



DSFI e-NEWS

For information about Down syndrome in INDIA

Saijee

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Gift From God



Let me introduce to you Avnish Aditya Tiwari (Binney), who was born in March 2014 and has turned exactly five years old this year.

I am proud to say that he is my son and the most special gift I have received from God. I feel blessed!

When a single man adopts a child, it puts him way outside the societal norms. The world certainly looks at you differently, but even the way you look at yourself undergoes a drastic change. From being a bachelor to becoming a father – I suddenly found myself flipping roles after Avnish's arrival into my world. Being a father is definitely not easy, but what makes it special is to be a father to a child with Down syndrome. I would like to thank my understanding and supportive parents who have showered their grandson with loads of love and Rekha Maa, Arpita, Humsafar Family (Support Group for Down syndrome Parents India) and workplace that has shown a lot of support for my son.

I want to believe that it would be the same as he grows up. But deep down I know and slightly fear that it won't be so. Nevertheless, it is always better to accept the facts early on and prepare yourself well to deal with them. I have come to realize that Avnish may start facing challenges from his early pre-school days.

I am sure he would do great with music, art and activity learning, but he might struggle with the concepts of language, grammar, mathematics and the sciences.



My vision for Avnish is far from building his IQ (Intelligence Quotient). I'd simply rather hone his EQ(Emotional Quotient). I want him to grow to know and witness the beauty of nature – the fluttering butterflies and buzzing bees around a bush of fragrant roses, the sound of a fresh-water stream, the whistling wind as it rushes through an army of tall trees, and the captivity of gazing at a starlit night sky. I wish for him to play with colours and to paint his life's canvas with many bright ones. I want him to feel the healing touch of music and to know how each note brightens his mood. I wish he learns to dance, and dances like he doesn't care about who is watching him. I want him to dream and believe and create for that is the real purpose of life. I wish for him to fly so high that he takes his thoughts farther than ever. And I wish this for him and all children. I hope to show him the better side of the world and I hope he finds a community that supports the same.

Avnish will definitely grow to be normal but I'd still love him to be different and unique in his own ways. It would be a pride to see how he stands amongst many and yet shines the brightest. It is therefore not only my responsibility but also my honour to give him the best and more – always and forever.

“I am learning from my son”

“I did not choose Avnish. I believe it is he who chose me. My son was my inspiration, my driving force, who helped me fight the battle. It took almost one-and-a-half years to finally get his custody but it was all worth it,”.

“Avnish was 22 months old when I brought him home. Since then, I have been learning so many things from my son. The child who was born with special needs, and had serious health issues including a hole in his heart, started walking within six months. His health showed remarkable improvement. He was enrolled in a play school in six months and is now in pre-primary school. All of this was nothing short of a miracle,”.



Life with Avnish

“Teaching a child with special needs is totally different. Their toys and books are different from those that children generally play with. It takes days to teach them a single alphabet. We have a special educator for Avnish, who guides us. Speech impairment is a major problem for children with special needs. As parents, we have to constantly explore ways to teach them. For now, he has learnt about 200 words. Avnish likes to play with animals. If he likes anything, he will start imitating it. He has been enrolled in a normal school, one of the best in Pune. He has started to comprehend a lot of things; he is toilet-trained and knows his school timings. He has also performed at the annual function in his school,”.

Way forward

“Right now, we are in touch with over 5,000 parents across the world through social media and WhatsApp. We have started our own support group called Avnish Social Welfare Society. We are counselling parents who wish to adopt a child, and also those who have differently-abled children.

Avnish and I have also been travelling across the country, and visiting schools and colleges to spread awareness about Down syndrome, among other issues. Recently, I also started working on a project that aims at providing employment to people with special needs. For now, I am trying my best to help change people’s attitude towards children with special needs while raising awareness about the same,”.



-Aditya Tiwari

“Dar Ke Aage Jeet Hai”



Art is not bound to Religion, Caste, Race, Ability or Disability. Art has a power to Energize, Alleviate, Improvise and Enhance a body in a cephalocaudal direction.

Shourya Rawat a 23 year old beautiful girl was born with Down syndrome in the capital city New Delhi. Her mother Indumati Rawat says that, “I don’t feel that she is a child with the special need. But, I would rather say the extra genes (chromosomes 21) are not her weakness they are her strength which motivates her to fight many obstacles, what may come”. Moving with immutable rhythm and unswayed by the milestone developmental delays in Shourya’s journey, her mother with a brave soul adapted a technique to convey all her commands and exchange of dialogues in a rhythmic manner to develop a prolong memory. Her mother believed to adopt the pace of the nature, as her secret is patience! As Shourya stepped into the adolescence stage she developed a unique perception to see life, her failures became her strength Shourya addresses her favorite dialogue “Dar ke Aage Jeet Hai” which means ‘Defeat the fear to win’, the disheartens turned her into more loving and lively person. Shourya along with her academics is pursuing a multimedia based program from associate partner of her school from AIMS Media Pvt. Ltd an education solution company based in New Delhi, which develops flagship and customized multimedia based programs to educate persons with special needs with the well applied techniques while keeping in mind multiple challenges what may occur. Her mother says that there are many positive impacts being observed during the program such as; enhancement of technical skills, she became more confident through multiple self esteem building activities which are the part of the curriculum and enhanced her cognitive skills by effectual pedagogical concepts and support of the faculty member of AIMS Media. Shourya is now able to create posters, attempt image manipulation and cropping etc. Shourya believes” Faith is to fear nothing, stand unswayed, and the power to surmount any obstacle”.

-AIMS Media Pvt. Ltd.

Against All Odds



Ishwinder was born on January 27, 1997. The family was on top of the world and welcomed the new family member. He had low body weight, low muscle tone and features associated with Down syndrome but to us it was no indication of anything as we were ignorant about it. Our pediatrician broke the news that Ishwinder may have Down syndrome and advised us chromosomal test which was conducted at the Genetics Department when he was a month old. The result confirmed chromosomal disorder-Trisomy 21. He had 47 chromosomes instead of 46 and this extra chromosome made Ishwinder SPECIAL. He had problems with speech, intellectual disability, special facial features and was more liable to infections. Future seemed challenging for the family regarding his care and to make sure that his brother's future is also not affected.

Early years

Ishwinder had delayed milestones but our concern was not his education at this moment but to teach him the basic daily things of life which a normal child learns on his own. Tests and visits to doctors was a regular routine for us now. We were told he had a hole in his heart which may fill with time but for now no treatment was required. We had hardly recovered from this shock when Ishwinder had to undergo a series of scans as he would throw up often after the feed. This time he was diagnosed with duodenum stenosis –a condition where there is partial obstruction due to narrowing of duodenum and the food does not pass easily. He underwent a surgery for it at the tender age of six months at CMC Ludhiana. Ishwinder returned home after 12 days. Things got better but he was more prone to infections but Ishwinder faced and tolerated everything with patience and this kept us motivated. His father Dr. Kuldeep Singh Associate Director KVK had a positive attitude throughout and provided support to his family. Acceptance is the first key towards success. We accepted Ishwinder as he was and so did the relatives. His father completed special courses and we attended workshops where-ever we could. This helped us a lot and we were introduced to Mr. Amarjit Singh Anand a parent and President of Down syndrome Parent Association Jalandhar. He has been our first and constant source of inspiration, guidance and the force behind us to move further.

Sibling bond

Balsher his elder brother an engineer and Ishwinder enjoy a loving and healthy relationship. They support and encourage each other to move further in life. Balsher keeps in touch with his progress and visits his vocational centre when at home. They share jokes and keep each other's secrets.

Schooling

At the age of five when Ishwinder had recovered much he started attending a main stream school for few years which provided him inclusion and boosted his self-esteem. We regularly visited Rohtak where Mr. Dhall from Prayas was very cooperative and his team would provide us a schedule for three months to follow at home. This provided us the guidelines about how to go about. Later Ishwinder was shifted to a special school as his school was till class one only. Ishwinder pursued his education and cleared class 8th from National Institute of Open Schooling .At present he is preparing for the 10th Standard examinations. He joined Chaanan Vocational and Skill Training Centre run by Chaanan Parent Association Jalandhar where he polished his fine motor skills.

Sports

We were always concerned about his health as Persons with DS are prone to thyroid, obesity etc. He joined Sanjay Karate School (SKS) in Jalandhar. Their team was kind enough to start special classes for Ishwinder and his friend Navjot a smiling lovable boy with cerebral palsy .Both of them have advance purple belts now and lots of well-wishers at SKS. Recently he won gold medal at Clash of Titan in 7th OGKFI National Karate Championship at Hoshiarpur.

Ishwinder regularly participated in the State Special Olympics Games for special children and won positions. This became a platform for him to develop and showcase his sporting skills which greatly boosted his confidence and for us to meet other parents of special needs children. We shared our experiences and tried to come up with solutions for the problems which were faced by us all. As our cause was common we became a big family. Every child was our child. Meanwhile Ishwinder showed interest for Badminton. He joined regular classes and was a part of the team in the stadium. He possesses a strong observation and the healthy, positive atmosphere around him kept him learning. Thanks to all his teachers, coaches and friends which included children and adults.

Father turned coach for his son

November 2013 brought good news that Ishwinder will be representing India in Asia Pacific Special Olympics which were to be held in New Castle. His father took training as a coach and accompanied him to Australia. He participated in Olympics where athletes from 40 countries participated. Ishwinder won a bronze for his country in 100m and stood fourth in 200m races. The exposure brought about a remarkable change in his behavior .He became more focused, responsible and learnt to manage his emotions .These achievements and recognition further boosted his confidence and he learnt to face the cameras and press happily.

In 2016 he went for badminton Nationals to Jamshedpur and won silver medal for Punjab. He attended a series of camps organized by the Special Olympics to improve his various skills

Recognitions

- State Award to Handicapped for his outstanding achievements from Department of Social Security and Development of Women and Children Punjab

- Cash award of Rs.25000 by DSFI for participating in the Special Olympics
- Honoured by district administration on various occasions.
- Mr R.S. Hundal President SCAN Nurmahal a renowned NGO recognized his hardwork, determination and honoured him on Annual Sports day function.
- Invited to MGN Public School during the summer sports camp to motivate around 200 athletes and to create awareness about PWIID among the younger generation.

Career and.....Impact on society

Ishwinder's confidence, determination and readiness for job helped him face the interview for a post in judiciary. He is the first person with intellectual disability to be selected as a supporting staff in Punjab and started his govt. job in District and Sessions court Faridkot in Punjab which is 145 km away from home. Ishwinder has been staying in PG for a year independently and learnt the ins and outs of the working in the courts. Staying alone and managing on his own brought out the best in him proving this true...Give them wings and they will learn to fly. There was not a single day when he was not willing to get up early at 3 am to catch the train for the workplace on weekends. He has made many friends and well-wishers at his work place. His presence has sensitized the court employees regarding Down syndrome's needs and abilities. Recently Ishwinder got transferred to Kapurthala near his home. In a short span of time he has made a place for himself here too. He is totally independent commuting to his workplace and in his working there. He is very conscious about his salary messages and operates his bank account.

Multitalented and a responsible citizen

He loves to work on computers, is a good dancer, model and an artist who likes to draw and colour. He wants to contribute to the society and not be a burden on it. He actively participates in awareness camps, plantation drives and Swatch Bharat Mission programs. He regularly donates things and cash to various institutions for disability. He donated cash for Kerala flood affected on his own after watching the TV channels. He has been exercising his right to vote in the elections with responsibility.

He is a loving, happy go adult whose positivity is very infectious and he is spreading happiness around. He is a good planner and a mind reader. He often treats his special needs friends to a movie or plans a trip for them from his resources and feels good about it.

Message to Parents

This didn't happen overnight. It took years of hardwork, patience and faith. We as parents feel the exposure given to Ishwinder in the early years made much difference. We would like the parents of special children to deal with them as we do with a normal child. Walk with them in the beginning and behind them once they are confident and give them opportunities to polish their capabilities. Each child is a special gift to us from God and we need to love, love and love them much. We are thankful to God for this GEM in our family who has unconditional love for all. He has set an example for many and raised the bar for himself. He has given HOPE to many parents proving that every child is gifted .They just unwrap their packages at different times.

- Dr. Kuldeep Singh

What a wonderful year it is!

The Beginning of New Year started with the cycling camp. Saideep surprised me with his major development i.e riding his cycle without supports which we were trying for the last so many months. Hats off to Deepa and her team and of course to Rekha maa who always provides the support to take up new challenges. It was such a mesmerizing experience for all of us. Until this day he never went out on his own, but reaching this major milestone, gave him confidence. At the end of January, he went to his school picnic for almost a whole day at Adventure island, an amusement park. No nausea while travelling, which he usually complained with us, no fear, no tension and even no complaints. And most importantly he enjoyed it all day.



After these beautiful two months, **March** brought us tension! With his final term exams of class Five. We worked very hard and I could see the pressure he was trying to cope up with. Gradually it built a fear in me too whether to continue his schooling or not. But with the support of my beautiful family and people around me, I finally took the right decision for **Saideep**. With their suggestions and counselling we passed another test. He cleared all the exams with good marks which enabled us to have a positive communication with his principal to work according to his needs. Now he is enjoying his schooling more than before. **March had not ended yet** when another major event came up - the celebration of **Down syndrome awareness day**. It's hard to even to express in words the joy it brings to see **Saideep** ride a bicycle at one of the most prestigious place of India i.e India **gate, in cyclothon** and also perform in a dance **flash mob**. I could see sparks in his eyes even when we were rehearsing for it. Now, whenever he cycled my eyes can only witness a free bird with new feathers.



Now April came with beginning of class Sixth and most exciting event than we could imagine. For the First time Saideep participated in a **painting exhibition "dreamsphere"** with 20 other participants (special need kids)He showcased his five paintings made under the guidance of his arts teacher. We got tremendous appreciation and led to the sale of his two beautiful paintings. This was a very motivating experience for all of us.



Next what! A STAGE PERFORMANCE-a big no no from Saideep always.

All these years my biggest worry was his stage fear. He never had performed alone on the stage until he participated in Master n Miss Bravura young auditions. That day I discovered the other side of my child. He danced and chanted a few mantras in front of the huge audience with unimaginable confidence. Tears rolled down my eyes along with extreme happiness and a fulfilling smile to see his performance. All the trisomy-21 kids were welcomed to perform in finale.

May welcomed us with another joyful event of Master n miss bravura young finale. Although he became nervous for Rampwalk, but there was still an urge to perform. Enthusiastically he changed his outfit and gave a bold and amazing dance performance all alone. The hall was filled with applauds and overwhelming response to his performance.



Merely a half year has passed and we have had these wonderful opportunities, overcoming of many fears and emerging challenges-which he had already started working on. I have discovered the zeal to create my place, my child's space.

All these moments have given me the confidence to believe that nothing is impossible for our kids. There are limitations but there is nothing that they can't do.

I love you my son and a big thank you to all the people around me- my family, relatives, society and especially the people associated with trisomy-21.

BELIVE IN YOURSELF AND YOUR KID, JUST WORK ON THEM.



-Alka Gupta

Sharan – our superstar all rounder



Sharan was born on 9th November 2000. We are based in Ahmedabad.

Sharan is a hardworking and dedicated boy always ready to learn new things. Initially we struggled a lot regarding his health and academics but we overcame them with a lot of effort. Since the last Seven years he is studying in Pearl Special Needs Foundation and is currently appearing for his 10th Standard NIOS exam (National Institute of Open Schooling). From the new academic year he will be going to a Vocational Centre of the same school.

Since his childhood we have exposed him to different activities. He is taking training for Keyboard, Painting, Karate, Yoga etc. He has excelled in all the fields. He has cleared two exams in Keyboard, won many prizes in Painting competition and has achieved Green Senior Belt in Karate. Like all our other kids he is very good at dancing.

Though Sharan's progress is still under process, we as parents would like to share that all the above has been achieved by our constant support and Sharan's hard work and dedication. We strongly believe that our kids can do wonders if we provide them with opportunities and support.



-Parini Delhivala

Paving Way for Hope with Dance - My Experience with Aditya



The three-year-old, Aditya hid behind his mom. His naughty eyes slightly peered at me. I noticed his innocent face and smiled at him with a wink. His mom hesitantly asked me if I could teach him to dance. She slowly revealed about Aditya's Down syndrome. She was not sure whether a regular dance teacher would accept him. His eyes evinced deep love for dance which resonated with my passion. I had no clue about Down syndrome yet I could not say no.

My mind filled with questions. I researched on Google, referred a few books, and interacted with parents, special educators and experts. Later, I requested his mom to be patient and give Aditya and me time to connect with each other and find the best possible working method. She kindly agreed to it. The next day I wondered how to commence Aditya's first dance classes. With a simple idea coming to my mind, I allowed him to move anywhere he wants. He started moving around freely and loved playing while other children danced. This went on for the next three months without our realization. Aditya had not learnt a single dance step yet formally. Once in a while I used to ask him if he would join in, he would nod his head and say "NO".

One fine day, I decided to firmly instruct Aditya to dance. I had determined to make him try his first dance movement. I really wanted to observe his moves and know what dance means to him. I was firm and he agreed. He joined the rest of the kids, took a place without much ado. I was totally surprised; Aditya showed me the exact steps to the dance we had choreographed for a song. I had my hands on the waist with my mouth open with astonishment. Aditya had grasped every single step taught to other children with precision. That day, I hugged him tightly. I realised that all the while he had been keenly observing and paying attention to the class in a way I never understood before.

Day by day, I saw Aditya transform with dance. During his first few classes, other children complained often that he pulled their hair or pushed them. I made Aditya understand and also the other children. After a few more days, Aditya was a star in the class. Everyone wanted him around, he was the one who knew the steps accurately than anyone else. I quietly saw him from behind and admired his dancing skills.

I could witness changes in his behaviour. I learnt to believe – “**slow and steady wins the race**”. From not being able to stand at a single place, he gradually learnt to stand in a line with other children. He had better control over his movements, he gradually learnt to be organized and follow the structure provided in the class. He mingled with other children and enjoyed every class straight from his heart.

I could notice his mind and body were synchronizing with each passing day. I knew the trust his mother had on me and our collective patience had paid off. Dancing had helped him to a greater extent than our imaginations. It had inculcated discipline in him. It was an ultimate revelation that patience, and perseverance goes a long way. Aditya strengthened these fulfilling qualities in me making me a better teacher and a learner.

Today Aditya is 12 years old and till date continues to enjoy dance and movements. He has great control over his body and does not take any movement-based therapies currently. His parents see him dancing at parties and expressing himself to the maximum. He also has used the lessons he learnt in the dance class to help him learn how to ride a cycle and various other motor based activities. After almost a decade later, I still can't stop feeling happy and proud thinking about Aditya.

So my dear parents, dance is a wonderful medium for Down syndrome to channelize a child's physical energy into a positive stream. Love, care and firmness to discipline lays a strong foundation. By setting small milestones, we can achieve what we can want. Dance brings the change in your child which you never expected earlier.

You can observe transitions when a wobbly neck gains control, when your child knows how to use his free time constructively and learns the importance of physical activity for his well-being. He makes an inherent effort to balance his body like others not mechanically but by his own will and for the sheer need of wanting to get the move right. You will see your child socialising normally with other kids at a party when they dance freely to the musical atmosphere. The social acceptance increases significantly, the child no more becomes a recluse.

Dance provides the structure and framework to the child. When your child gets attuned to it, you can see the wonderful changes that this art has brought in the child. I have worked and working with many children with Down syndrome. I have witnessed children improve tremendously with dance.

So, let's dance with kids and see how our lives will transform together!

After all dance is the language of the soul.

-Simran Godhwani

Dia's Chronicles

I am desperately waiting for my Dear Baby to come into this world. On the labor table ,I hear whispers ...What ? What is it ? All Okay and then Doctor Tells ..It s Down syndrome Baby Girl.

Down syndrome is a genetic condition that leaves its impact on each and every organ of person with Down syndrome. But Does that mean it makes her weak or in competent ?

NO ,Not at all.Each individual with this condition is as strong as any other human being. All we need is little attention and some care .Which we may need otherwise for other beings too. So where does the difference come.

I will name her Dia.Dia is her own favorite ,she loves everything about herself....Here is some conversation between Mumma and Dia

Dia -Ma how were my early years?

Baby due to this extra copy of chromosome you had hypotonia.Your muscle tone used to make you feel chubby, cute baby, but it made you struggle to achieve your milestones. We did some interactive play way exercises that eventually helped you smile, walk and speak like any other kid.

You know, When you were born you were full of love .Kids with Down syndrome are the most loving children on earth. So you are not special. We as parents , are lucky to be chosen as parents of a kid with Down syndrome. I am as proud of you as I am for Mumuksh your brother. Not Just because I love you But because you deserve that. As all you kids with this condition can be wonderful painters, chefs, models, dancers ,gym instructors or just anything you wish to be.

Dia-But am I lucky to receive you as a parent...I think I am .As You already getting my regular health check ups done so that I can bloom with full vigor and vitality. You knew at the time of birth that I may need all assessment if all my body organs are working at their best and if not they needed some fixing.

Yes, we did every bit needed; there was not a big deal. It could be like we take care of any other typical child. We got your eye checkup, ear checkup if you can see or hear properly, Heart tests if you are not having any Cardiac anomaly. Thyroid tests as if your thyroid levels are good, endocrinologist suggested keeping TSH little higher side will improvise your health and you will surely grow at better pace. Ultra sound as you might not have any physical congenital anomaly, and all regular blood tests .You know what like I always say you are a winner and you came out of all this with flying colors.

Dia- Hey this is my first birthday !!!

Where is my gift ?

Dear Your first gift is Deworming ,timely vaccinations ,re assessment of all Physical tests,blood tests and Mental DQ test.

Re examining eyes ,ear,echo ,CBC ,Thyroid,Urine are must

Mommy shall I ask something ,Since birth you are giving me so Calcium,Zinc ,B Complex ,Multi vitamin.

Why ? I eat everything you give me Milk ,curd ,green vegetables ,Daal...Then..

Diyu..these vitamins help you grow faster with high immunity levels .We all need vitamins .So whatever food we eat these get stored in our body .But in kids like you they don't store and daily foods sometimes we are not able to give 100 % balanced diet ,sometimes the food quality is not good.So I really cant rely on these .Giving top us supplements makes me feel comfortable that you are getting what you need.

Its just one calcium and some multivitamin with b complex and other vitamins..

Thank you mama!! I love the taste of these and wont bother you in taking these.

Mommy some time I feel itching in potty place (Anus) you told it was worms..I eat healthy, wash my hands daily, How cum I have worms.

Bacha, worms can happen to anyone and in your case I have seen its really very quick .They will take all your nutrition. We must kill them. We will do this deworming program from your birthday Day ,Three day,seven day ,One month ,Three months and 6 Month and then same...next year...I am sure it will be really helpful in your health.

Wow mummy ! That s a good idea...

Now I am 2 ,I have started walking with support ,I wish to run quickly ..I don't like aunties telling you why she doesn't walk and you smiling at them.....

Diyu ,Let them say what they have to ..we ll take our time..we will do regular physiotherapy and occupational therapy and make sure all your muscles develop good and when you walk it smooth and your bones are not having pressure for same. Else I have seen some kids develop knee joint and eventually spine issues.

OKKK..No worries...I will do as you say ..i love when you play with me and tell me we are doing therapy baby..how funny exercises you do...he he

Mommy when will I start speaking...

Baby we are doing oral exercises they will help you develop muscle tone, we have developed lot of vocabulary ..Look you can point and identify so many things from home and scrap book. I am sure its just any time you will start talking

Mama I have started floating in swimming ,I love playing with water ..I hope there is no therapy there..

No honey its a play therapy it indirectly helps you develop tone ,balancing and locomotor skills..but we want you to enjoy that not be a doctor or therapist for you...

Yes sure Ma

I am 2.5 years ,I have started walking,I said dadda...you know daadu keep telling me ye dadu ye diya...so I spoke daadu first...

After 5 years

Things are going like this for many years

You are growing at a beautiful pace. You speak ,walk ,do everything independently, You do modelling ,dance ,studies.....and every day you surprise me with some of your wonderful actions...

Today you are 8.5 year old, you have had 2 surgeries. But your infectious smile. Contagious hug and affectionate nature still makes me fall in love with you like I held you in my arms like the first time.

-Dr Kamna Sharma,(BAMS ,B ED Special Education)

Building her confidence at the Gym



'Sahithi' is a young adult with Down syndrome, living in Secunderabad. Her parents have started sending her to a local gymnasium called "sweet burn". It has been five years since she has been attending this fitness center, with constant encouragement from Mrs. Babitha Jacqueline Xavier, a certified functional and celebrity trainer. Initially when Sahithi joined, she was not able to perform activities- such as continuous jumping, skipping and hopping. Sahithi is now able to do workouts such as exercises with ropes, tyres, etc. the professional trainer says it is important to understand the needs of these children. As, individual with intellectual disability, they may have certain associated health conditions such as thyroid or other hormonal imbalances, and obesity problems. She suggested light weight resistance exercise for Sahithi rather than heavy weight lifting. Her regular work out has reached a consistency of one hour duration now. Customized programs are important for individuals with special needs as they learnt by imitation, modelling, prompting leading to a gradual fading. Also immediate reinforcement is the trick of training, says the physical instructor. Sahithi enjoys the gym. She has not only learnt physical activities but also made friends here. On a few occasions, she takes the lead in some exercises as well and guides new learners.

-Bharathi E. S.

The break of dawn – confidence Reborn

A 3 day women only meet was organized by the Down syndrome Federation of India (DSFI) at Umaid Haveli, Jaipur. DSFI is always ready to spread awareness about Down syndrome and assists persons with Down syndrome and their families by providing them with accurate information about the condition. The Federation organizes seminars and workshops on both national and international levels on a regular basis to spread the awareness.



But the reason for this “Women only” meet can be attributed to the experience and farsightedness of Dr. Surekha Ramachandran, President of DSFI. Dr. Ramachandran believes taking care of the mental and physical wellbeing of the mothers of persons with special needs is essential. Because taking care of a child with special needs is a huge challenge in our society, the mothers are not able to take time out for

themselves. Thus to maintain an equilibrium between their families and their societies becomes a huge task in itself.

The main aim of this meet was to help the mothers take some time out for themselves, especially since most of them were mothers of younger children. The other reason for this event was to help the mothers open their heart to the mothers like themselves, thus rejuvenating themselves before they face their world again.

As the saying goes – “the heart will take heart from the fact that we are traveling in the same boat”. The specialty of Rekha madam is that she takes special care of everyone who is connected to her. Rekha Ma has the unique ability to remember each one’s name and their likes to the smallest detail. There were a variety of programs on entertainment and dance, gifts for everyone - a towel with the name of the individual embroidered on it I felt my eyes moisten – it was as if someone has given me my identity again. Obviously our name is our identity, right?

The Rajasthani folk dancers had company with the mothers enthusiastically dancing with them. Mothers discussed amongst themselves the issues – big and small- that was a part of their lives as they raised kids with Down syndrome. Rekha ma told everyone that they needed to stay as recharged and as happy in their homes as they were during the 3 days at Umaid Haveli. This is essential for mothers - a happy mother makes happy children and happy families! Rekha ma has promised to arrange for such events in the future too.

There was a common thread that connected all of us mothers from the various parts of the country who came to the 4 – Star Umaid Haveli at Jaipur – being the mothers of at least one special child. This meet was organized for mothers to provide a few moments of reprieve from their busy lives. Before I tell you about these ladies, I would like to take the liberty of referring to all these “special” mothers as “girls”. Because today they have come here to live their “Girlhood”, not to generally talk about Down syndrome.



We have all attended programs on Down syndrome before this, but as a families. But we used to find ourselves taking care of the family – the husband, the children and attend the various lecture sessions there too. But here there was no such thing – it was just fun and more fun all the way.

I am not trying to judge on what is right and what is not. What we experienced, what we heard, how we lived – that is what I am narrating here. I am not going to take anyone's name here – all you need to know is that it is all about girls, about women. Yes, my name is Parul. So let me begin with me. After my heart replacement surgery, battling my physical and mental demons, I find myself completely friendless now. Some of this could be the after effect of my surgery. And some friends, probably find me less useful after the surgery, so might have kept me in the sidelines. Some friends have cheated me. I am now in a phase where I am trying to get my life on track. It is so bad that I have actually lost faith in humanity, so I am unable to trust anyone - not even these friends of mine here who share my joys and sorrows.

I try and weigh every person who asks about my wellbeing. I look into the depths of the eyes of my friends who care to know how I am, who want to know the reason for my silence. When one loses faith in friendship, these are testing times for friends. They have to try real hard to win back your trust. They are bearing the cross for those friends of yours who have betrayed you or snubbed you. But luckily for me all my friends are stubborn mules. They never went back, never lost faith, they kept enveloping me in their arms, to tell me that life is all about faith, about trust in friends. Some of us look sophisticated and some simple. But when you dig deep, each of us is full of love and pain. When they tell stories from their lives, no one can judge who has faced life's brutality the most.

When people see girls or women in short dresses, they believe that these women cannot handle their household duties, are not polite and someone else must be taking care of their children. But ask me how caring and loving these girls are! It is just amazing to see them handle their houses. And it is not that they do not manage their social lives either. It is one such friend who took care of me the whole time. Her love for me made me feel so complete.

Some of our kids have grown up – I mean 20 years and above. They are facing a different set of challenges. Some children do not speak, some have become silent, some have physical issues, like weight loss, some have gone into depression – each phase has its trials.

There is a girl in our group. She is an amazing dancer. But she had to forget all about dance. It was just her, her home, her in-laws, her children. Just imagine how long would she lead this life, and probably she wouldn't mind if this made people in her home happy. But that was not to be. So during the last meet, all the girls sat throughout the night and encouraged her to take up dance again.

And this time when she came, she had started dancing again! The balm that we had applied on her old wounds had worked. Now there were no wounds, only self-confidence. She stopped caring about what the world around her said. She stopped taking others' words to heart. She was glowing. She had forgotten all her old wounds. The maturity of her thoughts was to be seen to be believed.



There was another girl. Her in laws blamed her for having a special child. She had no freedom to do anything she wanted to. When she came here she had fought half her battle – had learnt to drive in spite of stiff opposition. After talking her heart out here, she was determined to go the full distance and stand up for herself. Some people just need a sympathetic ear that listens to their problems. She had found it here.

There are also some who have lost the link that tied them to us. Yes they have lost their special child. What can be more tragic than this?

They are already connected to us. And now their pain can never be eased. People feel that we are giving them moral support. But the fact is that these large hearted women are the ones who stand by our side as a pillar of strength. The smile on their faces tell us “C’mon my friend, hold my hand, and let’s walk on.”

Some girls are upset because of unsupportive husbands. They want to learn techniques to make their husbands more loving and helpful. But this is not a place where they teach you this trick. Instead you are taught to feel beautiful and grow into stronger women. You start looking beautiful and everyone around you starts taking notice. Their complaints decline.

Some of them have made their hobbies as their source of income. They have actually earned the money to pay for their trip here. I met some of them who have lost weight and are radiating confidence. It takes a lot of effort to challenge one’s physical and mental abilities.

If I were to talk about what it means to be the mother of a special child in just two lines, then add to the regular mom role two extra duties – taking their children for therapies and make them do these exercises at home. Teaching our children is a job that requires loads of patience and hard work. You teach them something today and 10 days later they have forgotten it. And even after you keep aside the physical efforts put in, the biggest fear for any mother of a special child is who will take care of them after we are gone.

Then there are the eyes – both in the family and outside –sometimes at the mother and sometimes at the child – as to what is this? We mothers learn the skill of ignoring those eyes and not get perturbed by them after years of practice. Rekha ma heard everyone individually. She did not want her girls to be sad at any point in time. Rekha ma’s vision is that every woman has to be happy. She wants them to be bold and self confident whether it is relationships, family, children, social life – whatever they do, they should stay happy – and this is one of the aims of this meet. If we have been able to make arrangements for our kids for 3 days, I believe that we would definitely be able to do something for their future after us too.

It is not that all of us can share what is in our hearts with everyone. I have seen the pain in the tears which many girls shed when they laughed out a lot. It was as if they were surprised to be laughing. They are asking themselves if they have the right to laugh like this. They are wondering about what reality is – the tear that they shed or the laughter that they just shared. Their sadness is something that is entrenched in their hearts and they probably would not share it, ever. It is at this moment that Rekha ma calls them to her side and embraces them. And this is the balm, the hope that this hug transfers to the girl. A new realization dawns that the laughter and happiness she just shared is as real as the sadness that she feels. And as Ma puts it – laugh like this even when you go home and this laughter, this happiness will overpower your feeling of sadness.

As we leave, Rekha Ma has given each of us a fistful of joy. Our eyes are now lined with confidence. She has clothed us in the garb of courage and determination. And the feeling that “I am the Best”. Our hands now pumped with the elation that comes from saying “Me first”. And we have left shining, glowing, with our heads held high, all smiles towards our homes and at the distance I can hear the song “It’s my life....”

-Parul Singh

My Experiences in Canada



We reached Victoria, British Columbia, Canada during the second week of May, 2019 after stopovers at London and Vancouver. Lalit enjoyed the flight especially during the take off and landing of the aircraft.

Victoria is a small island and the nearest mainland is Vancouver. Summer has just started here and the temperature yesterday was 27 degree C. We overcame our jet lag in about two days time.

Through the local press we came to know about a walk being organised by the Greater Victoria Down syndrome Society in support of people with Down syndrome. The event was on 2nd June, 2019 at Beckwith Park, Victoria from 10 a.m. to 1 p.m. On the said date we reached Beckwith park. It was a beautiful sunny day. After registering ourselves, we interacted with the people who had come there. There were about 25 children with Down syndrome with their parents and friends.

Games like basketball, shooting, fishing in a small plastic tub, bouncing castle etc. The kids enjoyed it thoroughly. They were encouraged to play them. Lalit too played as you can see from the photographs. I could see that the kids were treated like any other normal children. So much of love and affection was being showered on them.

After enjoying the games for about an hour or so, we were asked to assemble for a walk around the park. The walk led us to a trail around the park which was excellent. Victoria as such is full of greenery everywhere but then going for a walk through the trail was a fascinating experience. We were with nature. Plenty of tall trees. It was like going in a forest. I could see so many birds and also saw the small sparrow which this generation kids have not seen in India at least in Chennai. There was a small pond with ducks in them. It was just fabulous. Though the kids were enjoying, we were enthralled at the experience. We finished the walk of about a kilometer in about half an hour. We were given some snacks after the walk which was quite delicious too. Needless to say there were a few sponsors for the event.

What I could feel here is that the Society as such and also the Government is very caring about these kids. They treat them with respect in fact lot of respect.



-Kishore Gupta

Self-Advocacy - The National Movement

I am going to share my experience about Self-advocacy for Persons with Down Syndrome (DS) in particular and for persons with Intellectual Disability (IDs) in general. My first and foremost experience is that, generally, old parents don't believe in Self-advocacy, whereas young parents do believe in Self-advocacy and want to implement it for their as young as 10 year old son or daughter. Until now, parents have been their children's best advocate - protecting them from harsh realities of life. But the earlier we parents empower them to advocate for themselves, the more prepared they will be for life ahead - no matter what path they take. Our children must be prepared for self-advocacy.

Initiation Of Self-advocacy

Self-advocacy movement was initiated in Sweden way back in 1968. A group of people with DS and ID sitting in the meeting of parents who were discussing about the services provided to them. Persons with DS and ID raised their hand and wanted to speak about the changes in services provided to them. They gave the list to the parents and asked the changes to be included in the parent advocacy efforts. Now the self-advocacy movement is alive and growing. It is an international movement.

Powerlessness And Empowerment:-

Before I proceed further I would like to explain the meaning of terms "POWERLESSNESS" and "EMPOWERMENT" in context to Persons with DS and ID.

Powerlessness: People with DS & ID have internalized negative attitudes towards themselves. They think that collective action by them would not make any impact or influence the community or organization. This is because they are not taken seriously; they are devalued, marginalized, neglected, isolated & segregated. They are seen as incapable & not having their own opinion, desire and wish. They are left out of decisions and not allowed to decide how they should live their lives. They are perceived as dependent on others so they are not provided necessary services.

Empowerment: This is an interactive process through which persons with DS & ID experience personal and social change and learn which enables them to take action to achieve influence over the community and organization. They need to be provided information about themselves and the environment. This can be done by giving them exposure, freedom and bringing them into mainstream. Empowerment means giving them power and authority to take decision. Empowerment is a lifelong process.

What is Self-advocacy ?

During my association with Self-advocacy movement in India I found following definition the most appropriate.

"Understanding own strengths and needs, identifying personal goals, knowing legal rights and responsibilities, and communicating these to others".

This definition is applicable for persons with DS & ID with entire range of functioning level. To elaborate the definition I would say that Self-advocacy is - speaking-up for oneself and things that are important to persons with DS & ID, speaking for those who cannot speak, asking for what one needs, expressing one's thoughts & feelings, speaking for rights, fulfilling responsibilities, doing one's own thing, helping each other in the group, being presentable, understanding appropriate and inappropriate, taking control of own lives, protecting self from danger, being able to take life decisions without influence or control by others, being

able to develop and carry out a plan, sharing problems, being part of a support group, being part of the real world, knowing the life skills like practical life skill, social skill, academic skills, vocational skill, skills for employment, and above all getting rid of words like, 'Mentally Retarded', 'Crippled', 'Handicapped' and 'Viklang'. I don't mean that the Self-advocates (SAs) need to have all the skills; at the same time Self-advocacy is not limited to above skills and aspects of life. Self-advocacy includes innumerable skills and aspect. Asking for support is also self-advocacy. Every individual living under the sun needs support. Its degree of support may vary, quantum of support may vary or its methodology may be different. Self-Advocate too needs help and support. Rather asking for support is the right of Self Advocate. Self-advocacy refers to the civil rights movement.

In the Indian Context, the term "Self-advocacy" is little known. Many people give it a negative connotation like "fighting" for one's rights. Self-advocacy does not mean that getting everything one wants. It does not mean being uncooperative, slang, awkward, bad-tempered and rebellious against family, society or Government.

Importance Of Self-advocacy In Context Of Rights of Persons with Disabilities (RPWD) Act, 2016

Disability movement has been through different models viz. traditional or religious model, medical or charity model, social model and human rights model. It is in this human rights model that Persons with DS & ID started to struggle for their rights. It is recognized that they have the rights to be included in school, college, job, etc.

With enactment of RPD Act, 2016 Persons with DS & IDs are empowered with legal capacity – means they have right to enter into any contract and own and inherit the property and control their financial affairs. Another aspect is Limited Guardianship – means mutual understanding between the guardian and Person with DS & ID which is limited for specific decision and operates in accordance with the will of Person with DS & ID. Persons with DS & ID may modify any support arrangement and seek the support of another. In this context Self-advocacy has paramount importance in the lives of persons with DS & ID.

Self-advocacy In India

Self-advocacy was brought in to India in 2008 by several groups of parents. It took 40 long years. This delay is caused due to diverse Indian conditions like culture, varied financial status, varied exposure, socio-economic status and above all mindset of parents and society. Parents' groups and organizations want to remove these barriers and make sure Persons with DS & ID who live in urban as well as rural areas, become aware that they have the rights to decide for themselves, express their wishes, how they would like to live their lives.

Formation Of SAFI

Parents' groups and organizations, through Self-advocacy want Persons with DS & ID to understand that they can choose on their own or with support from family and friends and when, where and by whom they wish to get support. Parents believe that Persons with DS & ID have the right to make life's decision without undue influence or control by others, Persons with Intellectual Disabilities (PwIDs) have a voice of their own, have right to speak up. They initiated action to establish a nation-wide network of Self-Advocates through formation of groups of Self-advocates across the country.

Parents' groups, to achieve its objectives, initiated the self-advocacy training programs, created SELF-ADVOCATES FORUM OF INDIA (SAFI) and offered the opportunity for self-advocates to be heard at the various forums nationally and internationally. Self-advocates Forum of India is national organization of Persons with DS & ID promoted and supported by Parents' groups. SAFI chapters have been established across the country.

Action Plan For Self-advocacy

Over the years parents groups have taken remarkable strides in strengthening the Self-advocacy movement. Parents groups intend to take Self-advocacy movement to grass root level. To achieve this parents groups have planned three tier training program:

Tire 1: Training of Trainers (TOT): This is an intensive program conducted in two phases. The first phase is for 3 to 5 working days. This training is conducted by experts in intellectual disability field. In second phase, the trainees have to complete the 7 weeks training programs with prospective mentors and self-advocates as elaborated under Tier 3 training programme. This is like internship for trainees to get on hand experience.

Tire 2: Training of Mentors (TOM): The trainers trained at TOT will conduct mentor training programs. The mentors will learn on the job by participating in the full module of training along with Self-advocates as elaborated in tier 3.

Tire 3: Self-advocacy Training of Persons with Intellectual Disability: The mentors trained at Tire 2 shall carry out Self-advocacy training program at district and taluka level with the help of local organizations under the supervision of Master Trainers. This will be 7 sessions training program i.e. one session per week for 7 week.

Self-advocacy Training Of Persons With ID (Tier 3)

In India, needs and requirements of people vary after every few kilometer. Hence, different training modules are prepared depending on socio-economic status of the self-advocates in the group. Training programs are drawn over a period of time (one session per week for 7 week), giving enough time to the Self-advocates for practice of skills and to the mentors to evaluate progress of Self Advocate. An activity based format with interactive sessions for real-time development of self-advocacy skills is used. Any adult with DS & ID is the only criteria for participation in the self-advocacy training program. There is no restriction on participation based on any other criteria.

Planning Program

Meticulous planning is done by the master trainers before commencing the actual training program. All organizations working in the field of DS & ID from the region participate in the self-advocacy group. Depending on the strength of the organizations that are willing to participate, a certain number of self-advocates from each organization are drawn.

Actual Training Program For Self-Advocates

The first day of training is for rapport building and assessment. During subsequent 3-5 days of training following exercises are practiced:

- (a) Express one's like and dislikes, (b) Plan an activity within available resources, (c) Distinguish between appropriate and in-appropriate, (d) Express one's feelings about family, (e) Develop confidence, (f)

Listening activity, (g) Express spontaneously in informal situation, (h) Develop trust, (i) Identify helpers and public places in their community in case of emergency, (j) Make appropriate use of community resources, their availability, requirements, (k) Express expectation from community, (l) Need to say “NO”, various technique to be assertive, (m) Develop self control, (n) Accept each other as they are, (o) Develop concentration, (p) Collect data and specific information about helpers from their community for future use like, phone numbers of police station, hospitals, etc. (q) Activity to boost energy and coordination, (r) Identify one’s strengths, limitations, (s) Awareness of health issues, and (t) Hygiene.

During these 3-5 days training the self-advocates learn some of the following skills:

(a) Always be presentable, (b) Be well dressed, (c) Be careful of their body language, (d) Be appreciative, say “thank you”, (e) Be accommodative, (f) Be respectful, (g) Be assertive-means talking calmly and respecting other person’s feeling, (h) Speak clearly, (i) Take their time when talking, (j) Ask for time when talking, (k) Ask for time to think if needed, (l) Be ready to compromise, (m) Accept their condition to themselves, admit their condition to others, (n) Understand own learning style, (o) Know their needs, (p) Know their rights and responsibilities, (q) Know where to go for support, (r) Plan for future, (s) Have a very good idea of what they want and why they want, (t) Rehearse what they speak, (u) Maintain eye contact, and (v) Election system.

While practicing these exercises the mentors play role model.

On the last day of the training program, a meeting of representatives of all participating organizations is organized to review the training and plan for the future.

Monthly meeting of the group

Once the training is over, the entire mantle of responsibilities shifts to the now “Self-Advocates”. Having undergone the intensive training, their innate abilities to know what they want and to decide for themselves definitely undergoes a sea change. Mentors only play the role of supportive actors in the entire drama that would unfold and are with them in case of any crisis. The learning principle in self-advocacy involves consistency and repetition to reinforce learning through each step and maximize understanding. So monthly meeting of the group is a “MUST”. The self-advocates assisted by mentors and in collaboration with the participating organizations conduct the meeting. They ensure that every monthly meeting has one capsule of agenda items decided by the self-advocates themselves and one capsule conducted by the mentors for advancement of their self-advocacy skills. They decide days, dates, time, and venues for monthly meetings and assign responsibilities amongst Office Bearers and members of the Self-Advocates’ group for various tasks of the monthly meetings. They decide the agenda for the first meeting and need based workshops, visits of the self-advocates to local organizations and visits to the group by local activists and visit to local civic bodies are also planned during these monthly meetings.

Further advancement

The Self-Advocates’ group members also start working on addressing public at various social gathering in educational institutions, parents’ associations and other such organizations to create awareness about their abilities and rights. Meeting of self-advocates from other regions is arranged to facilitate sharing of information. Refresher courses are organized for mentors as well as for the self-advocates after some ground experience for structured training in knowledge and skills which would be required. Three National Conventions of Self-advocates each in Delhi in 2013, Udaipur in 2015 and Bangalore in 2016 were held and

forth one is scheduled to be held in Nagda, MP in Nov 2019. The convention is attended by over 250 participants comprising of Self-Advocates, mentors, parents. Some of the self-advocates trained in self-advocacy training programs addressed public meetings at national and international levels like National Parents' Meet, World Down syndrome Congress and World Congress organized by Inclusion International.

Role of mentor

A Mentor is a supportive individual who voluntarily accepts the personal and professional responsibilities to guide the self-advocate, using his/her knowledge, communication skills and patience to enable the Self-advocates to move on to higher levels of functioning in their lives on day to day basis. Mentor must have the leadership qualities like trustworthiness, interest of others at heart, good at encouraging others and must be able to energize through enthusiasm. Mentor should be non-judgmental and should maintain confidentiality. Mentors should have deep commitment to fostering self-sufficiency. Mentor should believe that SAs have an inherent desire and ability to progress and trust that SAs know what to do and how to do whatever he/she wishes. The role of mentor is to unearth the latent potentials in SAs, aid them in making life decisions, assist in trouble shooting personal and social barriers, and introduce them to new opportunities that provide extended support. Mentor should enhance knowledge and understanding of self-advocates about the opportunities available in community and guide them in handling of specific situation and should let Self-advocates take the final decision.

Mentoring is not teaching and coaching, not telling them what to do, not telling them how to do, not doing things for them. Mentoring is not about providing them everything that they want. Mentoring is not about sympathy. "Mentoring is a win-win for everyone." Mentoring is more of an attitudinal change in self as well as in Self-Advocates. Mentors play the role of "Role Model" to their mentee.

Role of parents

Parent must believe in the capability and strength of their son or daughter. I believe that every living creature has some ability so have the persons with DS & ID. Parents should understand the concept, importance and how self-advocacy is going to help their ward in particular and society in general.

I believe that the first mentor of any person is his parent as parents play the major role in development and grooming of a person. But mentoring persons with DS & ID is quite different. One of the objectives of self-advocacy training programme is to make self-advocates to open up and speak up. I have observed in many training programmes that self-advocates don't open up and speak up in presence of parents. Sometimes it so happens that parents don't like what their wards speak at the training sessions and sometimes parent tries to prompt their son/daughter. So parents should keep themselves away from the training sessions and let trainers and mentors take care of their wards. Parents should support the mission wholeheartedly as without their support this movement will not be successful. Parents can help in providing logistic support during training programmes.

- P S Burde

(The writer is General Secretary of Parivaar National Confederation of Parents Organizations working for PwIDDs and Father of Pranay Burde, twice National Awardee and recipient of WSDS 2014 Award)

Research Paper - Comparative Study on Aquatic Therapy vs. Exercise for Toddlers with Trisomy 21 (Down syndrome)

Background

Down syndrome (DS) is a common genetic disorder which has the incidence is about 23000/yr live births in India. In comparison to normal children, Down syndrome Children have weak hip abductors and knee extensors. Maintaining a state of equilibrium is limited or compromised in children with mild to moderate levels of motor impairment. Swimming is one of the best ways to maintain and improve the motor fitness in low IQ level individuals with Down syndrome. This study is to analyze the aquatic therapy session in comparison with the regular physiotherapy session with assistance of physiotherapist. The comparison is gauged using various observations.

Materials and methods

This is a single center study and children with Down syndrome aged 6 months to 4 years, confirmed by Karyotyping or genetic analysis will be selected for data collection. The criterion for subject selection is children with Down syndrome having complete neck control without medical issues. This study is to see the difference in outcome of treatment methods used. Study group and the control group receive the same set of physiotherapy exercise for 5 days a week except that the study group gets aquatic sessions in addition to exercise for 2 days a week. A questionnaire is used for assessment to know the physical development of the child before the study at 0 week and 6 weeks later.

Results

Our study results revealed most of the parameters studied on the Down syndrome children namely sitting, creeping, standing, crawling, pushing, moving, walking and kicking improved significantly ($p < 0.01$) on Down syndrome children who underwent both exercise and aqua therapy when compared to children who did only exercise.

Conclusion

Combination of water and land exercise is an effective strategy to improve daily activities in Down syndrome children. It was noted that combination of exercise and aqua therapy showed significant improvement in many motor parameters in Down syndrome children.

For the full paper, visit our website www.downsyndrome.in



-Dr. Priya Chandrasekhar, Dr. Surekha Ramachandran, Ms. Mithula V., Ms. Srilakshmi R.