

COUNTRY REPORT SRI LANKA

2018

Country Analysis

Sri Lanka has a population of 21.44 million (2017) and 1.6 million are reported as disabled and there is 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.

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

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. Furthermore a discussion with the Indian high commission was held on extending our services to the estate sector in Kandy district.

Sri Lanka offers degrees in Special Education at Open University of Sri Lanka, Short term courses for teachers and parents of children with special needs, Diploma in special Education at National Institute of Education which promotes inclusive education in mainstream classrooms and workshops on safeguarding children with speech and language disabilities. At present a number of 130 special education units in the Western Province, 116 units in the North Province and 105 units in the Southern Province are established in government mainstream schools in Sri Lanka with many unreported number of special education units in private schools in other provinces serving children and adults with special needs. There are 50-100 NGOs that have established training centres to provide services to children with special needs.

Programmes implemented in 2017- 2018

Broadcasting radio programmes

Broadcasting of two radio programmes Island wide with a parent, two adults with DS and the Vice President of the JRCDS, Dr.Dayarathne, was an attempt to educate the Sri Lankans on DS and experience sharing. It created a platform for an open discussion where many parents and teachers were able to pose questions and to connect with them. JRCDS received many inquiries after the radio programme and motivated to join the organization. Many inquires were referred to the Ragama Medical Hospital

and hospitals in the respective areas where the inquirers reside. After this effective Island wide radio programme, the membership has reached to a number of 228 members.

Professionals to serve

JRCDS provides the service of supporting students to pursue their higher education in following areas at Indian Universities. They are expected to bring the knowledge and skills back to Sri Lanka to serve the people with special needs.

1. Audiology speech language pathology
2. Physiotherapy
3. Social workers
4. Psychology

Since 1996, 150 professionals have graduated and working in Sri Lanka as well as in other countries. All of these professionals work in the established resource pool to work all across Sri Lanka and their service is available to other countries on inquiry, especially to the member countries of the Asia Pacific Down Syndrome Federation.

Dream cricket festival

In collaboration with the Rotary Club of Kandy, Dream Cricket Festival was organized for the third consecutive year. Around 300 persons with intellectual needs participated in the event. The concept Dream Cricket is carried out by the veteran Australian cricketer Rick Mc Carthy in Sri Lanka to build confidence and promote participation and socialization of persons with intellectual needs. He has shown a green light in introducing extending the services to other member countries in the Asia Pacific Down Syndrome Federation. (Interested parties can contact JRCDS on education@amasa.lk)

Tree planting campaign to celebrate the Down syndrome awareness month

A tree planting campaign was carried out by school children, children with Down syndrome and the Roteractors to create awareness on DS in the society.

Developing a mechanisms to coordinate with government departments

A successful discussion was held with the Secretary to the Minister of Public Administration in order to carry out the survey in all the Divisional Secretariats and in other government departments to gather information to understand the specificities that needs to be addressed in implementing programmes. The draft survey is forwarded to the relevant ministries for their suggestions. The survey will be done first within the Kandy district and then gradually reaching the Island.

Motivating principals of five pre-schools to accommodate children with DS as a pilot project

Discussions with the Preschools principals were done to make school culture and environment conducive for children with special needs especially for children with DS. This will start with 5 schools expanding to 25 schools in AGA¹ divisions in Kandy district. The teachers of the pre-schools will receive training and they would be constantly observed and supporting services would be given by the Department of Education.

Foreign training for teachers of special education

A proposal was submitted to the Department of Education on providing short term foreign training to teachers of special education attached to the Department of Education. The training will be done in collaboration with the Samvaada Institute of Speech and Hearing in Bangalore, India

Distribution of medical record books to families with persons with DS

A medical booklet is being developed to be distributed to families with persons with DS and these will be distributed via hospitals, NGOs, schools as well as home visits. The booklet records the continuous medical details of individuals with DS. The booklet was developed based on the medical booklet developed by Down Syndrome Federation of India, which was received at the Asia–Pacific Down Syndrome Federation conference in 2017, New Delhi.

Follow up programme of the last year's medical camp

A medical camp was organized for persons with DS in 2017. Follow up programmes were carried out this year to 85 participants who became members of the organization. Programmes in terms of medical support and counseling were organized and the support is currently being continued to the members.

Strengthening international relations

A travel Programme for a 100 member circle of international families having children with DS was introduced and 4 families from Russia, India, Maldives participated in the programme. And JRCDS expects more families to build ties with the families having persons with DS in Sri Lanka.

Volunteer services

A new programme was introduced where volunteers who are following courses in special education to visit homes of persons with DS and to carryout assessments and refer them to relevant parties as well as culturing a positive attitude in the family members of their family members with DS. This service will be extended to more families with more volunteers participating in.

¹ Assistant Government Agents

Challenges

Attitudes of parents and society and limited resources

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 and the services such as allied health services and education are confined to urban areas. This limits their capacities to reach their fullest potential in life. The attitudes of parents towards their children with DS are still widely negative in Sri Lanka. Converting those attitudes positive is still a challenge. Also most parents are still reluctant to accept that their children have to live with the condition of DS. Hence JRCDS/ proposed Down Syndrome Federation of Sri Lanka expect to extend the services as well as awareness to the rural areas as well.

Difficulty in raising funds

Most of the civil society organizations working for special needs are self driven and are challenged by the availability of funds.

Status of the Down syndrome Federation of Sri Lanka

There are a lot of legal issues pertaining to registering a federation in the name of Down Syndrome Federation of Sri Lanka. The government of Sri Lanka requests the following requirements to be satisfied in order to proceed with establishing a Down Syndrome Federation Sri Lanka/Authority.

- 1) To provide the number of persons of DS in Sri Lanka
- 2) To provide the number of organizations working exclusively for DS in Sri Lanka
- 3) Department of Social Services requires a master plan of the Down Syndrome Federation

The following steps are being taken to satisfy the government requirements

- 1) Master plan is drafted, which will be briefed at the Asia Pacific Down syndrome Federation Confererence.
- 2) Project plan to carry out the survey is developed which is required in establishing the federation.
- 3) Establish grass root level associations in each district as well as request other organizations that work for DS to affiliate with us.

It is possible to register the federation as Down Syndrome Federation Lanka, but our effort is to establish it once and for all in the name of Down Syndrome Federation of Sri Lanka.

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Jinendhi Resource Centre for Down Syndrome/ Proposed Down Syndrome Federation Sri Lanka
