



ASIA PACIFIC
DOWN SYNDROME
FEDERATION



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APDSF E-News

APDSF Newsletter

January 2020

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PRESIDENT SPEAK



Hello everyone:

Wish you a very Happy New Year!

The last year has been quite action-packed for the APDSF. There were APDSF events all over the region on the occasion of World Down Syndrome Day. The Federation's representation at the UN was widely appreciated. We had a self-advocate speak along with her sibling which was applauded at the UN. This has given us the idea of having more Self-advocates representing the region this year.

Our Medical Committee has also started its journey now. The first meeting of the Medical Committee at Japan in November 2019 was successful where new ideas were shared, giving the APDSF more information to work on this year.

The AGM at Dubai was attended by 12 countries and many action points came out of that meeting. It was heartening to see how countries intend to take the goal of an inclusive world forward.

For the first time the AGM was attended by representatives from China. Having interacted with various countries at the AGM, they are planning on having their first Self-advocacy session in April 2020.

We are reaching out to many more countries to assist them by spreading awareness and providing information that we have at our disposal. This is our contribution in making the region a Down syndrome friendly place.

Regards,

N. Ramachandran

President – APDSF

APDSF AGM 2019 – December 7-8, 2019

The 3rd APDSF AGM was organized at the Shangri-La Hotel, Dubai on the 7th and 8th of December 2019. Representatives from 12 countries spoke about Down syndrome in their country and the steps taken to help raise awareness about Down syndrome as well as how they are helping persons with Down syndrome lead meaningful lives.

Representatives from the following countries attended the AGM:

1. UAE
2. Sri Lanka
3. Mongolia
4. Australia
5. Thailand
6. Singapore
7. China
8. India
9. Pakistan
10. Myanmar
11. Maldives
12. Japan

Representatives from Nepal and Bhutan were expected at the AGM, but due to personal reasons they were not able to attend. New Zealand had sent in their country report to be presented at the AGM.

The first day, 7th of December saw all the countries presenting their country reports. It was a good session with a lot of positives emerging from it. Delegates offered a lot of inputs on how things were being done in their countries and the progress being made by each country for persons with Down syndrome was phenomenal.

The 8th of December began with the Executive Committee meeting where the President, Vice Presidents and Executive Committee Members had a closed door discussion on matters pertaining to the region. This was followed by the AGM where members were given a heads-up on the EC meeting and then informed about what needs to be done by APDSF to take the organization to the next level.

Mr. Paul Zanon, a special invitee and an independent observer provided the vision for taking APDSF ahead in the afternoon session. The session highlighted the advantages that APDSF had and how to leverage them to improve the lives of persons with Down syndrome in the Region.

The meeting was followed by the APDSF Awards ceremony at Old Dubai where a traditional meal was laid out for all the delegates. The delegates were given an opportunity to dress up like a native Emirati and pictures taken. The Awards were not a surprise and the winners were presented with a plaque and certificate.

APDSF also was a part of a self-advocacy session on the 9th of December 2019. Organized by the Emirates Down Syndrome Association, this event saw many self-advocates discussing their lives and achievements. The session was conducted by Dr. Surekha Ramachandran, President of the Down Syndrome Federation of India, Ms. Jo Chopra, a known self-advocacy expert from India, Mr. Vanchig Ganzorig from Mongolia, CEO of Down Syndrome Association of Mongolia and Mr. Angus Graham, Vice-President, APDSF. The topic for the session was –Independent Decision Making by Persons with Down syndrome.

The AGM had a lot of take-aways regarding the actions that countries need to take to help persons with Down syndrome lead socially inclusive independent lives.



Self-Advocates with Mr. N. Ramachandran, President - APDSF



Delegates at the Cultural Event before the Awards Ceremony



Country Report in Progress – 7 December 2019



AGM in Progress

INDIA

2019 has been the year that has seen India move from learning, understanding, to actually doing. For the first time in 35 years changes that have impacted the lives of persons with down syndrome and their families have taken place. In spite of the differences in language, culture, customs and traditions, the Down Syndrome Federation of India has been able to make a breakthrough and reach out to more parts of the country.

India in the 80s and 90s was a time when persons with disabilities were a huge liability on families. They were considered a curse in many families in India. One of the primary reasons was the lack of awareness amongst the doctors and parents. No support was forthcoming. It took 35 years for India to experience and witness change in attitudes.

APDSF has played a key role in India's development.

- The Passport from Singapore was a boon for India, which is being used by a lot of parents here
- Mongolia has helped give us a different perspective to using sports as a medium to help persons with Down syndrome. Increasing rates of physical activity in persons with down syndrome helps reduce obesity, as well as associated secondary health conditions. Every state in India has started sports activities like football, swimming, surfing, cricket, cycling, athletics, and inclusive walkathons and marathons leading to confidence and independence in the persons with down syndrome
- From Australia, India learnt to fight for a separate status, which now seems would become a reality. The confirmation that Down syndrome will be now given a special certificate at birth and intervention in both medical and therapeutic areas will be addressed by the state government. A directive has also been issued from the government about school education being compulsory for every child
- From Indonesia, India has learnt the importance of teachers understanding the condition better. Teachers training centres have been set up. To help teachers to understand Down syndrome the federation has created a curriculum



- Nutrition forms an important part for any person – and persons with Down syndrome need to have a good balanced and healthy diet. Sri Lanka helped in understanding this perspective

Over the past 5 years, India has:

- Helped parent empowerment through parent support groups
- Helped provide medical empowerment through conferences
- Created medical teams created across states
- Help set up early intervention units in every state and in local hospitals
- Started teacher training/ down syndrome
- Set up self-advocacy groups
- Created awareness in using talent such as art, dance and theatre and music
- Started using the social media platform – WhatsApp groups and spreading information using twitter and Instagram
- Regularly organizes family counselling
- Moving from state to state to help create an empowered society
- Organized Moms Only Meet for the mothers

I

India is moving ahead in its quest to make the dream of an inclusive society a reality. While we realize we are not there yet, there is no doubt that we will reach there soon.



Students from a College in the City.



APDSF celebrating WDSF at the United Nations Office in Geneva



India International Down Syndrome Conference 2019 at Chandigarh, India



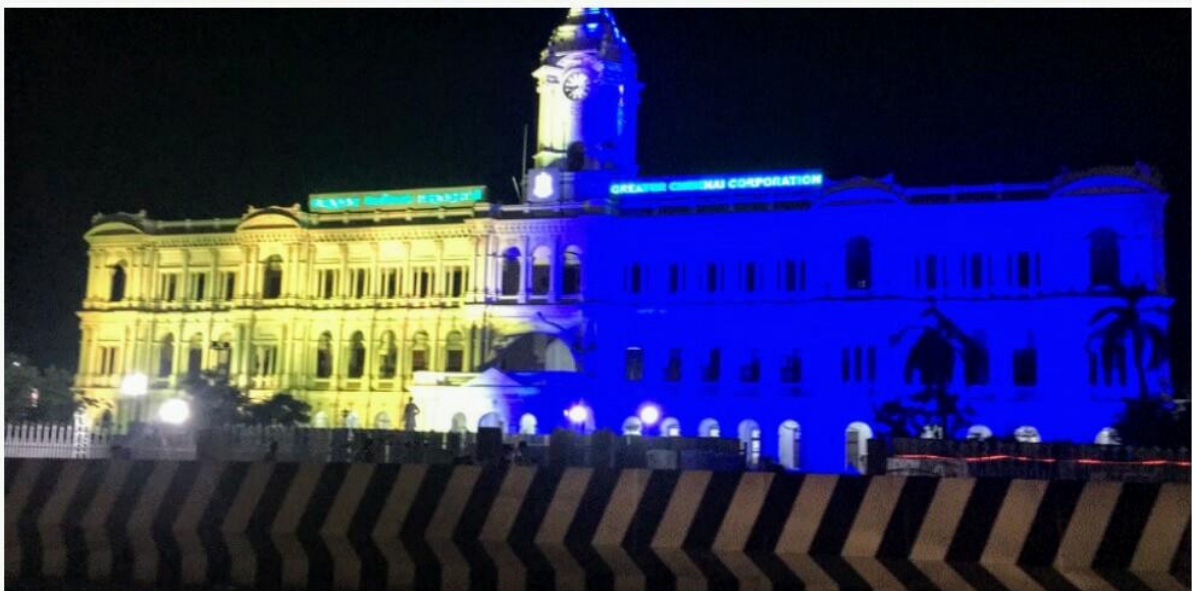
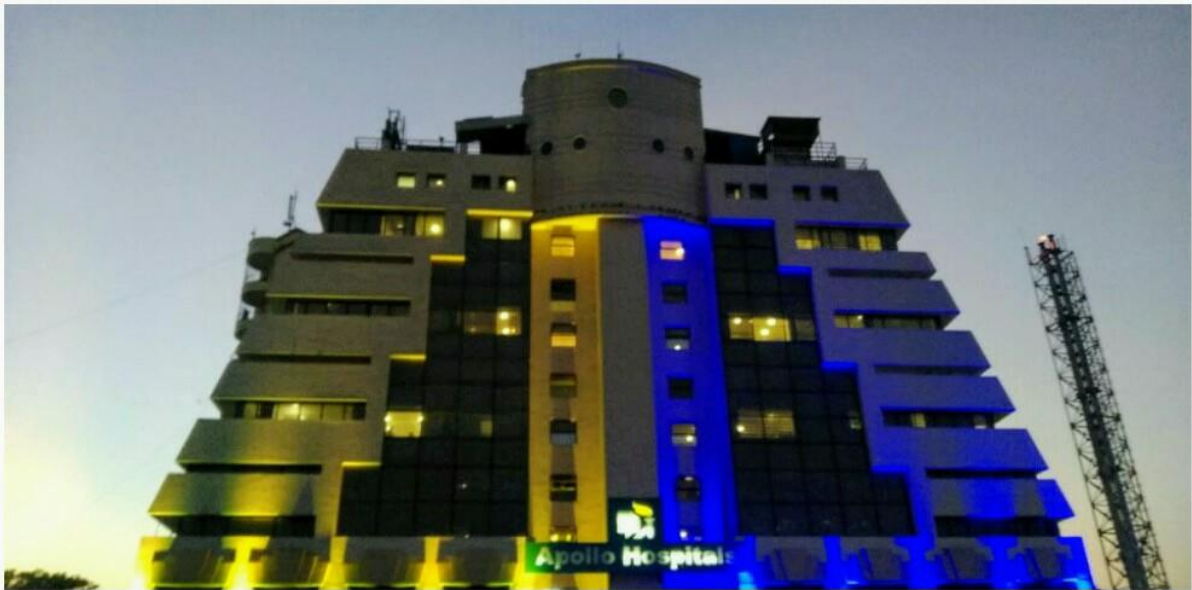
Medical and Health Camps



1st Course exclusively for Down syndrome at Bangalore, India

A historic first was achieved for India when The Down Syndrome Federation of India came up with the first course exclusively for Down syndrome in association with Information and Resources Centre at Bangalore, India. This course dealing with all issues pertaining to Down syndrome had parents, therapists, teachers, special educators and even had a doctor pursuing it.

The first batch of students had their viva on the 11th of January and passed out. The examination and viva was conducted by Dr. Surekha Ramachandran, President – Down Syndrome Federation of India. The next batch of students will be attending this 3 month course during the summer of 2020.



Lighting up of Buildings for WDSD 2019

JAPAN

Basic Information

- Total Population of Japan – 126 Million
- People with intellectual disability - 0.5 Million
- People with Down syndrome - 0.05 Million

Average Life Expectancy

- Women – 87.32 years
- Men – 81.1 years
- Persons with Down syndrome – Around 60 years

What has happened in Japan over the past year?

Expansion of choices in jobs and career for persons with Down syndrome

The choices of jobs for persons with Down syndrome has changed over the past few years. Instead of doing the regular jobs of packaging or body shop work, now people are choosing various other careers today. Japan now has people working in Baristas, a Monk, a weaver and even an MC who are breaking stereotypes.



Latest Updates

- We now find the need for treatment on conditions and diseases in adulthood
- Currently JDSS is seeing a lot of Medical research and programs to meet the needs became active. However there is more that needs to be done
- Japan Congress of Down Syndrome promote information exchange among medical professionals and third parties

JDS hosted Medical Committee of APDSF in Tokyo this year.



APDSF represented by President, Mr. N. Ramachandran, Chair-Medical Committee, Dr. Bhavani Sriram and Member Dr. Prakash Vemgal held productive discussions with JDSS Medical committee members

MONGOLIA

The 4th Asia-Pacific Community-Based Inclusive Development (CBID) Congress 2019 was held on 2-3 July, 2019 in Ulaanbaatar, Mongolia. The theme was **Sustainable Social Development and Economic Growth through Community-based Inclusive Development (CBID)**



General Agency for development of persons with disabilities

In December 2018, the General Agency for Development of Persons with Disabilities was established as an implementing Agency of the Government of Mongolia to ensure implementation of CRPD, Law on the Rights of Persons with Disabilities and relevant laws and resolutions



General Policy Advocacy on Inclusive Education

In April 2019, The Ministry of Education of Mongolia adopted an inclusive education rule.

The inclusive education rule aims to increase access to quality education service for children with special needs by strengthening **the inclusive education system at every regular school all over Mongolia.**



2019 Highlights by DSAM

- Registered Members of DSAM increased from 9 in 2008 to 513 in 2019
- 10 young adults with DS had special training to serve in Coffee Shop. Their mothers have been performed as job coaches. The project seeks a sponsorship



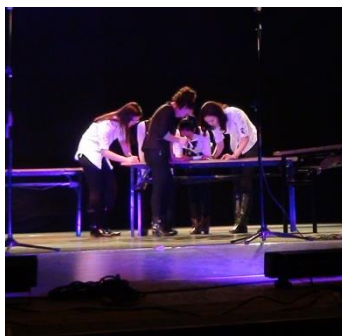
- Renovation of Early Intervention Center of DSAM for kids with Down Syndrome aged 0-6



- Inclusive class for 10 children with Down Syndrome at school #130 in Ulaanbaatar



- “Bus Stop” Australian inclusive film project in partnership with Arts Council of Mongolia. 8 adults with Down Syndrome have been trained to obtain filming skills and abilities from September 2018 to May 2019.



- On January 15, 2019. DSAM celebrated its 10th anniversary with over 350 members with Down Syndrome and partner organizations . It was a gathering of families who shared knowledge and new Information. The event was Sponsored by the Shangri-La Hotel Ulaanbaatar.



- Self-advocacy and Employment

By the year 2018 there was just one person employed (Ms Nomiun Ganbold, Shangri-La Hotel Ulaanbaatar). By December 2019 there are 10 adults employed by a business company (JCR Mongolia). Asian Fund Mongolia is hiring a young man with Down Syndrome in up coming January. All of them successfully completed a year-round vocational training at a coffee shop run by DSAM in Ulaanbaatar.





- Special Olympics and DSAM 2019



Successful participation in Special Olympics Summer Games in UAE in March, dozens of medals. DSAM now has a Joint MOU with the biggest TV station in Mongolia to promote Special Olympics and down Syndrome Association's activities.



MYANMAR

Myanmar Down Syndrome Association

Myanmar Down Syndrome Association has been in the forefront of creating space for persons with Down syndrome in Myanmar. The association helps members across various fields including Education and Sports. Below are a few activities that the Association organized over the last one year.

Educaton

MDSA organized the following for persons with Down syndrome in Myanmar:

- ❖ Workshops
- ❖ Awareness programme
- ❖ ECI pilot services
- ❖ Special need teachers' training courses
- ❖ Financial support





Workshops were organized in various places like Yangon and Mandalay.

Early Child Intervention Program



Special need teachers" training by MSEA

MSEA organized for a Teachers training program for persons with Special Needs. There were 5 batches for level 1 and 2 batches for level 2.



Financial support for Persons with Disability

Ministry of Education.(Department of Basic Education) has been supporting the disabled children since 2017-2018 academic years.

Health

Research activities have been carried out in association with MDSA.The results of these activities were presented in an event on the 2nd of November 2019.



Activities that were done to create awareness about Down syndrome across the country included sessions with parents and other caregivers.



The idea is to give a message that Persons with Down syndrome can live independently if given proper training.



Current issues



- Persons with Down syndrome are not being treated as per their age
- Limited number of government special need schools where not many of our children get proper intervention
 - There is a need for qualified private special needs schools
 - Our children have difficulties in accessing not only private special need schools but also at government special need schools
- Limited numbers of therapists in Myanmar
 - There needs to be more specially qualified people
- Financial support is not available for parents as well persons with Down syndrome



NEW ZEALAND

About the NZDSA

The NZDSA started in 1981 and the founding member established the organisation with the following three aims:

- To support the family with a person with Down syndrome.
- To support the person with Down syndrome.
- To bring public awareness to the issues surrounding Down syndrome.

The NZDSA remains a family/whānau-driven organisation:

- Informing and supporting families/whānau and people with Down syndrome.
- Promoting awareness of Down syndrome to create positive attitudes in the community.
- Advocating for the rights and inclusion of people with Down syndrome.
- Reviewing policies and lobbying government and other agencies.
- Providing resources to inform, educate and empower families/whānau, people with Down syndrome and professionals.
- Creating a leadership platform for people with Down syndrome.

VISION

People with Down syndrome are valued and equal members of their community, fulfilling their goals.

MISSION

To work alongside families, whānau and carers to support and empower people with Down syndrome to realise their potential and aspirations through all life stages and within all communities.

ESSENCE

Accept, understand and connect.

Report

The New Zealand Down Syndrome Association (NZDSA) is pleased to report that the 2018/2019 year has seen another year of solid provision of services to support, inform and advocate for the Down syndrome community in New Zealand. This has been achieved through core services such as the dissemination of information via our regular

E-news updates, our quarterly CHAT 21 journal, the website, and social media, our 0800 number, the development and provision of resources, and meetings with regional committees and volunteers.

Associated regional groups continue to provide one-to-one parent support, social and family events, and other activities that connect, educate and empower families.

World Down Syndrome Day celebrations remain a highlight in the NZDSA calendar with a range of events organised around the country.

We have continued to work to empower people with Down syndrome to reach their potential. This has been achieved through:

- the provision of self-advocacy workshops, including a workshop titled “Creating Awareness of Our Rights”
- a series of “Preparing for flatting” workshops run in collaboration with SuperGrans
- a youth development camp that focused on youth with additional needs in 2018 and a youth development camp for youth who are more independent
- social events to increase community participation and develop support networks
- the fostering of leadership skills through workshops that support the skills of the current STRIVE committee, as well as
- the development of skills for upcoming STRIVE members.

STRIVE is the NZDSA’s self-advocacy leadership committee that gives a voice to people with Down syndrome. STRIVE provides representation to the National governance committee, and assists with presentations at local events including workshops for Educators. One STRIVE member is a representative at the Ministry of Health Disability Consortium and in July 2018 a STRIVE member co-presented at the World Down Syndrome Congress in Glasgow.

The NZDSA has continued to advocate for people with Down syndrome and worked to create positive awareness in the community. We have visual resources that can be used to create awareness. We have provided representation at the Health Disability Consortium meetings and representation at Education for All meetings. We have completed a submission to Government regarding Education policies, and have continued to advocate with the National Screening Unit especially about the need for provision of value-based counselling for parents-to-be, provision of balanced information to prospective parents, and for improved health practitioner training especially on the valued lives of people with Down syndrome.

There has been ongoing collaboration with our networks over a range of disability issues and projects.

In August last year, we released a media statement in response to a popular soap programme, 'Shortland Street' which included a story line around antenatal screening. We were extremely concerned about the negative portrayal of the lives of people with Down syndrome, the negative, discriminatory and offensive language used on the programme, and the immediate suggestion by a doctor on the programme that abortion was a solution. This resulted in our President, Kim Porthouse, being asked to do a number of radio interviews on the subject. Kim and a number of STRIVE members were interviewed for a segment on NZ TV3 news. We also formally wrote to TVNZ to express our concerns and a number of people from our community wrote letters of complaint to the Broadcasting Standards Authority.

We have also been contacted by other media at other times to provide information and comment for articles on screening issues.

In addition, with numerous changes in the disability sector, the NZDSA has actively engaged in systemic advocacy to address discrimination and to maximise on

opportunities to ensure that our members' needs are considered and that the rights of people with Down syndrome are upheld. Disability System Transformation in the MidCentral region has seen the NZDSA proactively advocating on various platforms as well as providing education to our members in this region so that they are empowered to engage in the system transformation prototype, Mana Whaikaha.

The NZDSA has also developed additional resources to support our current New Parent Pack. The additional resources are

- ❑ *Little One* booklet, written by parents, which is an inspirational booklet that also aims to answer initial questions parents might have about their precious baby.
- ❑ We have also created digital stories with families sharing their stories. You can access these on YouTube
 - Congratulations: <https://youtu.be/h2KO2zLYVn0>
 - Couch Conversations with Parents:
<https://www.youtube.com/playlist?list=PLQV3ZA7wKm69dPS69-YmmovuYfpz7V-TI>

The NZDSA receives no government funding and therefore has to invest time to secure funding through grant funding, fundraising and donations to carry out all our services and activities. This year a few key fundraising events included Ride for the Kids and the NZDSA Ball. Not only did the events generate funds but were also an opportunity to raise awareness of the organisation and allowed our members to connect and engage in a celebratory event.

The NZDSA has been established for educational and charitable purposes within New Zealand, in particular:

- ❑ To provide new parent support.
- ❑ To promote the welfare of people with Down syndrome and their families/whānau.
- ❑ To provide up-to-date information that is accessible to families/whānau, particularly new parents and other interested parties.
- ❑ To provide regional support groups throughout New Zealand.
- ❑ To publish CHAT21, our quarterly journal.
- ❑ To produce resources and information.



- ☐ To host a website: www.nzdsa.org.nz
- ☐ To offer support- freephone number 0800 NZDSAI 0800 693 724
- ☐ To provide information to medical practitioners, students, educators and community organisations in order to enhance their interactions with people with Down syndrome
- ☐ To provide ongoing links with and among families
- ☐ To establish and maintain relationships with other disability organisations
- ☐ To respond to political and social issues by making submissions to government bodies
- ☐ To initiate and manage projects that will have a direct benefit to people with Down syndrome and their families
- ☐ To maintain links with international Down Syndrome Associations to ensure a flow of current knowledge and information

Working together to enhance the inclusion of people with Down syndrome within the community

SRI LANKA

Sri Lanka has a population of 21.44 million (2019), and 1.6 million are reported as disabled. There are no statistics available on the number of persons with Down Syndrome (DS). This is recognized as a barrier in delivering a national-level service to persons with Down syndrome. In Sri Lanka, children with DS are accurately diagnosed at birth. However, the support and follow up systems available for persons with DS are not adequate in the country. Furthermore, the services such as allied health services and education are confined to urban areas. This limits their capacity to reach their fullest potential in life. It is observed that most parents of children with DS in Sri Lanka carry a negative attitude towards their children.

Changing their attitudes and behavior remains a challenge. Further, most parents are still reluctant to accept that their children must live with the condition of DS.

Jinendhi Resource Centre for Down syndrome (JRCDS) is the only organization that works exclusively for persons with Down syndrome in Sri Lanka, despite there are many organizations working for persons with intellectual disabilities. Our vision and mission are to introduce and implement a national level programme with the purpose of educating and improving the skills and capacities of persons with DS. This would enable them to contribute to the society. The approach we follow is to create a caring society for persons with DS in collaboration with the government, schools and civil society organizations as well as the private sector.

The Open University of Sri Lanka offers degrees in Special Education and short courses for teachers and parents of children with special needs. Diploma in special Education at National Institute of Education promotes inclusive education in mainstream classrooms and workshops on safeguarding children with speech and language disabilities. At present, 130 special education units in the Western Province, 116 units in the North Province and 105 units in the Southern Province are established in Sri Lanka with many unreported special education units in other provinces serving children and adults with special needs. However, there isn't a national-level coordination between these different institutes.

Last year as the first step, JRCDS has initiated discussions with the Ministry of Public Administration, Department of Education, and The National Youth Council on implementing a programme to reach the persons with DS Island-wide, starting from the Kandy district. But this was failed due to lack of manpower and funds for transport. However, we have commenced to establish many Down Syndrome associations in the country. The goal is to establish 100 fully functional Down Syndrome clubs or associations by mid-2021. This is the best strategy to form a national organization to serve the DS

community in Sri Lanka, with an efficient network throughout the country. Already 3 associations have been established.

PROGRESS IN 2019.

1. COUNSELLING

Our website (www.geyef.org) has reached to many people in Sri Lanka and *psychological counseling* is one of the services we provide through “*Jinendhi Center for Psychological Services*”. The team consist of qualified and experienced team of professionals. All discussions are kept confidential.

During 2019, apart from regular counselling sessions, we received 17 calls from families having a new born DS child. They were unable to handle the situation and requested us to take the child for adaption or inquired for recommendations on a place to handover the child. Most of them were ready to offer a good donation to us as well. Miss. Chami Basnayaka, a volunteer for JRCDS carried out counseling sessions with this group. I had to intervene in a couple of cases over the phone and personally visited their residences. We managed to change their mind.

These 17 families have now accepted the child. We consider it as a valuable service and an achievement of JRCDS.

2. DEEP DOWN ART PROJECT

This is an event organized by the European Down Syndrome Association, providing a platform for children with DS to show their vision of the world. We Informed all the known NGOs in Sri Lanka and disseminated information to families having children with DS to respond and participate. We submitted an art work of Jinendhi, which got accepted and she was recognized.

3. SURVEY

We implemented many strategies to get an accurate estimation of the total number of DS children living in the country. The government social service department have statistics of disable children but, do not specifically recognize DS children. We made several requests in- writing and through personal visits to the offices - but not enough man power and resources to identify or segregate the data and identify DS children. It's a difficult task, which we are planning to complete in the future and apply for funds from donor organizations.

As mentioned earlier, we decided to form DS Associations or Clubs throughout the country and associate with local religious institutes. The minimum number of DS children should be five, to form a club/association.

Project plan in brief:

1. DSA or clubs - village No 1.

The local Buddhist temple used as the center. Director Board consists of 7, as follows: "Grama Seva Niladhari" or midwife of the area, 2 parents of children with Down Syndrome, any 2 interested persons or teachers, a priest as the adviser for the team, and one of our directors or field officers of JRCDS.

Once we formed 100 DSA or clubs, we can form the DSF Sri Lanka or JRCDS Sri Lanka. We must find money for each club for initial registration and other expenses. Expected amount per club is Rs. 10000.00, which we must request from a donor organization.

Already 3 DSA's have been formed: Anuradhapura, Batticaloa and Kandy. We funded these associations through our own funds to get established. After 3 years of struggle, we have figured out the best approach to form a DSA. With many more clubs/associations established throughout the country, we will be able to get the more DS people signed-up for our programmes.



4. DOWN SYNDROME AWARENESS MONTH.

Three successful awareness programmes were implemented in Anuradhapura district.



5. LIVELIHOODS SUPPORT GRANT PROJECT — SELF HELP LOAN SCHEME

It started with the simple idea that the underprivileged families having a DS child can improve their Socioeconomic condition if they are provided with financial resources to start a business or to improve the existing small-scale self-employed business. This is an indirect way of helping a DS child. When we visited the DSC families, we found that they are already involved in small- scale businesses. Already one loan was given to a family.

6. WORLD DOWN SYNDROME DAY CELEBRATION

We organized a successful medical camp with the University Rotaract club, at Thurstan College Colombo. More than 100 DS children participated. Art exhibition was also organized to send the arts to Deep down Art exhibition in Mexico.



7. ART THERAPY PROGRAMME FOR CHILDREN AND ADULTS WITH DOWN SYNDROME, COUPLED WITH A COUNSELLING PROGRAMME FOR PARENTS

In parallel to the preparation for the deep-down art project, an art therapy session was conducted, coupled with a counseling program.



8. MEDICAL HANDBOOK FOR DSC

A medical handbook was designed, printed and distributed at JRCDS-organized medical camps and mailed to many organizations for distribution.



9. PROFESSIONALS TO SERVE

This is a unique, sustainable programme. As usual, we managed to motivate 3 girls and one boy from Sri Lanka to pursue a Bachelor's degree in Audiology, Speech Language Pathology. One student is from MASLP, Maldives. Further, we had two Physiotherapy undergraduates.

10. MEDICAL SCREENING

Dr. Dayarathna of JRCDS conducted free medical examinations for DS children At Matale (20 children) and Anuradhapura Hospitals (18 children) in Sri Lanka. JRCDS announced this programme by displaying a poster in the hospital. Dr Dayarathna with his colleague did the examinations and a medical record book was given to each family.

11. HAND BOOK ON DOWN SYNDROME IN LOCAL LANGUAGE

We have completed a book written in the local language, Sinhalese, containing vital information on Down Syndrome. This is still under review – Mrs. Sunethra Galgamuwa of JRCDS, who is a retired Biology teacher authored the book.

12. INCLUSION FOR CHILDREN WITH DOWN SYNDROME IN PRESCHOOL LED BY MUNICIPAL COUNCIL IN KANDY DISTRICT

It is vital for children with Down Syndrome to start their education at early stage with a trained teacher with necessary facilities in a conducive environment. This project will establish and strengthen the enabling conditions for developing cognitive communication and interpretation skills of children with Down syndrome to reach their fullest potential in 25 pre-schools in Kandy district. This project includes teacher capacity building, creating a child friendly environment in preschools and raising awareness of parents. We spent around two months to develop this project: visiting pre-schools and interacting with teachers, parents and officials. Project proposal was submitted to USAID-Sarvodaya small grand project fund, which is currently under review.

To date, we have 102 registered DS children with our organization. But, 99 % of them are from underprivileged families in rural areas of the country. We cannot use them to raise funds as we believe it's inhuman to show them in public to request for donations. This is a policy of our organization. As such, we need to find money to uplift the standard of their families and provide medical and other services such as the speech therapy and psychological counseling services.

GOVERNMENT INTERVENTION:

In addition, we have contributed to the following causes during the last years.

1. Salary increments for teachers in special education units – this would motivate qualified teachers to join the profession
2. Last year more money was allocated by the department of education to the special education unit
3. Open university of Sri Lanka conducting a Diploma course in Special education
4. National institute of education introduced a certificate and diploma course on special needs education
5. Department of social services have 414 children homes. But not exclusive for DSC
6. In general, government is giving Sri Lankan Rs. 5000 for every disabled child, but not exclusively for DS. However, DS children of under-privileged families will get this money from the government

THAILAND

The subject of Down syndrome in Thailand can be summarily looked at from 3 different views, namely:

(I) State Action;

(II) Efforts from Civil Society

(III) Challenges and Ambivalent Outcomes

(I) State Action;

- A good timeframe to appreciate the progress is in the period between 1997-2017
- Following the 1997 constitution, two legislations are directly beneficial to people with DS, namely, (a) the Education Act 1999 and (b) the Employment Act for the Disabled 2007

THE EDUCATION ACT 1999

- The Act aims at the integrated education policy
- Children with DS are eligible to enroll in the mainstream school, not just in the 'special schools'
- This gives profound opportunities for them to physical as well as intellectual development
- It has also impacted on the 'visibility' and the rights of people with DS
- The social recognition, as we are all well aware, is a fundamental condition for the development of people with DS

THE EMPLOYMENT ACT FOR THE DISABLED 2007

- Officially coined as "the Act of Enhancement and Development of Quality of Life of the Disabled".
- It is also very impressive, if not more so than (A).



- In three articles (No. 33-35 the details of which can be discussed on the floor), the government and the employers (of a sizable size) are to provide employment opportunities and funding to individuals with disabilities and to the organizations involved
- These measures are coalesced with a number of operating mechanisms, e.g., commercial and criminal penalty, tax reduction, social sanction and approval, etc

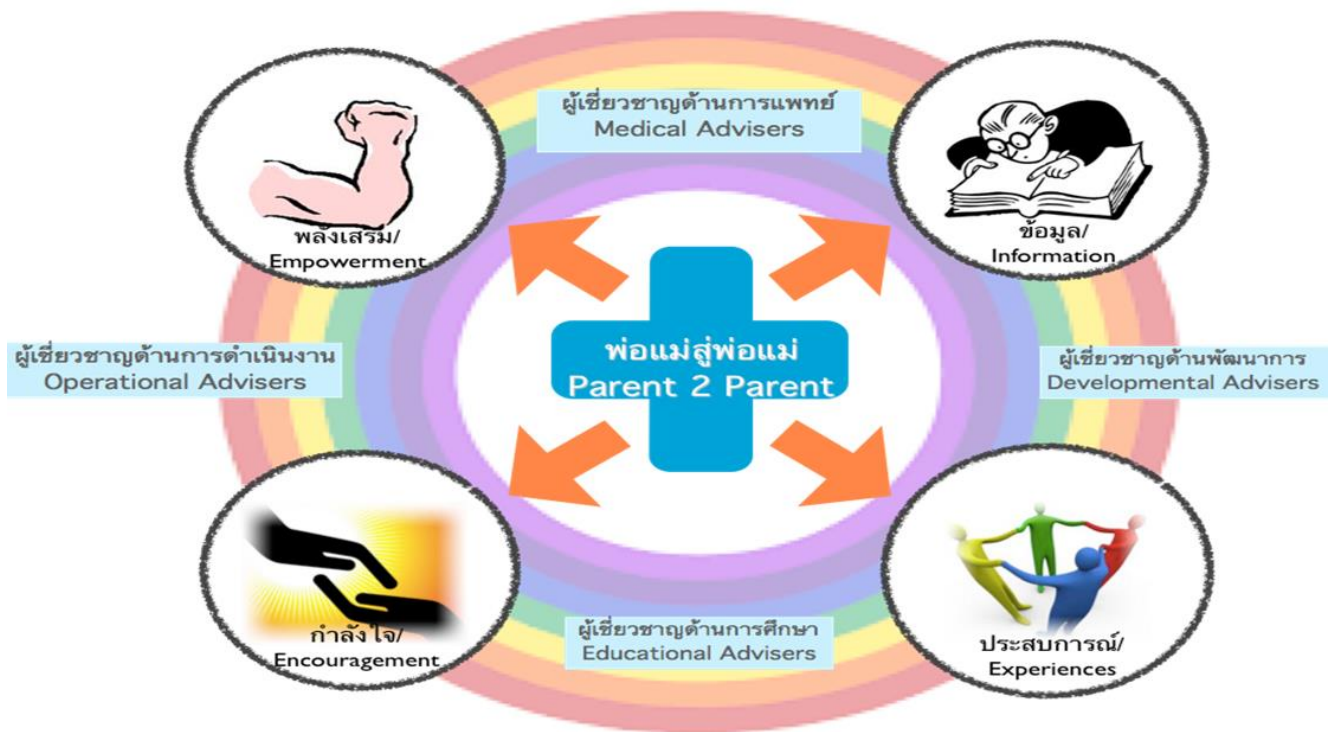
E.g:

A foundation in Chiang Mai (The Healing Family Foundation) has received some substantial financial support from a mega department chain store in succession for the last two years. A DS person receives \$ 3,713 per annum, and the total 10 qualified persons are beneficiaries of the scheme this year.





The Rainbow Room Foundation which is a special needs centre has a model that integrates all stakeholders



(II) EFFORTS FROM CIVIL SOCIETY

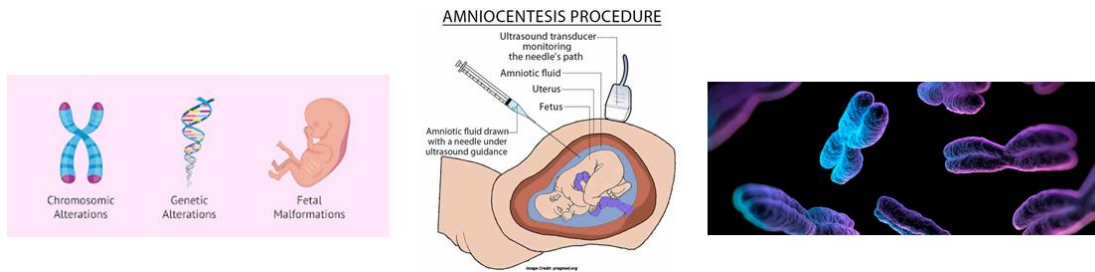
- Though these laws are a cause of pride for us, a note of precaution is also necessary
- They are the legal infrastructure from which the civil society is to work on
- Up until now the concrete and effectual outcomes vary in time and space
- Many other organizations, for various reasons, are not yet in a position to benefit from the laws
- Moreover, countless disabled persons are not organized to take collective efforts
- The laws remain 'dead words' for the majority of people with DS



(III) AMBIVALENT OUTCOMES

- As the causes of DS have become a public knowledge, the Amniocentesis test has increasingly become a common practice
- Contrary to our wish and opposition, the practice has now been included to the list of healthcare rights, and entitled to medical low-cost service

- What is overlooked is the right to existence of DS foetus, and the risks of the practices



To summarize

- Our success in the state realm, therefore, needs to be coupled with the strength of people with disabilities (and their guardians, in the case of people with DS)
- In this respect, admittedly and unapologetically, we see it not as a success on our part
- There are some notable individuals working for the cause of people with DS, but they are few in number
- This is a challenge along with other numerous problems we have been facing in Thailand