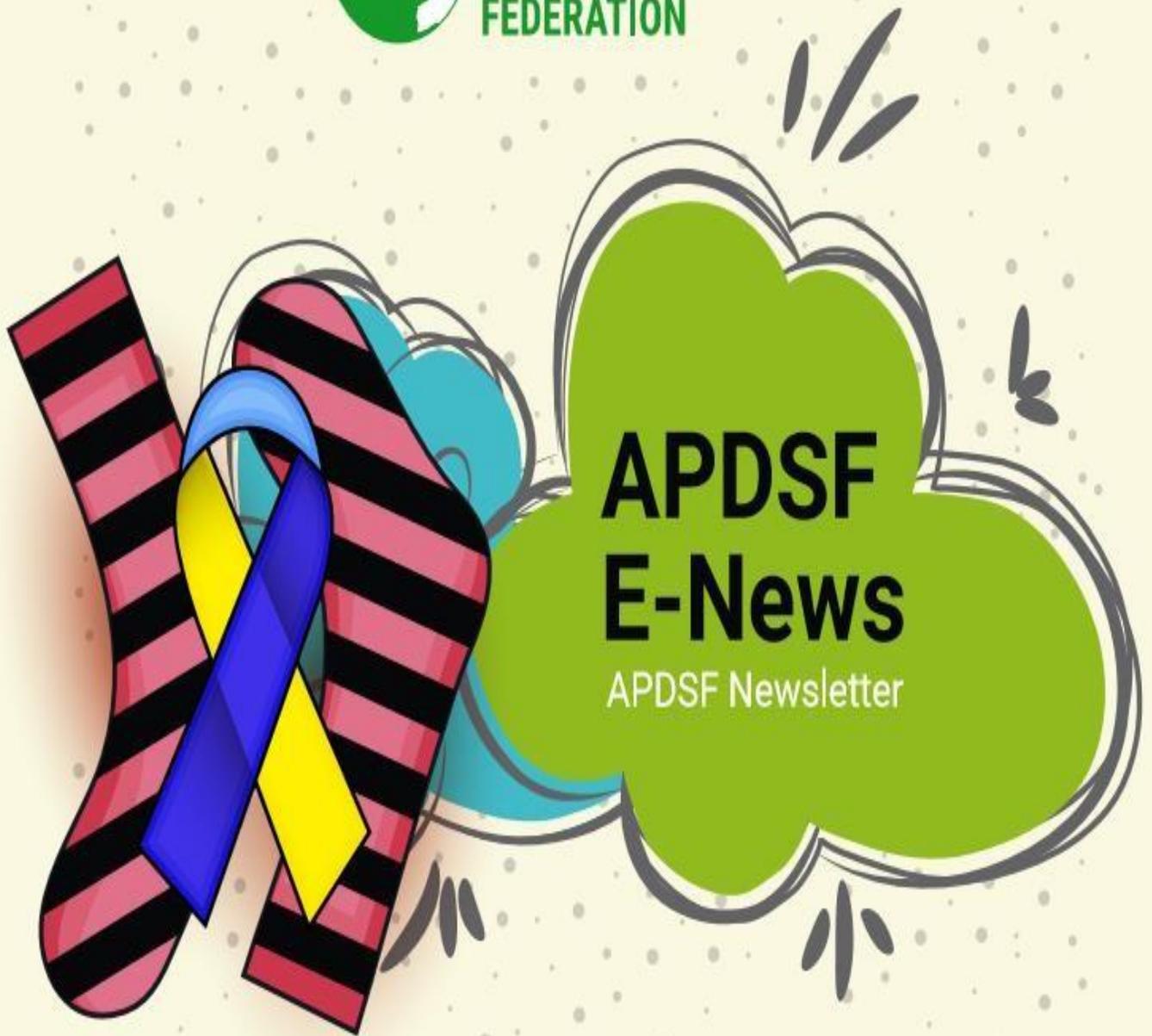




ASIA PACIFIC  
DOWN SYNDROME  
FEDERATION



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*July 2020*



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## PRESIDENT SPEAK



Namaskar!

After the Corona outbreak the world has started believing in this Asian way of greeting one another. In the previous newsletter, I had expressed hope for better times to send out our next newsletter. But the situation is yet to come fully under control as we see.

However, we can still connect, still celebrate people with Down syndrome and their families. This edition is a testimony to parents and their resilience and the support they have received from their dear ones with Down syndrome. This edition is sure to encourage us to look at the positive side of things however dull a situation might seem.

We thank all the countries who have taken the time out to send us their articles and do hope that the next edition of the newsletter has more participation.

Please stay safe and keep your families safe.

N. Ramachandran  
President - APDSF

# India

## COVID-19 Cannot Dampen the Spirit

When the coronavirus outbreak happened, no one thought that it would reach the Pandemic proportions that it has reached today. The world went on lockdown. India was no different.

The biggest issue in any place during a lockdown is how to keep the children under check. During lockdown, it was expected that everyone including adults and children were supposed to stay indoors and not expose oneself to the deadly virus. Persons with Down syndrome being one of the most vulnerable of the lot were expected to stay indoors. No meetings were allowed and a crowd gathering was deemed illegal.

Under these circumstances the World Down Syndrome Day 2020 which was planned on a grand scale was not celebrated as expected. However, the children and parents made sure that their special day was celebrated.

### What did parents do during the lockdown?

DSFI conducted a survey which proved that the lockdown was a time that helped the families come closer. We had 218 respondents for the survey. A partial result of the survey is given below:

<b>How close are all the family members?</b>	Close - 42, neutral - 13, not close-4, Very close -158
<b>Who is the closest to the person with Down syndrome</b>	43 of the 218 are close with all family members.
<b>What is your family's usual response to your child with with Down syndrome</b>	Do not like - 1, Ignore - 1, Love - 196, Neutral - 10, Like-9
<b>Has the lockdown brought your family closer?</b>	Yes - 169, No - 12, Maybe - 36
<b>How much time do you spend with your gadgets? i.e - laptop, smartphone, gaming, tablets etc</b>	2-4 hrs - 88, 4-6 Hrs - 25, <2 hours - 83, >6 hrs - 21
<b>How much time do you spend with your family?</b>	2-4 hrs - 31, 4-6 Hrs - 49, <2 hours - 6, >6 hrs - 131
<b>Were you satisfied with the routine you had before lock-down? (To understand on how a time like this brings a change in perspectives)</b>	Yes - 113, No - 48, Maybe - 56
<b>Tick options where there are changes in habits since lockdown?</b>	Maximum change was seen in time spent with family with 167 members seeing a change closely followed by House work where 154 people found a change in habits. 22 people found a change from all their previous habits.
<b>Does your partner help you with household chores?</b>	No - 16, Sometimes - 56 Yes - 142; Blanks - 4

<b>Were they helping you before the lockdown</b>	No - 57, Sometimes - 66 Yes - 100; Blanks - 5
<b>How did you keep your children occupied?</b>	Games, Creative Activities and Household work kept the kids busy at home during the lockdown.
<b>What were the activities you undertook for your children based on the previous question?</b>	
<b>Were you at a loss of ideas for keeping children engaged?</b>	No - 98, Sometimes -92 Yes - 28; Blanks - 1
<b>Were you and your partner in agreement on the the daily routine?</b>	No - 63, Sometimes -53 Yes - 99; Blanks - 1
<b>Did you feel at any point lonely or in a stressful situation?</b>	No -77 , Often -19 , Rarely -64 , Yes-55
<b>How is the mood of your entire family during the lockdown?</b>	As usual - 80, Bored -28, Happy -96 , Snappy -1 , Unhappy - 10
<b>Have you been in touch with other group members?</b>	No - 47, Yes -168
<b>What were the primary points of discussion?</b>	
<b>Were the discussions positive?</b>	No - 1, Sometimes -57, Yes -159 ; Blanks - 1
<b>Tick on the options if any of these problems have increased during lockdown.</b>	
<b>What are the positive and constructive things you are indulging in to deal with the present situation?</b>	Spending time with the Family was one of the most positive things that happened during the lockdown with almost 186 respondents, which is almost 86% of the total respondents. About 35% of the respondents felt that Me Time was the positive thing that happened during the lockdown.

### **How the Children were kept occupied?**

1. Games – Children were taught new games and were made to involve all family members. Games were sourced from websites, experience and DSFI also provided them with some fun activities which they could do from the confines of their homes.
2. Activities – There were a lot of activities which parents provided for their children. This included Arts and crafts from materials at home, coloring, painting, writing, reading, studying using various devices including Flash cards and craft work. Parents also ensured that the children had a healthy mix of study and fun so that they do not get bored
3. Home-Work – Children and adults with Down syndrome were made a part of the various household chores. This included cleaning and cooking where children were given responsibilities. This again was done with the whole family. This family time not only helped persons with Down syndrome understand what it was like to do work at home, but also helped in their motor skills.

DSFI also made it a point to provide tips on a daily basis through one month of the lockdown. Tips were both social and medical in nature. Simple cures, activities for the children and adults with Down syndrome and competition. All of this helped build a bond within the family, which probably would not have happened during regular times.

A song and dance video was recorded with children from all parts of the country to the same music. Due to



the lockdown we could not get all the kids together. Instead, the kids were made to dance and send their videos via WhatsApp which they happily did. You can enjoy this using this link <https://www.youtube.com/watch?v=RKofDv79LJc>



IIDSC (India International Down Syndrome Conference) 2020 was planned to be organized at Raipur, Chhattisgarh from the 28<sup>th</sup> to 30<sup>th</sup> May 2020. However, due to COVID-19, it had to be rescheduled. However, the Federation not wanting to disappoint parents and children organized a webinar in which experts in the field of pediatrics, physiotherapy, psychiatry, nutrition and yoga provided valuable inputs. This was held on the 28<sup>th</sup> of May 2020. Over 200 parents participated and benefitted from the views of these experts. Dr. S. Suresh, the Chair of the Scientific Committee of DSFI moderated the meeting.

Parents are keen on learning new things and DSFI is providing a platform. Webinars are being organized on various topics that are important for parents. Starting with Immunity, ENT issues, Pubertal issues, there are a lot of webinars on the pipeline where parents can ask the expert their doubts which are clarified immediately.



Dr Surekha Ramachandran - Learning to De-stress (Hindi)



Puberty and Related issues Dr Nina Vaidya



Immunity DS Dr Shaïmi Gupta



Sleep Apnea Dr Mohan Kameswaran

Parents have been a source of strength and support during these times. They have proved once again that nothing, not even a deadly virus can dampen their enthusiasm and spirit.

# Australia

People with Down syndrome and intellectual disability in Australia have gone through a lot of changes since the coronavirus pandemic outbreak. Down Syndrome Australia has been at the forefront of providing up-to-date information about COVID-19 to them and their families. We developed an extensive resource page and have provided regular updates, including information in Easy Read. You can access these resources here: <https://www.downsyndrome.org.au/resources/coronavirus-information/>

With our borders closing and people from all states and territories needing to physically distance for several months, our member organisations have moved many of their programs and interactions online with Zoom meetings. This has helped to keep people with Down syndrome connected throughout this tough time when everyone has needed a bit of extra support to navigate our new way of life.

People with Down syndrome and their families in Australia have come up with some really creative ways to keep connected to their communities and their mental health in check. Coffee catch-ups, dance parties and workshops have been happening across the country, all online from the comfort of everyone's home.

One family from regional Victoria thought outside the box to keep their brother Jon connected to his community by encouraging people in town to become pen pals with him and send him letters. Since March he has received hundreds of letters and parcels, not only from his hometown, but from all over the world. Their story will be featured in the August edition of [Voice magazine](#).

You can subscribe for free to receive a copy here: <https://www.downsyndrome.org.au/get-involved/subscribe-to-voice-and-newsletters/>





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Down Syndrome Australia has been working very closely with the Australian Government during this time to advocate for people with Down syndrome and make sure health care is not being limited to people with disability based on quality of life judgements. We have made sure the health care system continues to treat with disability equally and encourage decision makers to be making ethical decisions.

# Bangladesh

## COVID-19 RESPONSE

### Activity Report

**Down Syndrome Society of Bangladesh** is a platform for children born with Down syndrome and their parents. The sole purpose of this platform is to inspire children born with Down syndrome by enabling them to help change the world and assist them in special needs advocacy, education, employment and social inclusion.

It is important to note here that Down Syndrome Society of Bangladesh has been working in collaboration with government and NGOs for long time to ensure basic education, health care services, equality and rights, social inclusion for people with Neuro-Developmental Disability (NDD) specially person with Down syndrome throughout the country.

### Impact of COVID-19:

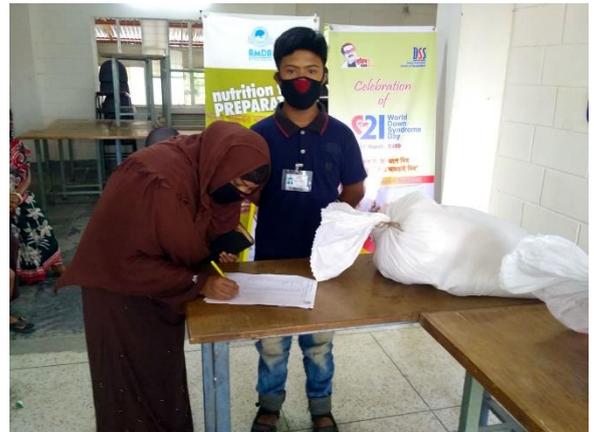
COVID-19 has spread all over the world including Bangladesh in recent times. The pandemic is affecting all the aspects of our lives. Especially the working class people are living in a very miserable situation due to current COVID-19. As an initial impact of the ongoing lock-down and general holidays declared by the government, the day labourer, poor and distressed people are suffering from lack and shortage of basic food stuff and other daily necessary items to lead their life smoothly. In these emergency situations, it has become an urgent demand to provide necessary food items for these poor, marginalized children and people with NDD, Down syndrome and other forms of disability.

### Emergency Relief Operation

The main objective of the relief mission is to provide food and financial support for the disabled family members, day labourer, poor men and women who going through a very hard time due to lack of food and money during COVID-19 in the country.

The emergency relief operation has started in the month of April and it will be continued until the situation becomes normal and better.

As a response to this catastrophe, a nine-member response committee has been formed to ensure proper and successful relief operation in the targeted areas among the target beneficiaries. The team has already started



its operation and up to 20<sup>th</sup> June, 250 families have been supported with basic food items and financial support in different locations.

Under the relief operation, following food items have been provided to per family with some necessary groceries for Ramadan:

SL No	Item	Quantity
1.	Rice	11 Kilo
2.	Dal	2 Kilo
3.	Potatoo	3 Kilo
4.	Oil	2 litre
5.	Red flour	2 Kilo
6.	Chira	500 gram
7.	Salt	1 kilo
8.	Chola boot	1 kilo
9.	doubli	1 kilo
10.	Muri	1 Kilo
11.	Soap	1 Piece



### Awareness Raising Campaign on COVID-19:

An awareness raising campaign is also running create awareness on COVID-19 among children people with Down syndrome. Through online platform awareness is raising to every child for protection from COVID-19. Awareness raising has been already uploaded from Junior self-advocate and self-advocates of the DSSB.

<https://youtu.be/wuhC7NzJgZO>

In order to promote inclusion, it is demanding support emotional and mental health through involving people with Down syndrome in virtual discussion, education, sharing family's lifestyle with each other during home stay. Here, parents are involved to make video clips of their children/adults with their daily routine activities to keep them busy which is a big amusement for people with Down syndrome.



to  
and  
videos  
to  
group

FIGHT COVID-19...

Awareness among our children with Down Syndrome!!

<https://web.facebook.com/DSSocietyBangladesh/videos/240675346997090/>

FIGHT COVID-19...

Awareness among our self advocates!!

<https://web.facebook.com/DSSocietyBangladesh/videos/234091984358869/>

FIGHT COVID-19...

Awareness among our children!!

<https://web.facebook.com/DSSocietyBangladesh/videos/2339340089693811/>

FIGHT COVID-19...

Awareness among our Self Advocate!!

Stay at Home...Stay Safe...Cheers!!

<https://web.facebook.com/DSSocietyBangladesh/videos/161530918547602/>

**Challenges/ Limitations of the Relief Operation:** We are having a shortage of necessary items/supplies though there is a huge demand among the community for food supports. Besides, shortage of PPE and lock-down situation is a major challenge on our part to make the operation successful. Upon receiving grants/supports from all corner of the society, we would be able to reach many more in the days to come. Let us join and collaborate together to assist the vulnerable community who are in danger due to the epidemic.



### **An appeal from-Down Syndrome Society of Bangladesh:**

In response to COVID-19, DSSB has already started Emergency relief operation for the marginalized families targeting **1000 families**. In the meantime we have reached out to about **250 families** with food stuff and cash support. We have already raised an appeal to generate support. Please find the enclosed video clip herewith for your reference

<https://www.youtube.com/watch?v=E656ahE8Vvk>



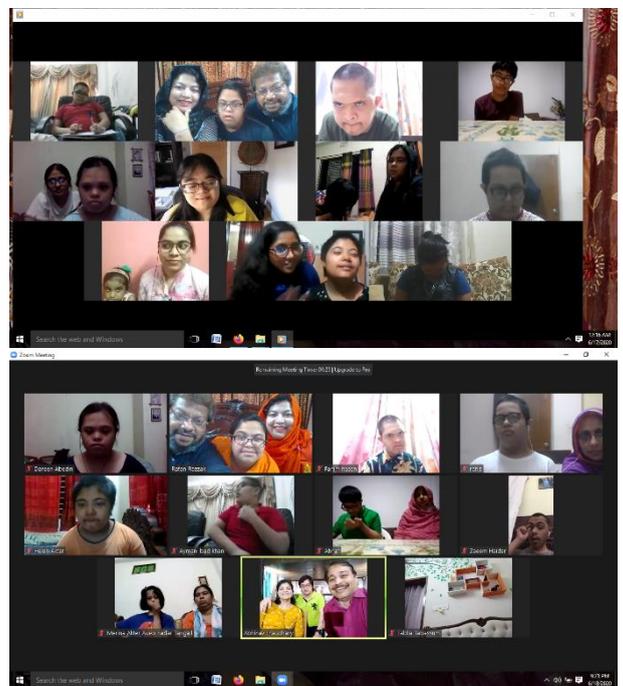
### **DSSB Online Day to Day Session:**

The Society has already conducted Seventeen (17) online sessions since the beginning of April 2020. Many promising children and adults with Down syndrome have also connected from other countries like India, Pakistan, Dubai, Australia in these online sessions. The instructors and the learners are happy to get connected with each other and share their day-to-day experiences and learning in the online sessions conducted. The online sessions have now become a global platform for children and adults with Down syndrome living in various corners of the world.

<https://www.youtube.com/watch?v=A9qk-wUqjT0>

Amazing online interactive session with children and adult with Down syndrome. All the students have actively participated in these sessions. These sessions cover physical exercises and education.

[https://www.youtube.com/watch?v=kF\\_ntT1DjxQ](https://www.youtube.com/watch?v=kF_ntT1DjxQ)



### **ADD-DSSB ONLINE TRAINING:**

ADD Bangladesh has organized an "Online Training on Disability Context & Rights of Employment for Person



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with disabilities" with DSSB under Inclusion Work project which was held on 10th June at 4:00 PM. The executive members of DSSB have been actively participated in this training program. This training program will have another session soon. [https://www.youtube.com/watch?v=Pqe7Mv\\_qXIQ](https://www.youtube.com/watch?v=Pqe7Mv_qXIQ)



# China

During Chinese New Year, the sudden COVID-19 disrupted lives and work of many people around the world. It is not only the country, government, frontline doctors, nurses, and patients who are fighting the disease, but also our ordinary people. Recently we interviewed several Down's families to get a close look to know their ordinary life during this tough period.

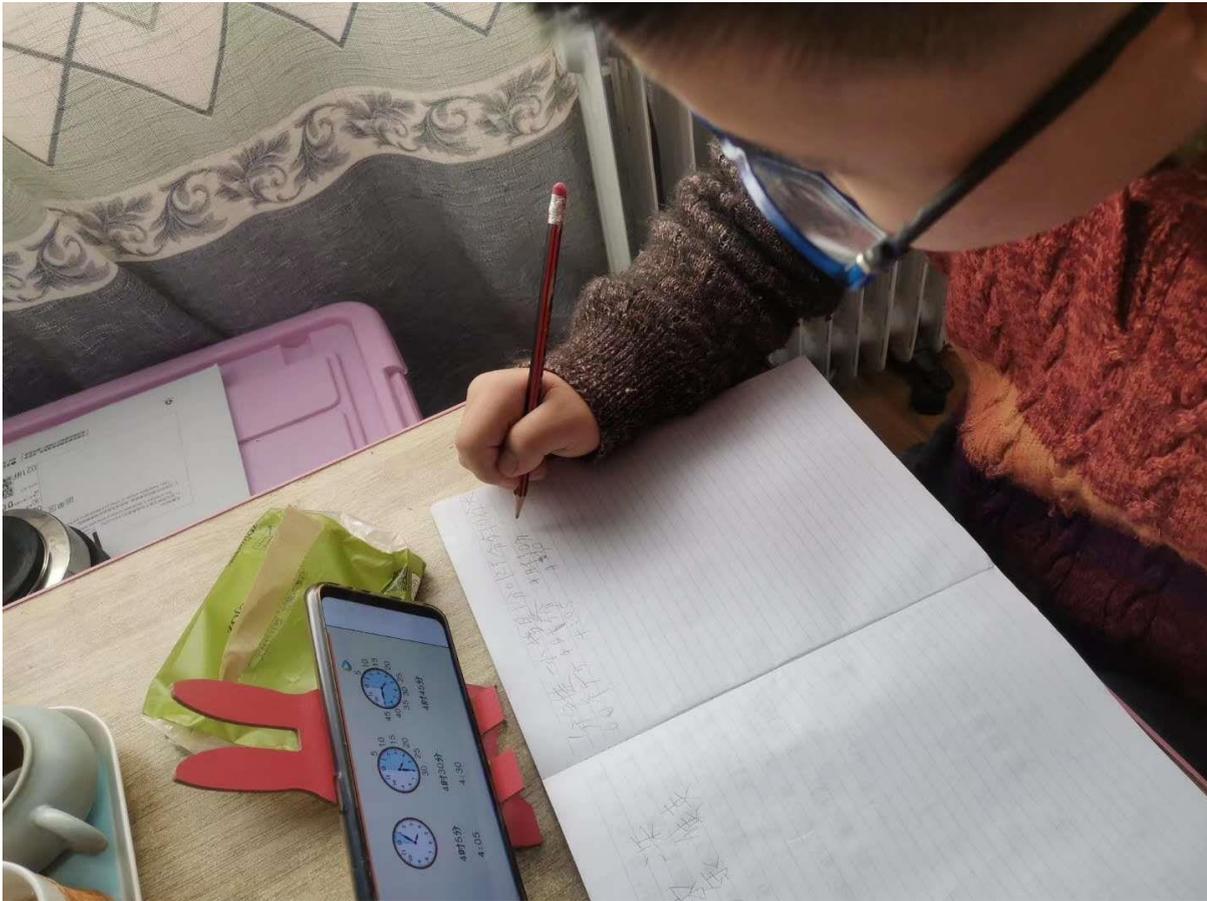
**First of all, when affected by the sudden COVID-19, we need to reformulate a reasonable life plan and study plan.**

The COVID-19 disrupts the normal life of Down's families. Parents are more likely to be anxiety than the children, they worry about the children' safety, health, study , etc. But look at these children, they feel very happy cause they do not need to go to school. HAHHA~

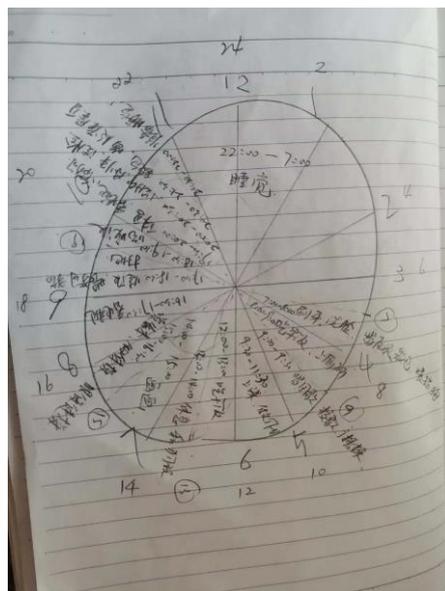
So how can our parents help children manage their own time at home? Each child's living habits is different, parents need develop a reasonable time calendar according to their own children. For example, Ms. Ge (Can's mother): Draw a timetable and paste it at home, and synchronize with an app to help her remind the time to get up, have breakfast, and study every day.

When starting to make a time plan, parents and children are best to participate together. Every member makes their own timetable and follow them. With the parents' persistence and continuous reminders, the child's habit will gradually develop. Ms. Ge's feedback from her son (Can): In general, a new small habit will take about one week to grow, and it is easier to accept later.





The following clock is drawn by Ying Yue and his mother. It's his daily schedule. In the morning, online lessons, homework, and at noon, he can help mom cook or arrange himself, and in the afternoon, games, sports, etc. Ying Yue's mother said: every afternoon at 3 pm, my grandfather took him to the garden downstairs for one hour and being with nature.



**The second point, parents need to teach safety protection measures and education of the COVID-19.**

For example, according to the age of the child, use TV, pictures, performances, etc. to help the child understand the virus.

At the beginning, Ying Yue said: 'I can kill the virus'. His mother replied: 'The virus is invisible and we can't touch it. We need to be careful at all times'. Therefore, we need to teach children the necessary of safety protection, such as: taking temperature every day, wearing masks when going out, changing clothes, disinfecting, and washing hands after returning home.

Ying Yue's mother said that when took the bus, Ying Yue would take off his mask. The reason why he liked taking off his mask was their ears were soft and widened, and it was not easy for them to fix the mask.

The following is how she used small objects at home to help Ying Yue Fix the mask.。



**Tips:**

During the COVID-19 tough period, these important prevention habits are not easy to grow. Parents need to do them together and help them easily developed.



**Third, stay positive and optimistic, because the mindset of the parents will affect the children.**

Parents' excessive anxiety will affect their children's mental health. Some parents' work is affected by the COVID-19. If you bring pressure and anxiety into the family, the child will definitely feel your mentality. You can use the first point of time management to overcome your anxiety and insist on developing good work and life habits.

Parents need to pay attention to the COVID-19 prevention measures, maintain a stable mood, give children a positive and optimistic attitude to overcome the COVID-19, and create a stable and harmonious atmosphere for the family.





**Finally, although the COVID-19 period is tough, we need to live our simple lives as what we usual do.**

China's COVID-19 prevention measures are well controlled. The safety awareness of the Chinese people is relatively high. Thanks to the resources and protection provided by our country, most of our people do not need to meet the death and tough period in our normal life.





Self-advocacy started one year ago, from Shanghai to Xuzhou, and then online, we are sure that children will become better when we insist on this activity.





Recently, Can's family went to Yellow mountain by self-driving, it is a mountain with an altitude of more than 1800 meters and a very beautiful scenery. With the encouragement of his parents, Can not only completed all the mountaineering activities, but also overcome his fear of heights.



Last week, Chinese traditional Dragon Boat Festival, Ying Yue's family wrapped zongzi (traditional Chinese rice-pudding) together and enjoyed a very happy holiday.





Although it is a hard period in the world, we'd better take good measures to prevent the COVID-19, do not give up the hope of overcoming the virus, and strive to live a good life.

Look, these are beautiful moments in Down's life during this hard time, they maintain a positive and optimistic attitude. And how about you?





# Bhutan

## **Tenzin Yeemin's life at home**

Tenzin Yeemin has been a source of inspiration for her parents and her brothers ever since she was born. The doctor had told her mother that she may only be able to survive for about two days. She was diagnosed with Down Syndrome. The doctor shared what may happen at the worst state. She was told she may not be able to walk or talk and to not have much expectations from their daughter. When her mother heard about this, nothing could express the sadness she felt at that discovery; to might have only few days for her only girl child when she had only started seeing the walls of the hospital. However, Yeemin was strong enough to tackle her condition and survive through this stage. It was a miracle for her parents to see her live every single day thus, they started hoping for better years. Against all odds, they say to themselves that their daughter is like a box of surprises which unfurls with the passing day. She went to physio for two years and improved her gross and fine motor skills. "I was scared that she may not be able to walk since her progress was slow compared to other children her age but now, I can't even catch up to her when she runs," mother said smiling. Tenzin Yeemin has two older brothers whom she loves to play with and seeks their company.

This year has been an abominable time for their family. The coronavirus pandemic has disturbed their mental state however it is not the worst the family had faced. The miracle they experienced when their daughter survived is more than an inspiration to tackle the present situation. Her mother makes sure the family practices good hygiene. She made a slight change to the routine by minimizing those activities that requires physical contact with others. Yeemin's brothers plays with their little sister at home and they go for a stroll in the evening.

Her mother would have Yeemin spell out words and sounds by showing through her lip movements. She is one of the sources of motivation for the social workers at ABS, as to see her dedication and effort to continue the intervention at home is helping with Yeemin's progress. She and the father make sures to dedicate their time to their family and survive through this pandemic together.



## Picture story



I brush my teeth every morning and at night



I do my homework assigned by my teacher



I have two loving brothers whom I love to play with



My mum makes sure we are all together



I don't forget to wash my hands. Do you?

# Mongolia

## **BUJIN Bayanmunkh**



Because of the country's close proximity to China, the Mongolian government made an unprecedented decision to close all schools and kindergartens starting from January 25, 2020. The closures were originally intended to last a month, but were later extended to May 30. All classes have been conducted via TV and the internet.

Bujin Bayanmunkh loves studying in a school. She is missing her classes and creative activities she is used to having with her teachers. Worrying about emerging loneliness, Bujin's mum Oyuna tries to have quality time with a daughter reading books and doing some math.

Mum and daughter enjoy planting vegetables and flowers, and taking care of their bees.

## **Anand Munkh**



Anand Munkh is a cute and clever boy at his pre-school age. The whole period since the pandemic was announced by WHO, he has been staying at home, at standard apartments not very far from the downtown.

His family hopes that an uncertainty with coronavirus situation will be terminated before the fall. The reason is that Anand is carefully getting prepared for school!

His mum Chuluuna spends time for him, teaching his basic skills for school. Anand has already learned the Alphabet, and he liked the speech therapy classes in special school #25.

As Anand's mum keeps busy working, she usually goes for a walk with a son late evening. Family is planning to move to a summer house where Anand can enjoy green grass, sunshine and free motions in open air.

### DULGUUN Byambadorj



Parliamentary elections were held in Mongolia during the pandemic, on June 2020.

It has been the 3<sup>rd</sup> political election for a self-advocate with Down Syndrome Dulguun Byambadorj. He voted for the previous Parliament in 2016, and took part in Presidential elections in 2017.

Dulguun has been advocating for constitutional right to vote of those who have been labeled as intellectually disabled with no ability to participate in any legislative elections. His short interview has been broadcasted by Eagle TV, which is main news channel in Mongolia. Dulguun was wearing a T-shirt 'Asia-Pacific Down Syndrome Federation 2019'.

His parents try to keep Dulguun alert preventing from boredom and lazyness, to encourage doing exercises in order to lose weight.

### Elberelt Bayarmagnai



On 16 April, 2020 The National Emergency Commission of Mongolia made a decision to re-open gyms, fitness clubs, swimming pools and saunas in Ulaanbaatar under strict guidelines to prevent the spread of coronavirus. Under the new rules, fitness clubs and resorts avoid gatherings of people above 10, conduct the sanitization every two hours and check everybody's temperature.



As a Special Olympic's athlete, Elberelt is regularly having swimming classes with his coach and enjoys such a freedom after a long period of lockdown. Family tries to prevent him from inactive style of living, encourages sports and healthy diet.

He listens to music, relax in summer house, spends more time with his sisters and brothers. Most importantly, Elberelt started a part-time work in a business company during the pandemic!

## **NINJBADAM Ulaan**



Mongolia is continuing repatriation flights since January 2020. MIAT Mongolian Airlines has been conducting Government chartered flights to different destinations for evacuating Mongolians stranded in foreign countries.

Ninje and her mum took the chartered flight from Australia, Sydney. Upon arrival in Ulaanbaatar they were screened, tested and put into a 21-day quarantine. Ninje has covered almost 14 hrs of flight! She was afraid to be tested positive for COVID-19, but they were healthy. Mum tries her best to prevent her from anxiety and obesity.

Ninje likes comfortable hotel rooms after limited aircraft space, and enjoys reading and painting.

Patient mum and daughter desperately want the quarantine time to end, to leave the hotel and enter their OWN home after such a long adventure!



### **ANAND Munkhbaatar**

During the pandemic all classes for school have been conducted online, via TV and internet. Anand Munkhbaatar liked it, especially native language and physical exercises.

Sometimes he received homework paper directly from his teachers.

The advantage of Anand's school is that professional teachers who are specialized in Special education can teach at everyone's level of learning, including students with Down Syndrome and autism.

Anand has had a special training in Hotel Hospitality. During the pandemic time. On June the 5<sup>th</sup> his family was extremely happy congratulating their beloved boy on getting a certificate!

At the same time, parents focus on properly cooked dishes, and active style of living for Anand to keep him safe and alert.





# Myanmar

Myanmar Down Syndrome Association(MDSA) would like to wish you all to be safe and healthy during COVID-19 era. Today, we'd like to share the indomitable spirit of our parents of people with Down syndrome and how they have found ways to keep their families safe.

We all completely follow the instructions and guidelines by the Ministry of health and sports, Myanmar. Our Myanmar Government respects our citizens and cares for all of us. Therefore, they release the up-to-date news from different channels so that the Persons with Down syndrome families can easily follow up and keep on the track of the Ministry. Therefore, no person with Down syndrome has suffered COVID-19 until today.

Moreover, Persons with Down syndrome families seek for the awareness and do self-care by wearing masks, washing their hands, doing the medical check-up for themselves, staying at home and doing social distancing because they are aware that doing self-care can protect not only themselves but also others.

The MDSA also provides the needed health care for example, injected seasonal flu vaccines not to confuse seasonal flu with Covid19.



In addition, the parents support the children both physically and mentally. They always check the feelings and mental situation of the children during the COVID-19. If they find out that their children look bored and not active in daily life, the parents let them entertain themselves by dancing with them, chatting, and share the household chores in order to make them active and alive. Some children do sewing, practice computer typing, watch boxing, help in selling shops, ironing the clothes, play the guitar, watch TV and the parents create an inclusive play zone with siblings.



Last but not the least, the best thing among the Myanmar Down Syndrome parents always have strong communication through different ways. They share the information and the ways of staying safe and how to pass the time of Covid era effectively.

As the chairperson of MDSA, I really appreciate the work and warm heart of the parents and children for their resilience.

To sum up, we are still lucky as any of our children with Down syndrome suffer from Covid but we all are very worried if the future is not certain in the current situation. Most of the parents are nervous about how they can get the special health care for those little and soft children. We all hope that our Government has the best plan and implementation. On the other hand, we also need to help to be accessible to apply to the Government's supporting program and others sharing & caring programs.

I do believe that one seed can't be the whole field but all the seeds can spread the whole world. Let's try together and let's have the strong resilience to fight the Covid.





## Together We Can

As everybody know COVID-19 viruses is a pandemic disease. So everybody around the world had to weather this storm. During COVID-19 Storm there are a lot of losses we have faced.

In this case, we (a child with DS family) would have to face all kind of problems like other family have. But we have to care about our child with DS who don't know about the situation.

In Myanmar, we had our first positive case in the end of March 2020. So the Government announced all schools, some businesses and public places to be closed. Everybody should stay at home and follow the announcement of MOHS.

During stay at home period, my family enjoyed our family time. I had to explain about the current situation and COVID-19 to my children. Especially I had to explain to my elder daughter. She is 17 year old person with DS. I used awareness song and social media to explain it to her so that she could understand the situation and how to follow the MOHS guidelines. I had to change her daily schedules such as group activities ,gardening, helping in the kitchen, making hand wash soap and share with family and friends , donate Mask to her friends, learning computer typing etc.

I would like to share other families' experiences. This information is collected from DS family Myanmar Facebook page. Some adult person with DS are worried about the disease. So most of them stay at home. Some have shifted to the village to avoid the crowds and have organic fresh food. Listening to music, playing games, dancing, drawing, coloring, attending online classes of their school and online meeting with their friends are activities to keep them busy. One young girl with DS is learning to drive a car with her sister.

In our country, most people follow the MOHS guide. When we had the Lockdown, the Government arranged groceries for poor families. Some Donors, local NGO, Foundations, Associations etc are trying to donate for the people and volunteering at hospitals .Our Leader Daw Aung San Suu Kyi is working on the National level COVID -19 Controlling Committee as a Chairperson. The discussions have been shared live to public through the social media. She also created handmade masks and announced a mask making competition for all Myanmarese. Most Myanmar people around the world participated including me, some PWDS and family members.

As for our PWDs community, Ministry Of Social Welfare and MFPD have PWDs COVID 19 Emergency Response Committee and try to help PWDs who have tested positive or who are in quarantine. DPOs like MDSA are trying to support these members.

Now Our Country is passing second wave of COVID-19.And I am sure we can pass this pandemic, If we are together.

Myo Pa Pa





# New Zealand

Kia Ora

Covid 19 has dominated the news and impacted on everyone in New Zealand and has meant changes in all aspects of our lives. We certainly have all developed resilience during this time. I think we have all found ways of adapting and navigating challenges in our personal and work lives. Despite the challenging times of lockdown, it seems that many people have exited Levels 4, 3 and now 2 having gained some worthwhile perspectives and I think some of us will try to hold onto new habits that we established, or continue to enjoy new rhythms we have developed.

However I am aware that for some families and whanau, including ours it has meant a greater demand on personal resources as we stepped into the gap to meet the needs of our whanau as natural supports, paid supports and service providers were no longer able to provide the usual support or activities during lockdown. I am also aware that some families and whanau chose not to have support people included in their bubble because of higher risk potential.

Whilst we had anecdotal information of how our community was coping in lockdown, the NZDSA thought it would be valuable to circulate a survey so that our advocacy efforts would accurately reflect the experiences of our community during the lockdown. I have included below the survey results which you can read. I think the key factor highlighted in this survey, which isn't surprising, is that family and whanau are the ones who continue to provide support in crisis and that whilst service providers or support people can opt not to provide support, this is not an option for families and whanau who are expected to step up and provide all the care and supports that are needed.

One positive outcome of lockdown was that the Ministry of health recognized the need for more flexible use of funding and the usual constraining criteria were removed which led to families and whanau demonstrating creative ways to address needs while upholding the principles of enabling good lives. I have heard parents say that if greater flexibility of funding was allowed during lockdown then it should continue after lockdown and that the momentum cannot be lost. Therefore the NZDSA will continue to advocate at a national level for disabled people and their family and whanau for this to continue and for more choice and control on how they use disability funding.

You might be wondering what impact COVID 19 had on the NZDSA. We are fortunate that the NZDSA continued to operate throughout the lockdown levels and restrictions. Our mailboxes were flooded with COVID-19 information that was overwhelming at times! Whilst all this information was informative, not everything was pertinent to the community. So the NZDSA team decided to filter relevant and key information and share this with our community via our newly launched website.

We also shared current information via Enews and other social media platforms. Unfortunately, we do not have email addresses for all our members so we are aware that some people may not have received information. So please go to the NZDSA website and see that your information is current.

As we are moving to Level 2, the NZDSA recognized that some parents had concerns about returning to school so we contacted the Ministry of Education to ask if they would host a webinar to address questions. The ministry agreed and opened the session to the wider leaning support community. I joined the session and noted that almost 500 people attended.

I have enjoyed the opportunity to link into a range of national and international zoom meetings or webinars addressing a number of topics which have also included opportunities to advocate for issues that our community is facing



The NZDSA had a number of workshops scheduled during lockdown which we moved online where possible and we have rescheduled other workshops. We also hosted Zoom meetings for Self-advocates and parents who had workshops scheduled and we have had regular meetings with our STRIVE members as well as NZDSA committee

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### **Lockdown survey reveals fascinating statistics**

*The NZDSA recently conducted a survey to find out how people with Down syndrome experienced the Covid 19 lockdown period. We want to thank the 90 families who took the time to respond to one or all three surveys. Editor COEN LAMMERS has looked at the responses.*

The recent Covid 19 lockdown was a forced experience shared by all New Zealanders, but for every family those weeks had a different impact.

People with Down syndrome experienced the weeks without their usual routines differently than others, as they may not have always been able to fully understand the threat the virus was posing to our community.

For their families, the challenges were quite different and for many whānau, having to care for their families, including a child with special needs without the usual routines and support, was not always easy.

Most of us however know that our children, and our families, are a lot more resilient than many give them credit for and the NZDSA survey proved just that.

One of the most positive statistics from the survey showed that 90% said that their well-being had been the same as usual or even better, while 10 per cent did not feel so good and one parent had been feeling very badly during lockdown.

When asked about their child with Down syndrome, 90% of the respondents said that the well-being of the child had been the same as usual or better, with 10% feeling that their child's well-being had been negatively affected by the lockdown.

A few parents reported the lockdown caused anxiety in their household, about the global pandemic, about their jobs, and in cases when their child was particularly vulnerable to any virus.

The overwhelming majority of parents raved spoke about the quality time with their family and how they enjoyed life slowing down a bit, to reconnect with the other members in their household.

"If this is what retirement is like, bring it," wrote one parent.

While most children coped really well, almost all respondents mentioned how much they missed their missed their friends.

On the flipside, most children really enjoyed spending so much time with their parents and siblings, especially the older siblings who moved back home during lockdown.

The biggest challenges mentioned by parents were boredom and change of routine. Most of the children rely on their weekly routines, so many parents invested a lot of energy into creating new daily and weekly routines to give their children some new stability at home.



The universal love for electronics was a handy fall-back and many children enjoyed a lot more screen-time during lockdown, but parents struggled to wean them off the devices.

Parents also reported that their children struggled with social distancing, so recreationally outings could be a challenge. This would specifically be tricky if they would bump into friends or neighbours and the children were not able to touch their friends.

For the parents themselves, getting no breaks and no support, day after day, was exhausting and a quarter reported to feel lonely during lockdown.

“He was glad lockdown was over because he was sick of me being the teacher,” said another parent.

Many of the respondents shared their frustration of not being able to fully explain the nature of the pandemic and why they had to stay at home.

Some young people were particularly affected by not being able to see their friends or family during lockdown and were confused what was going on.

“He couldn’t see his grandparents for so long that he thought they had died!” wrote one parent.

Most parents managed to help their child comprehend the situation by talking about bugs and the importance of washing your hands, which seemed to make sense to most children.

Only a small number of respondents had to deal with behavioural issues triggered by lockdown, including some anxiety and aggression, but in some cases that settled down as the new reality set in.

Some parents reported that their child had some toileting accidents, while others mentioned that sharp increase of screen-time caused some “cold turkey” aggressive reactions when parents started to reduce the screen time.

One parent reported that their child decided she “was never going back to school”, but that the teachers made the return so exciting that she was keen to return.

From the families who responded, the person with Down syndrome in the home were 19% pre-schoolers, 20% primary school age, 26% high school age and 35% between 21-45 years old. Only 2 per cent was over 45.

Of those children, 93% lived at home with family while only 2 per cent were in supported living, 1% living independently and 3 % in residential care.

Some the parents who were separated from their child during lockdown reported that it was “heart-breaking” not to be able to visit their loved one, but others reported that virtual meetings really helped to ease the separation anxiety.

Services and information

Obviously, lockdown hugely impacted on the normal services that were able to be provided and 75% of parents reported that their family was impacted, with 55% getting little or no service at all.

Even though parents had to cope without their usual services, there was a universal understanding that the pandemic was an extraordinary situation, so the number of parents unsatisfied with their services only increased slightly.

Many parents were disappointed that they were not contacted more often, of at all by their usual service providers, including more interaction with teacher aides, speech therapists and OTs through Zoom calls.



Most caregivers however were very relaxed about being left to own devices and understood that any physical interaction would create health risks.

From the 90 respondents only one was unable to access essential services or groceries and 11% said they could only get limited supplies.

Most people, 65% got their groceries at the supermarket, 31% shopped online while 15% used the priority shopping option.

As far as access to PPE was concerned, 27% said they could not get access, while 45% did not need to.

Of the 27% who did have access, the vast majority (68%) purchased it themselves, 7% received them from their service providers while 24% got them through their IF Host.

When asked about information about Covid 19, 85% was happy with the level of information they received while 15% would have liked to have seen more.

The Ministry of Health was the main source of information (79%) while others relied on information through their family networks (43%). The NZDSA (24%), the Ministry of Education (29%) and MSD (15%) were also mentioned as good sources, as well as support groups (31%), providers (21%) and funding agencies (27%).

Being stuck at home it is no surprise that social media and websites were used by 70% of families to find key information.

Families also received direct information through emails and newsletters (20%) or by talking to family and friends (31%).

## **Education**

The survey revealed that 52% of the parents provided some home schooling for their child with Down syndrome.

Of the remaining parents, 18% had not done any home schooling, while for 30% home schooling was not relevant.

Of those parents trying to continue their child's schooling from home, about a third found it difficult or stressful while two thirds said they managed without too much stress.

Among this group, around 20% felt that the schools had not provided them with appropriate material or support to learn from home. About half of the children who lived away from their family came back to the family home for lockdown.

While many parents had no concerns going back to school, more than half of the respondents were and are still extremely concerned about how exposed their children would be at school.

Many questioned their schools' social distancing and hygiene policies, especially in learning units and whether their child would be able to adhere to those rules.

One strong sentiment coming through the responses was universal confusion among parents whether their child with Down syndrome did or did not fall into the high-risk category under Level 2 or 3.



As a result several parents kept their children at home for weeks, even when all schools were back to their normal routines.

“She hugs people so we decided to keep her home,” wrote one parent, while another parent kept their child at home for eight more days due to medical concerns.

“We were extremely anxious and still are.”

### **New opportunities**

One of the most interesting revelations of the survey was that our families and support services discovered that the digital age is offering wonderful new opportunities to connect.

Parents enjoyed they were able to talk to their GP, speech therapist or teacher through their laptop and one wrote that “We will continue to do speech therapy through Zoom.”

Another parent reported that they will continue with online learning when their child is sick at home in the future.

With a higher demand for digital services, a lack of access to good internet or appropriate digital devices proved to be a huge source of frustrations in some households.



# Singapore

## **AES TAKES ON HBL**

Prior to circuit breaker, lessons for our adult learners were all held in physical spaces at DSA Centre and ILT Centre. When physical sessions had to be suspended, home-based learning (HBL) was introduced to minimise disruptions to their learning routine.

Shifting to the virtual world was a whole new dimension for our training officers, but nonetheless an enriching experience for all. The newly developed HBL materials adapted from the planned activity schedules for each group were introduced and lessons with the learners were conducted virtually thrice a week.

Despite being connected and learning with computer screens, learners looked forward to these online sessions where they are able to meet and mingle with their friends. Their enthusiasm were contagious and the screens were often filled with their happy smiles and laughter. Over time, the training officers honed their virtual teaching skills and were able to better engage the learners during lessons.

More importantly, caregivers also took on a more active role in their children's learning journey during HBL. By spending quality time with their child, it helped to strengthen their family bonds. There were even cooking and baking modules planned for the learners to practice at home under the guidance of their caregivers. It was certainly a collaborative effort between the training officers and caregivers to create enjoyable, impactful and meaning lessons for our learners.

## **HERITAGECARES @ HOME**

Our members and caregivers had a crafty treat as part of '*HeritageCares@Home*' - a pilot initiative by the National Heritage Board. The series of experiential art therapy workshop was conducted online by art therapist Loh Wan Ting from Red Balloon Therapy.

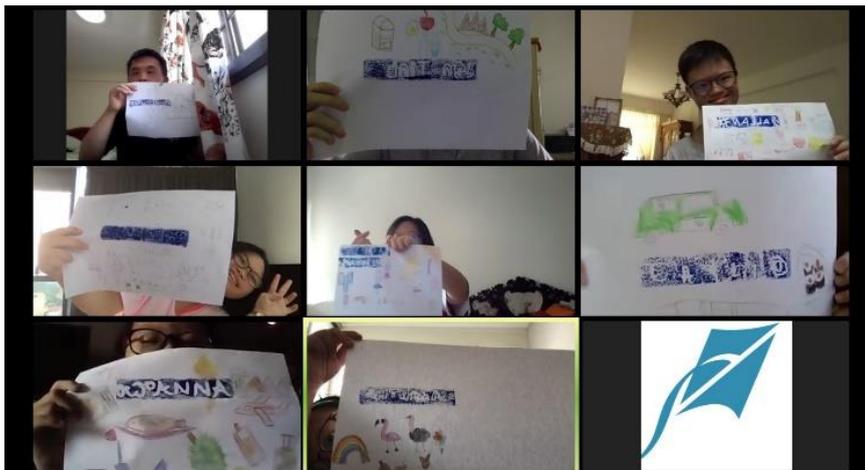
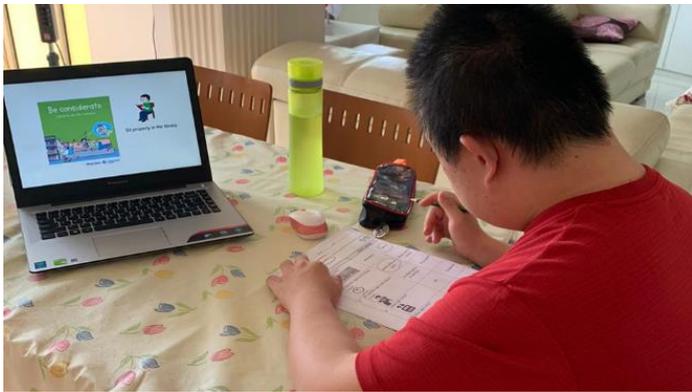
The workshop explored the theme 'Traditional Trades' where members learned about professions from the yesteryears such as the Handcrafted Goldsmith, Movie Poster Painter and Coffee Roasters. They unleashed their creativity by working on art pieces relating to the trade such as creating symbols to represent themselves (Handcrafted Goldsmith), using foam board and ink printing to create a story board (Movie Poster Painter) and dabbling in coffee painting art (Coffee Roasters).

Art therapist Wan Ting shared that "it was wonderful to observe caregivers and members taking turns to co-create an artwork that encapsulate the stories, thoughts and emotions each member had shared and bonded over the experience. "

Thank you National Heritage Board and Red Balloon Therapy for bringing arts to our members' home during this stay home period!



ASIA PACIFIC  
DOWN SYNDROME  
FEDERATION





# Thailand

## Monotony is the enemy of the people

The unexpected caught us unaware! All of a sudden *Phi Jaew* (*elder sister Jaew*) had to stay at home, as the Healing Family Foundation was closed from mid-March. Our way of life, particularly for her, had turned to be a perpetual weekend. She missed her companions at the foundation where she went to do weaving every day, but the weekend. One of the remedies was that we took her loom to do it at home. But it did not work very well. For her, weaving is not just to work on the loom, but it has to be done in the 'right' atmosphere. That is to play along while working and to be in the "crowd" of her friends and frequent visitors. Actually we had known this all these years, but the lockdown made us realize it more acutely. What have we learned from the Covid lockdown?

Though our house is relatively spacious, she still faced the predicament of "nowhere to go to". She did not like, or rather we had not trained her to do, to go to the sun. One thing was that it was unpleasantly warm. The other was, for her, nothing to be done in the garden. Her father renewed his interest in gardening. Though it could beautify our place somewhat, it did not lean to her liking. In retrospect, we were very much shortsighted, as we did not foresee the benefits of outdoor activities for her. As time went by and we did not even step out of our house, we could well see how unhappy she was. Her way of expression was that she wanted to go to Bangkok (we live in Chiang Mai, around 500 miles from the capital). But no air nor land transportation was in sight. We could not even travel to a nearby village which is the abode of our domestic helper whose care for her and for us are our life-saving.

We have come to learn that the monotonous life was not conducive to *Phi Jaew's* customary life. A general misunderstanding ingrained in the public mind (in Thailand) is that people with DS do not require anything very much. For us, nothing could be further from the truth. Monotony is a prisoner's way of life, or at the other extreme, a monastic life. We are not to serve a penalty, nor to reach nirvana too soon. (The latter is for Buddhist monks, best wishes to them!) Her life during the lockdown was pertaining to that! As soon as the train service was to about to resume, we got the tickets to Bangkok. It was not only to see her grandmother and younger sister, but also to move, to activate ourselves. She, her mother and our helper were there for a few days. That brought so much joy to her. After the return from Bangkok, she was very contented and much keener on weaving. We very much like active lives, as life is energetic by definition.

This, however, is not to complain about the lockdown. Thailand has performed something good, for a change indeed! As the endemic has subsided, the foundation would reopen on the 1<sup>st</sup> of July. We all look forward to seeing our friends and noises and, most important of all, the end of the sedentary life!

I would like to add here another thought from a friend:

" I think the hardest thing for our artists has been not having the social interaction and community with their peers .When I think of *Phi Jaew*, she is such a friendly and sociable person .She needs to be around her friends and sharing a creative activity is very meaningful to her .

If I was you I would see if someone could take *Phi Jaew* swimming regularly .She really loved swimming and that would be very good for her as she is aging . Whenever I come I will want to bring her to that nice German community pool . So I would just add that about social interaction and community being critical for people with disabilities because many of them isolated and can suffer from anxiety and depression. Now



with the pandemic it only makes it worse . I'm so happy she can go back to her place and so happy." Jeanne Calvit ."

Chaiyan Rajchagool ( Phi Jaew's father)

