particular technique or strategy worked well for Raza. He used to get upset many a times and could not express himself satisfactorily and this frustrated him a lot. Most of the time this frustration found an outlet in doing some wrong or most of the time he was unable to understand the nature of his misbehaviour. He had a habit of misplacing and hiding everything and it continued for a long time to come even our being strict upon it. Now for the past 5-6 years this habit has vanished off. Life in those days was pretty hard, trying to balance all my roles adequately was a nerve wrecking job and out of all the roles being a wife and daughter-in-law was the most taxing part emotionally, psychologically and physically. When I look back retrospectively I think my energies were wasted upon them fruitlessly. My resolve to keep Raza first priority never went wayward. In the initial period repeating few classes helped rather than dragging him on in a new class every year. During this time Raza and I had few traumatic incidences also. One such school behaved very callously towards Raza on complaints from other parents that they do not want Raza to sit with their children in the class. There was a demonstration in school by the parents and during that time Raza left the school by himself and no one bothered to look for him. School staff was busy in meeting the demands of their parents and meanwhile I reached to pick him up from school. He was not there!



No one knew where he had gone and all they could do was to tell me that they were not responsible for Raza in any way. To cut an ugly scene short we found him after a period of almost 3–4 hours and that time went by like a thunderbolt for me and with every passing moment I was drowning into darkness deep and deep. A nice gentleman had got hold of him and with Raza's help he was able to

bring him back. This whole incident left a mark on Raza and he was put off by the name of school and children. It took me almost 2 months to find a school for him and bring him back but luckily the said school was run by an American lady who had more compassion in her for Raza than all combined together. Eventually Raza started feeling comfortable and started to flourish in that loving environment. I had chalked out a strategy of working in a triangle with teacher and principal for Raza's benefit and it paid off most of the time. By the time he was in class 4 and around 10-11 year old it became difficult for me to keep on changing schools time and again. I needed a platform where staff did have the concept about rehabilitating Down syndrome children in main stream integration. I took advice from Raza's paediatrician and soon landed in Lahore on leave to look for better options there. After a search of 10-12 days I found a normal main stream school that was practically doing the integration thing. I had a detail talk with the principal and came back quite satisfied. We came back to Rawalpindi and filed for compassionate posting to Lahore through proper channel. It was granted after due opinion from Raza's treating paediatrician who by that time was head of the dept in Army Medical Corps.

We moved to Lahore in 2002. By that time my second born a daughter who was in class 4 and a high achiever throughout, and youngest son was 2 year old. I had been promoted to the rank of Major with consistent good annual commendation reports from my commanding officers. We got into the phase of settling down in Lahore. I was now in-charge of a Garrison Medical centre in Lahore by virtue of posting and seniority and my responsibilities at work place kept on increasing; management/administration had always been my field of interest. At the start of my army career I was given the opportunity for specialization which I decided to forego in order to give quality time to Raza. I started off Raza in the said school in class 4. Initial first year in the school was quite tumultuous for both of us. He was not settling down with the class teacher and she also was not ready to accept him with his limitations; in spite of the very convincing and positive attitude of the principal. Rather at few occasions she tried to create lot of misunderstanding for us. This scenario unsettled me to a great extent and I had to confront the principal. Eventually things started to settle down when Raza was promoted to class 5. There I could actually see Raza being accommodated amongst his class mates, a buddy system working for him, he made friends, and he was encouraged to participate in all class activities academic and otherwise. That particular class teacher built his confidence level. I still stuck to my strategy of 1 to 1 communication

with the class teacher regarding everything around Raza. My other two children were growing up fast and that in itself was an exhilarating experience for me, growth and development for them was so quick paced Masha Allah. Their studies, coaching, training and grooming in all form was solely my responsibility in addition to Raza. Praise be all to Allah, all three of them are turning out to be good, responsible and humble human beings. In class 6 we came across another American teacher in the school and that lady (Stella Akhtar) shared Raza with like a second mother for many years to come. In between the two of us we tried to bring out the best in Raza and to this day he is attached to her like a loving and respectful son. In same class with mutual consent between teacher, me and principal we started leaving Raza partially independent with his homework. Idea was that he should be able to understand, comprehend and find the relevant answers and solutions to his problems in study. This technique started paying off after another 2–3 years. This indicated improvement in his comprehension and understanding. After few years with school I realized that what the principal actually preaches about individualized education plan cannot be materialized due to lack of expert permanent staff; still the wholesome encouraging and accepting environment was a big help. Side by side key board playing, different sports (he likes to swim and play cricket), social and public movement, computer learning, religious grooming kept on going. In 2005 I took premature retirement from Army in order to settle down in Lahore permanently for Raza's sake, secured a hospital administration job in private sector, and completed a two year degree of Masters in Business Administration (Common Wealth Program offered to Quaid-e-Azam University). I had to leave hospital administration because of lack of feasibility for the children and joined an undergraduate medical college as faculty member in 2009 and still in the same field. Later I managed to complete my Masters in Public Health in 2011 and now M.Phil. in Community Medicine is half way through.

In 2011 Raza completed his High School and received his diploma in a decent ceremony at Al-Hamrah. He also received a special unique prize for maximum attendance in school for the past 9 years. The day was an achievement for Raza and I and his father, siblings, my parents all were too happy for Raza.

Raza was enrolled in the newly developed college an extension of the school, affiliated with Sargodha University for 4 years Bachelor in Education based on the same modified syllabus foundation. My aim is that he should be able to get hold of 40–50%, 50–60%, 60–70% concept variably

in different subjects according to his comprehension, be able to supervise initial junior class as assistant teacher and finally get a respectable job as assistant teacher. Trained and permanent human resource for this purpose lacked in the college extension, specifically for structured hands on training program; committed separate staff is required for this purpose. Raza will complete his Bachelor degree in May 2015 with Allah's help. I never compare Raza with his age fellows in academics but otherwise I am able to compare him; his level of responsibility, his caring behaviour, his loving and friendly nature, his congenial mannerism towards every one young or old and most of all his loyalty towards his loved ones. These traits are a prize in their own way.

These days Raza is moving confidently in social and public environment. He had a chance to perform his key board playing at a musical concert along with the 2014 winner Pakistan Idol singer, had been to three TV interviews and a live morning show and was confident in front of cameras, led a Down syndrome community awareness walk on 21st March 2015 on the forefront in Lahore, is an active member of Down syndrome support group Pakistan, likes to chat on face book, swims and goes for regular walks with me, loves to watch movies at home and Cineplex, listens to music fondly and knows a lot about singers, follows cricket and world wrestling federation matches regularly, is into doing summer internships at a special needs school beside other students from different schools, likes to travel both domestic and international, fasts regularly in the month of Ramadan for the past 7–8 years, is taking lessons in Quran recitation and is now on 20th *Sipara*, and above all wants to get married!

Our journey is not over yet and still so much more is to be achieved. Raza still has some limitations which can be resolved through a strong integrated support system.

CONCLUSION

In Pakistani culture and social setup some parents had experienced good support from their extended family while taking care of their DS child but the number is very less. Whereas majority have been dealt with negative behaviour towards the child and lack of comprehensive support frame work around them that could have helped to rehabilitate the child to become a confident and productive member of the society. All the negative experience of the parents and their psychological stress can be explained on the basis of the fact that disability rights are not part and parcel of Pakistani culture and the concept of political correctness related to disability is actually nonexistent.⁵

- I would request mothers with Down syndrome children to work with them on priority basis.
- Both parents must share this responsibility equally and on priority.
- Our government must look into building a cohesive main stream integrated rehab program for these children that works from day one of birth till transition to independent life.
- Government must collaborate internationally to get their human resource trained for this purpose.
- Enhance family and Community awareness and support for positive acceptance at all levels.
- Respectable job placement in accordance with their capabilities as per policy.
- Such planning and execution will open avenues for our youth with compassion to develop expertise in this field and makeup the work force.
- Family and community must commit to the aim of developing them into a positive productive member of the society.

- Work with compassion and not with the intention to collect credit and rewards to your name.
- Do not leave any stone unturned for your child, do not forget that he is differently abled so has other strengths that can be tapped to create a beautiful and beneficial person.

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