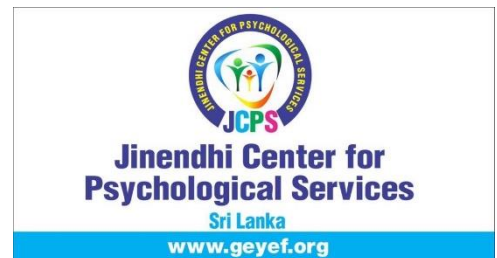


# Country Report - Sri Lanka

2022

Jinendhi Resource Center for Down Syndrome / DSF Sri Lanka.



## COUNTRY SITUATION

Our work was interrupted twice due to the Covid 19 pandemic and the unexpected economic crisis which led to political instability in the country. The country is recovering from these setbacks.

## DOWN SYNDROME SERVICE CENTRES

During this period, we were able to study the present situation of the country's available services for children with Down syndrome. Currently, there are no homes or centres exclusively for Down Syndrome children. All available centres serve children with special needs and multiple disabilities. Further, as we have noticed before the Covid 19 pandemic, 99% of service centres run by NGOs and the government are in urban areas.

### a. Ragama Rehabilitation hospital

This is an institute that serves people with all disabilities, not exclusive to down syndrome. Five of our professionals in Audiology and Speech-Language pathology who graduated from the Universities of Bangalore and Mangalore are working in this hospital attached to the Ragama Government Teaching hospital.

Further, a few of our physiotherapists who graduated from India are attached to this rehabilitation centre. Many children with Down syndrome are attending for speech therapy and other development activities.

### b. Serendip Children Home - North and East (Autism and Down Syndrome) *Funded by a UK organization.*

There are many charity organizations (85 in Colombo, Negambo, Kandy, Galle, and in the northern and eastern provinces). All are serving children with special needs not exclusively for Down Syndrome. This is a progressive step for Down Syndrome children. However, services are lacking in the remote or underprivileged areas of the country.

Thus, our concept or the vision to establish Down Syndrome welfare clubs is a must to address the DS children and adults in rural areas of the country. For the next two years, this is going to be our main task.



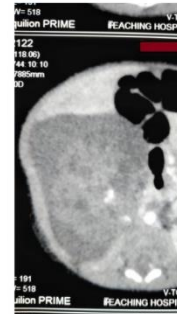
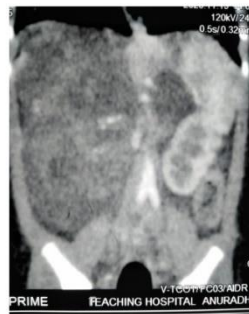
We managed to form 2 clubs prior to the Covid 19 pandemic.



### MEDICAL ASPECTS

During the last few years, covid pandemic and financial crisis affected in children with DS in many ways. Positive aspects of health aspects include;

1. Island-wide compulsory free screening for hypothyroidism with TSH for all neonates for 2 yrs.
2. Introduction of a special fast track for health issues in certain government hospitals (i.e., TH, Anuradhapura, DBH Dambulla)
3. Planning for special support with nutritional supplements for emerging malnutrition among children with DS in recognized rural areas.



CT scan images showing bilateral adrenal tumours

### **CLASSES FOR SPECIAL NEEDS CHILDREN IN REGULAR GOVERNMENT SCHOOLS**

There are 10162 government schools in the country. Currently, 950 schools have separate classes for children with special needs. However, they are mostly confined to urban areas. We have requested the ministry to expand these services to schools in rural areas.

Three years back, we requested the Department of Education to allocate more funds for the special education unit of the department. The secretary took it into serious consideration and revised the budget. This year, we have made the same request to the new government. The department of education has introduced a higher salary scale for teachers attached to the special education unit. This is to encourage more teachers to join this stream of service.

### **CLASSES FOR SPECIAL NEEDS CHILDREN IN PRIVATE SCHOOLS**

We have increased awareness and have requested many private schools to start a class for children with special needs, since 1996. Currently, 8 private schools have already started and are doing a good service. Two private institutions are conducting certificate courses on special education. However, this is also confined to urban areas of the country.

### **PROFESSIONALS TO TEACH IN SPECIAL CLASSES IN PUBLIC AND PRIVATE SCHOOLS**

We have motivated students to do B.Sc Audiology and Speech Languages Pathology degree in India since 1997. Already more than 250 students have graduated since 1997, and are now working in Sri Lanka and in many other countries. We are continuing the programme to date. This year, we have 7 graduates who returned to Sri Lanka and serving the country.

Many organizations have introduced courses starting from Diplomas to degrees. This is a positive development. Many students are now motivated and joining these institutions as it opens up the opportunity to go to Australia, Canada, and USA.

- a. Medical college under University Grants Commission, in northwestern province. Initially started as a 2-year diploma course. Now the university offers a degree programme.
- b. The Open University of Sri Lanka now offers a bachelor's and master's degree in studies related to children with special needs.  
-i.e., B.Sc. Speech and Language Therapy, B.Sc. in communication sciences and disorders
- a. National Institution of Education offering a diploma in Special Education. This is especially focused on promoting teachers to serve in government schools.

### **AGING PEOPLE WITH DOWN SYNDROME**

For all these 32 years, we did not have these issues with adults with Down syndrome. The economic situation may have affected the families having people with Down syndrome. We are getting inquiries and asking to help them to transfer them to a home for the ages. Aging adults with down syndrome is a growing problem for the family. Many are informing us about the

drastic changes in the behavior of people with DS as they grow old such as; Lack of sleep and disturbing others in the family, Sudden changes in behavior (aggressive behavior), and Memory loss.

The Parents and guardians want to hand over them to adult homes. We usually counsel them to look after them. But very serious cases were introduced to home for the age. Last week (October, 2022) one lady with DS aged 46 was handed over to a home for the elders. It will be a new program for us as we have to monitor the girl's progress. We have 32 members above the age of 30 years. This issue is under discussion.

We had a convocation with the Department of Social Services, and they requested us to submit a proposal. The subject is under discussion.

### **HOME FOR AGED PEOPLE WITH DOWN SYNDROME**

One home for the aged (*Senior Citizen Villa, Horana, Sri Lanka*) agreed to accommodate aged People with Down syndrome under our direct supervision. This is an encouragement to address this issue.

### **MOTIVATE AND FIND HIGHER EDUCATION OPPORTUNITIES FOR SISTERS AND BROTHERS OF DOWN SYNDROME CHILD**

- a. Give proper awareness to the other family members of the DS child as they are the people going to look after the DS child in the future.

Parents cannot completely look after the DS person of the family. They have to take the responsibility of looking after their sister or brother throughout their life span. This is another problem for parents. That is why families are looking for homes to hand over their adult family members with DS.

- b. Giving a proper education to the siblings of the DS child in the family. If the other children are well off only, they can look after their siblings with DS.

This year we managed to give an opportunity to one girl to join a Degree programme (B.Sc. Food Nutrition and Dietetics). She is now at the Besant Women's College affiliated with the University of Mangalore. We need to raise funds for this unique programme. We may not be able to give this service to all families. But at least we can assist.

### **BOOKLETS AND BOOKS FOR DISTRIBUTION**

We have already two informational booklet's .

1. DS child Medical Record Book
2. Diet chart for people with DS
3. New Book to be published very soon in local language. "Life with a Child with DS" "  
(name not finalized)

## DOWN SYNDROME AWARENESS MONTH OCTOBER 2022

This year we were not able to work with schools due to the prevailing situation in the country. But we shared our DS awareness posts in many social media groups.



## **STREAMLINE AND COORDINATE ORGANIZATIONS**

We are actively advocating for policymakers to impose a new law to make it mandatory for all child welfare centers, special needs and rehabilitation centers, and daycare centers to register with the relevant government institutes such as;

- a. Ministry of Women, Child Affairs and Social Empowerment
- b. National Child Protection Authority

We have initiated registering all special needs schools, and rehabilitation centers at the above government institutions to protect the children with special needs.

## **JRCFDS Mission**

JRCFDS is an extension centre. Implementation programs for People with DS in Sri Lanka. Further coordinating with the government, NGOs in Sri Lanka, and International Organisations in the world working for people with Down Syndrome

Dr. K. Dayarathna

Mr. G. A. W. G. Galgamuwa

JRCFDS – Sri Lanka