



ASIA PACIFIC  
DOWN SYNDROME  
FEDERATION



# APDSF E-News

APDSF Newsletter

## **President Speak**



Hello everyone:

Let me begin by wishing all of you a very Happy New Year! It is a pleasure to come to you with the second edition of the APDSF e-News. We are glad to note the developments happening in the Down syndrome world across countries in the region.

IIDSC 2017, which was held after the previous AGM in New Delhi was a huge success for India. We had more knowledge sharing on a common platform than at any time before. This is probably a take-away for all countries in our region since we share a common thread. Members should try and bring together parents in their countries to provide them with as much information as possible to achieve our aim – an Inclusive Society.

We have had our first Skype meeting of the Executive Committee last month to review developments and discussed ideas to take APDSF forward. This I believe is just the beginning of more interaction and deeper understanding with one another to make the region one big Family.

Wishing you all the very best for this year, when we take our next leap towards making society accept and give more respect to our children.

## AUSTRALIA

### First meeting of Down Syndrome Australia's new self-advocacy group- the Down Syndrome Advisory Network



Down Syndrome Australia held the inaugural meeting of our Down Syndrome Advisory Network (DSAN) in November. The DSAN is made up of people with Down syndrome from across Australia who will provide information and advice to the DSA Board and work with the DSA CEO to assist us in making sure that we are representing the voices of people with Down syndrome.

This first meeting focused on having an opportunity to meet other members, to discuss the terms of reference of the group and to find out more about what it means to be on an advisory network. The group also had a chance to decide on a new logo for the network and provide feedback to our design group.

It was a fun and engaging meeting and we talked about why members had joined the group. There were a range of reasons but it was clear everyone was excited to have a new challenge and to have a chance to speak out on behalf of people with Down syndrome. Some of the comments included:

- “I have always wanted to be a voice for people with Down syndrome.” Claire (QLD)
- “I wanted a new challenge” Andrew (WA)
- “My issue is about respect. We all need respect. We want people to respect disability in Australia” Matt (VIC).
- “I want people to see the person not the disability” Kylie (NSW)

We look forward to working with the DSAN to help us advocate for and with people with Down syndrome.

## BANGLADESH

### AMDA - Bangladesh

#### On Having a Brother with 'DOWN SYNDROME' ...An amazing experience!!



I am Fahim, a brother or guider, who has a brother with Down syndrome!!

At first we should know it is not a 'disease'. Even we cannot put them in the row of disabilities. But the main fact is to give them a better and unique guidance.

We can say that siblings are likely to have the longest relationship of anyone with their brother or sister with Down syndrome.

Rakin (16) and Rafan (9) are my two younger brothers. Rafan born with Down syndrome. He is the sun shine of our family. Basically, he used to make us laugh and make an enjoyable time for us (every member of our family). Even he is also an inspiration to us in every fact. But sometimes he used to over-react. Such as, some silly matters. But I have to manage him in various funny ways.

He is an Angle...changing our life in many ways!! I feel lucky to have such a brother and I thank to Almighty for the most valuable gift that He has given to me, my brother RAFAN...I Love You!!

Written By:

S. Fahim Razzak

HSC (2<sup>nd</sup> year), BAF Shaheen College, Dhaka



### **Motivational Story - Bangladesh Down Syndrome Association**



A group of people who was social worker and parents started to work for Disability since 1977 in Bangladesh. There is a Non- governmental organization “ SWID Bangladesh” established by Dr. S. Zaman, who was a philanthropist and social worker and was then special educator in Dhaka University with other seven parents and social worker. By creating social awareness some parents become inspired to give marriage of their young children with disability. I am a mother of Down syndrome Progga Paromita Roy. I became a member of this organization since 2000. I also inspired by seeing some successful story like- Mrs Monti is Autistic and Intellectually disabled become a successful mother of a brilliant son and a daughter. Mr. Shaheed is Autistic and married to normal lady. He became a father of a daughter and a son. By seeing this entire successful story I came forward and founded “ Bangladesh Down Syndrome Association” with direct supervision of Prof. M R Khan, National Professor and child specialist and with help of Prof. Dr. Mesbah Uddin Ahmed , a child Specialist with some other social worker and parents of Down Syndrome in March 2014. At last I give marriage of my daughter Progga Paromita Roy to a young boy in December 2014 as an awareness program. A lot social worker, parents, Government official were present in this ceremony to make it successful. In the meantime I came to know that Mr. Shanto is a Down Syndrome boy was married and become a father of 2 son who are normal by chromosomal studies.

By this time Progga Paromita become pregnant but 1<sup>st</sup> conception turn in miscarriage. 2<sup>nd</sup> pregnancy –unavoidable delivery at 5 months and baby expired after 1 hour. 3<sup>rd</sup> pregnancy continue till successful delivery after two Shiratker saucer . Now she gave birth to a normal female baby. So we come to conclusion that though there is a lot of trouble we can be successful for our specially need children as they can lead successful family life also. My request to parents with Down Syndrome son/or daughter, you can arrange successful conjugal life for them. Because every individual has normal biological needs either he/she is with Down Syndrome or any other disability.

## BHUTAN

### Jigme Choden loves story telling



Jigme Choden is an 8 years old girl with limited speech so uses sign language most of the time to communicate. She lives in Thimphu, the capital of Bhutan with her loving family. Jigme loves storytelling and her favorite book is "The very hungry caterpillar "by Eric Carle. Jigme is a great storyteller, just by looking at the pictures she can make up stories and can narrates it in Bhutanese sign language. Storytelling is very effective tool that can spark a Child's imagination and they become familiar with sounds, words, language and the value of the books. Social skills are developed through story books and they can learn about relationships and emotions. We also encourage parents to read stories to their children as it provides more opportunities to bond with their children. Story books are very important in every child's life and it can be a great companion in a child's life.

## INDIA

### Stepping ahead for a Better world for our Children

IIDSC was a game changer for Down syndrome in India. With an event that saw participation of nearly 150 families with over 450 delegates, this event was the first to talk about the positive side of what persons with Down syndrome were capable of. For parents, this was a revelation and for therapists and doctors a platform to share their experiences. The release of the book on Babli by the National Security Advisor of India, “Down, but not Out – Babli’s story” was another motivational push for parents.

India is a huge country with vast differences. The south, the north, the east, and the west – everyone has their own tongue, customs, habits and beliefs. The Down syndrome Federation of India (DSFI) has to ensure that the sentiment of each of them is taken into consideration when we try to improve the lives of persons with Down syndrome. That is why the whole therapy team along with Dr. Surekha Ramachandran has been visiting locations across the country. First, they visited Hyderabad in the South in November and then went to Raipur in the north in December. The camps that were conducted were an eye-opener for the parents as they realized how their kids can perform better with therapy and early intervention.

At Raipur, the Chief Minister of the state of Chattisgarh (of which Raipur is the capital), and his team including the Secretary of Disability Affairs was very keen on putting in place the right systems to ensure better conditions for persons with Disabilities.

The team will next move to the East – to Kolkata and then to Bangalore in the south-west part of the country. This is just the beginning as DSFI looks forward to securing a better place for persons with Down syndrome in the country. All by means of stepping out of its home zone and meeting people across the country.



## LEBANON

### Lebanese Down Syndrome Association Collaboration with AUB Continuing Education Center to create the “Next Step” program



The “Next Step” Program is a collaboration of the Lebanese Down Syndrome Association (LDSA) and the American University of Beirut’s Continuing Education Center that offers higher-education opportunities for youth and intellectually challenged adults.

The program is the-first-of-its-kind in the region, and will serve the individual needs and career paths of each student with an adaptable curriculum, set-up, tools and strategies, as well as the essential mentorship and guidance to nurture individual strengths and interests.

The “Next Step” program spans over a period of three years and includes academic courses with functional objectives as well as vocational preparation. The curriculum will be based primarily on the Life Centered Education objectives as published by the Council for Exceptional Children. During their studies the students will participate in internships for selected business platforms based on their career choice, and the program culminates with students receiving a certificate of completion from the Continuing Education Center-Regional external programs at the AUB.



## NEPAL

### Down Syndrome Association of Nepal

#### Early Detection /Diagnosis and Referral for Down syndrome, Autism and Cerebral Palsy The Ministry of Health,



Leprosy Control Division, Disability Focal Unit conducted 3 days training separately for Medical doctors and Physiotherapists a **#HISTORIC** program. This was the first venture highly appreciated and taken enthusiastically by participants. Training facilitated by Down Syndrome Association of Nepal (**DSAN**) and 2 other organizations. Welcome note and distribution of Training certificates by Mr Ashish Joshi, child with Down syndrome

This training will be very effective in early detection / diagnosis, referral and early intervention so as to get maximum productive outcomes.

According to WHO, 70% of disabilities can be prevented if proper care is taken during pregnancy, infancy and early childhood.

By detecting Down syndrome early and initiating early intervention measures like medical, educational/ therapeutic interventions, home training of parents and community awareness campaigns would help improve quality of life. Prenatal screening /diagnosis help parents to take informed decisions. Comorbid conditions could be cared for timely and the ill effects minimized.

## **Down Syndrome Society Nepal**

### **My Son & Me**

A person came to my office with his brother today. His brother was 22 years old and he was down syndrome. While conversing, it seemed that the person came to know about his brother's disability only when he got associated with Health Sector. His brother was already 17 then, and the people from his village used to call him a 'deaf'.

This is only a small example, through which my mind gets inspired every time to achieve goal on my own. I became more determined to fulfill my aim in life and reach to its destination.

But, today I look 15 years back where I was overwhelmed with joy when I gave birth to my son. But life had some other plan. I came to know my son was down syndrome. However, the changes which occurred in my life post his birth are most precious, regardless of the fact that he is down syndrome and when I listen to people saying that Shila Thapa is a successful social worker, I look forward to see my son and think he is inspiring me every day. I can never forget talking about one person and she is Dr. Rekha Ramchandran who appeared as a god in front of me and saved my son's life when he was struggling with life and death due to a heart problem. Dr. Ramchandran was a God in human attire, she was my son's savior. I was so much inspired by Dr. Ramchandran, that through this inspiration, today I am fighting for the rights of the people who are like the condition of my son. I was the first person to start working in the field of Down Syndrome here in Nepal. Our down Syndrome Society Nepal have been conducting awareness program and training to different people in society, lobbying with government sectors regarding the rights and running day care centers for the children of this state providing life skill training and special education. I hope this Society will also seek solutions to the challenges faced by parents like me in the near future.

## SRI LANKA

### “Jinendhi – raising to become an inspiration to gifted children in Sri Lanka”



Jinendhi Galgamuwa, born as a child with Downs Syndrome is evolving to become a social worker apart from her regular activities of being an office assistant. Even though it is something alien to Sri Lanka, in many developed countries children with Down Syndrome are raised to become independent, strong individuals who would engage in regular work as everyone else. Our humble ambition is to overcome this cultural barrier for Jinendhi and all other Sri Lankan children gifted with that extra chromosome. It is possible to train them to become such individuals, but needs the dedication of their parents and family. This is the synopsis of Jinendhi, who is transforming herself in becoming an ambassador for children with Down Syndrome in Sri Lanka.

Jinendhi is an office assistant at “*Amasa Study Abroad*”, and “*Global Environmental Youth Education Foundation*”, since 2008. Some of her regular activities in the office are;

- Being an active member in promotional programs
- Assist the secretaries at the office
- Photocopying and other routine office duties
- Greeting and serving tea for visitors, office staff and students who would be prospective graduates: All the students who has gone to India through “*Amasa Study Abroad*” knows her, as she was their first person of contact. They often bring her gifts as an appreciation.
- As a senior staff member, she is always recognized in functions such as certificate award ceremonies and felicitation events.

Recently, with the establishment of the “*Jinendhi Resource Centre for Downs Syndrom*” Jinendhi was promoted as an ambassador for social events and serves as the public relation officer. Some of the events organized by the center, where Jinendhi played a prominent role are;

- Youth vision program
- Dream cricket
- Hearing Aid donation program " Gift of Hearing "
- receiving new members for the JRCFDS.

“*Jinendhi Garden Villa*” is another venture where we have two-room guest house, under her name. She is the one who welcome the guests. Before leaving for USA recently, she went with her father to the bank and did her own money transactions. She has her own HSBC credit card.

With all these simple day-to-day activities, we want to expose her to the society and get the attention of the people. The message we want to deliver to the society is that you don’t need to build castles to help these gifted children, but it is the simplest of things that can actually change



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their lives forever. Everyone can contribute in this worthy cause, and thereby build a " CARING  
COMMUNITY FOR DOWN SYNDROME.

## VIETNAM

### Gia Dinh Special School



Title: **My Belly Dance.**

My full name is PHAM LE MY NGOC.

When I was 20 years old, my height was 1,36 m and weight was 60 kgs! Doctor said I should follow a diet program and do daily exercise. Luckily, my mother and I found out that Belly Dance which has been very good for me to keep healthy and fit.

After 7 years hardly practicing, I lost 9 kgs.. I enjoy very much practicing it in group, I feel confident among all participants, they admire my dance skills and respect me, then they always invite me to join to their Belly Dance performances on Vietnamese Festival yearly. Our group is Belly Girl belong to the Youth Association in Ho Chi Minh city.

I am also very confident and proud of being Down syndrome girl with my classmates in performances of Gia Dinh special school events, we together inform communities that Down Syndrome people have abilities to learn, work and enjoy life as others.



## KIANH FOUNDATION

### **Life begins at 13**

Le Van Viet is a 20 year old man with Down Syndrome, living in Dien Ban, an impoverished area of Central Vietnam. Viet spent his days at a local kindergarden whilst his parents went to work. This was the only place that would accept him, and his family counted themselves lucky that they had somewhere to send their son during the day, which is often not possible for the majority of children with disability in Vietnam. Viet learned nothing at the kindergarden and was shunned by the much younger children. This changed when he was 13 and he began to attend a special school run by NGO, The Kianh Foundation. Over 7 years, he learnt many life skills, basic numeracy and literacy, better communication and behavior management. This year, Viet was able to begin full time employment at a local paper making company, where he is a happy and effective member of staff.

For more information, visit our website [www.kianh.org.uk](http://www.kianh.org.uk)



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# COUNTRY REPORTS

## Report DSAN activities, NEPAL--- Sept. to Dec. 2017

1. 1 day Training to Medical Officers and Physiotherapists of different district and Kathmandu valley hospitals on early detection/diagnosis , early intervention and referral for Down syndrome -15<sup>th</sup> and 21<sup>st</sup> Nov.



2. Special Olympics Nepa, Family Leadership Training 30 parents of children with ID participated along with demo of Young athlete activities in Kathmandu - 11<sup>th</sup> Nov.
3. Free Dental camp for children with DS and parents DSAN / Sai Polyclinic and Diagnostic Centre, Kath - 3<sup>rd</sup> Dec.



4. Special Olympics Nepa, Family Leadership Training in Pokhara District and New family network formation- 16<sup>th</sup> Dec.



5. Free Medical Camp in Shikali, Lalitpur District with various specialties Diabetes and Eye screening , Down syndrome awareness program , Gynecology, Dental ,ENT checkups jointly organized by DSAN and Rotary Club- 23<sup>rd</sup> Dec



6. Planning for Menstrual and Dental hygiene Talk program for children and parents soon in January in association with SO Nepal.



## Australia

### Down Syndrome Australia

Down Syndrome Australia was established in 2011 as the peak body for people with Down syndrome in Australia. Our purpose is to influence social and policy change, and provide a national profile and voice for people living with Down syndrome. We work collaboratively with the state and territory Down syndrome associations to achieve our mission. Our vision is an Australia where people living with Down syndrome are valued, reach their potential and enjoy social and economic inclusion.

### Recent Key Activities and Achievements

A brief overview of key recent achievements by Down Syndrome Australia include:

- Launch of a self-advocacy network, the National Down Syndrome Advisory Network (DSAN) which is made up of people with Down syndrome from across Australia. This group will provide advice to the DSA Board and ensure that the work of DSA is guided by the experiences of people with Down syndrome. The Network had their first meeting in November and will meet on a monthly basis and the chair of the network will participate in DSA Board meetings. More information about the network can be found here:  
[https://www.downsyndrome.org.au/advisory\\_network.html](https://www.downsyndrome.org.au/advisory_network.html)
- Ongoing advocacy to ensure that the National Disability Insurance Scheme (NDIS) meets the need of people with Down syndrome in Australia including through involvement in the NDIS CEO forum and numerous consultations with representatives of the relevant Agency. We have provided a comprehensive submission to the Productivity Commission Study into the Costs of the NDIS ([http://www.downsyndrome.org.au/news/Productivity\\_commission\\_study.html](http://www.downsyndrome.org.au/news/Productivity_commission_study.html)).
- Submissions to Government on Antenatal care, public funding of Non-invasive prenatal screening, Disability Employment Services Reform, NDIS The Disability Support Pension and to the Disability Discrimination Commissioner on his priorities. Copies of these submissions can be found:  
<https://www.downsyndrome.org.au/submissions.html>
- Engagement with key politicians and stakeholders to continue our advocacy on a range of issues including health, inclusive education, employment, ageing and NDIS.
- Successful attainment of grants through the National Disability Insurance Agency to produce national resources on key issues for people with down Syndrome and their families and toolkits for community organisations to support inclusion. These



resources are currently under development but will be available on our website once completed.

- Improved reach on community awareness including through the launch of a national e-newsletter which reaches over 1000 people, and increases to our social media following by approximately 40% over the last year.
- The release of a new publication on Down syndrome and dementia which has been developed to promote an understanding of the links between lifestyle, health and dementia and provide information about supports and services for people with Down syndrome and dementia. (through a grant received from Dementia Australia):

<https://www.downsyndrome.org.au/documents/resources/health/DSA-DA-guide-for-families.pdf?>

- Finalising the Down Syndrome Australia 2017-2020 Strategic plan.  
[https://www.downsyndrome.org.au/work\\_strategic\\_plan.html](https://www.downsyndrome.org.au/work_strategic_plan.html))

## Mongolia

### OUR MISSION:

Rising awareness on Down Syndrome, promoting human rights and inclusion for people with Down Syndrome

### OUR VISION:

People with Down Syndrome are fully included members of Mongolian society and its valued tax payers

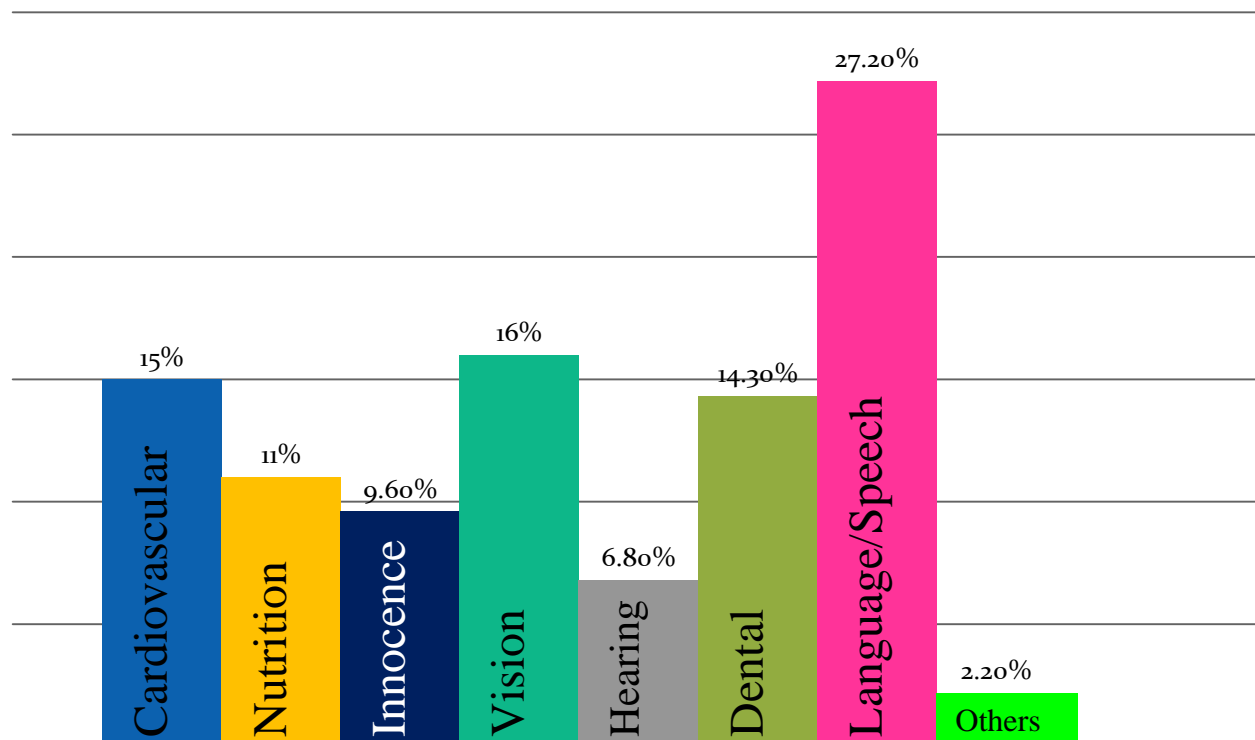
### Activities in 2017/18

1. EARLY INTERVENTION
2. COOPERATION WITH JDS. TOKYO VISIT
3. IN MAINSTREAM SCHOOL
4. YOUNG ADULTS PROGRAM
5. LIFE & SOCIAL SKILLS CLASSES
6. VOCATIONAL TRAINING
7. EMPLOYMENT / THE FIRST TAX PAYER
8. EDUCATIONAL SEMINARS FOR FAMILIES
9. CARYOTYPING TEST IN NEW CYTOGENETIC LAB
10. SELF-ADVOCACY / HUMAN RIGHTS
11. SPECIAL OLYMPICS /GOLD IN AUSTRIA
12. GREEN PROGRAM
13. MULTI-SPECIALISTS'SUPPORT GROUP
14. SPEECH THERAPY SUMMER SESSION
15. MASS MEDIA
16. 2018 Kick-Off: educational trip in every province of the country

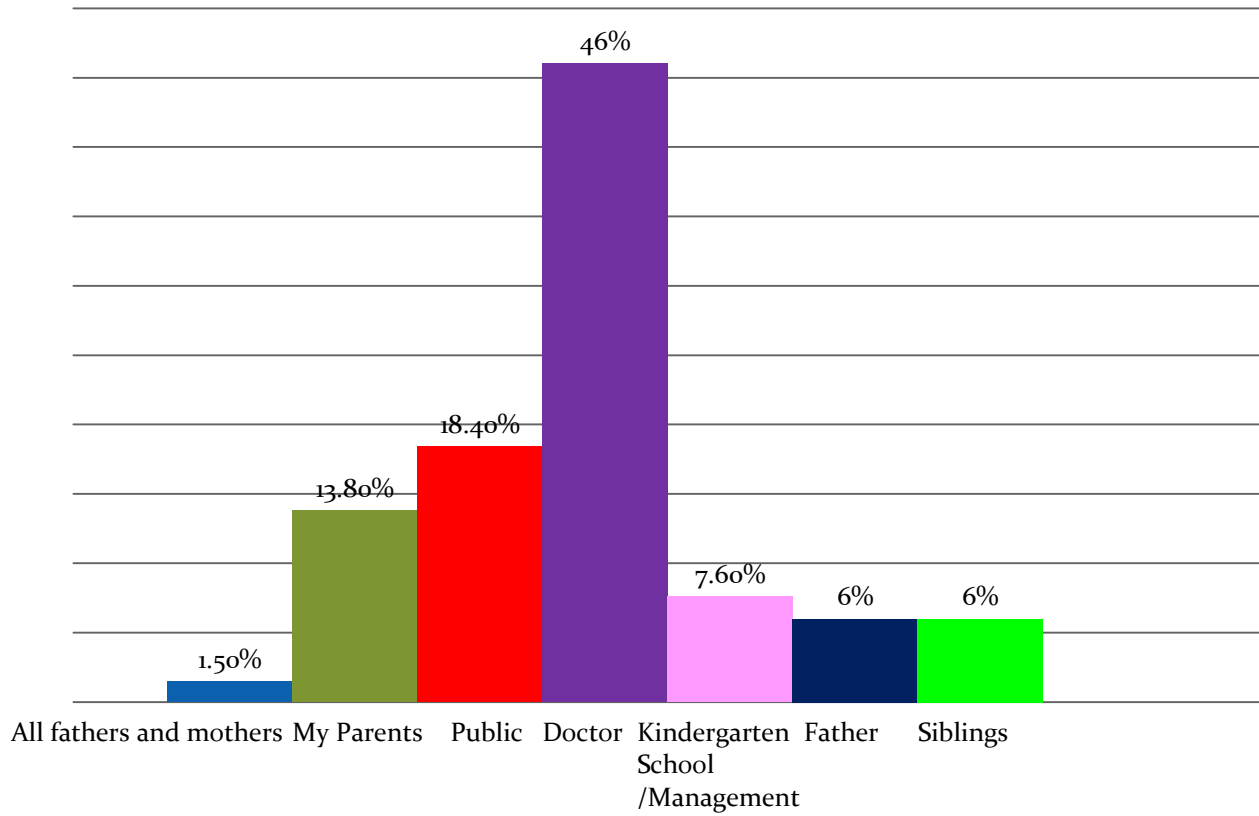




## What are the health related issues faced by persons with Down syndrome?



## Who hurts the child with Down syndrome the most?





## Report from India

### 1. IIDSC 2017 and APDSF AGM

IIDSC 2017 was the first time that persons with Down syndrome from across the country came together under the same roof. There were speakers – both national and international who shared their knowledge and views with almost 450 delegates from across the country. Hosted by the DSFI, this 2 day conference had a healthy mix of Medical and Social information for the delegates to glean information from. The feedback at the end of the event was that there was too little time for all the information. People wanted this event to be an annual affair and wanted to ensure that they do not miss out on any opportunity to provide a better life for their wards with Down syndrome.

Along with the IIDSC, the APDSF AGM was also organized where 11 countries from the Asia Pacific region discussed ways to make the APDSF a body that can address issues in the region and ensure a better standard of living for persons with Down syndrome. The APDSF delegates then attended the IIDSC 2018 which was a great knowledge sharing experience for all present.

### 2. Visit of DSFI therapists to various Centers across the country

DSFI and its team of therapists and counselors led by Dr. Rekha Ramachandran have been visiting various centers across the country to counsel parents and to provide them with information about Early Intervention and therapies to help their children with Down syndrome become more independent. These therapies help in building confidence not only among the children, but also the parents who can now hope for a better life for their children.

The first of these visits was to Hyderabad in October 2017 where nearly 50 persons were counseled over a 2-day period. A discussion session with various therapists from Hyderabad was organized where speech therapy was discussed for persons with Down syndrome.



The next visit was to Raipur, in the state of Chhattisgarh, where over a 2 day period, almost 70 families were met with. This state is not as forward as Hyderabad and parents were very thankful for the opportunity to be able to air their questions to the team of therapists and find some solution to the problems they faced. The Chief Minister of the State also granted audience to Dr. Surekha Ramachandran where he was very keen on bringing about

an inclusive society for persons with Down syndrome in his state. As a progressive CM, he was open to new ideas, which is what we as a country need.



### 3. Connect with New Zealand

During her visit to New Zealand, President of the Down Syndrome Federation of India, Dr. Surekha Ramachandran met with Ms. Zandra Vaccarino of New Zealand Down Syndrome Association. They discussed ways and means to share New Zealand's experience and India's expertise in this field of Down syndrome to improve the situation of persons with Down syndrome.



### 4. Impending visit to Nepal for Weaving Session

DSFI in association with DSA Nepal is planning to gift a loom to Nepal and provide vocational training for persons with Down syndrome there. The idea is to empower persons with Down syndrome there. A team from here led by Dr. Surekha Ramachandran, the weaving unit head and some persons with Down syndrome will be visiting Nepal in March to provide this training. This is also an initiative aimed at beginning the cementing of bonds between the countries in the Asia Pacific region where each country can share their expertise with another.