

Spain/Catalonia Fundacio Catalana Sindrome de Down



Internet: www.fcsd.org

Founded: 1984. Foundation

Present director: Katy Trias (Presidenta del Patronato: Montserrat Trueta). There are 9 persons on the board of directors



Katy Trias, director of the Foundation, has a brother with Down syndrome

Members: Because we are a foundation, we do not have associated members, but about 1800 families are related to us.

Finances: Membership fees; financial support from the Catalan government; donations; selling books, posters and services

Main goals

Our mission is to improve the quality of life for persons with Down syndrome and other intellectual disabilities, We work for the achievement of their maximum degree of dignity, respect, self-determination and wellbeing.

Services

- Counselling: The Down Syndrome Catalan Foundation provides support from the early days of pregnancy and after postnatal diag-

nosis until independent living. Therefore, we have different services according to the needs of the child at different periods in his or her life:

- The Down medical centre
- The centre for child development and early intervention
- Mainstream school support service
- Social skills and preparation programme, called PAS.
- Col-labora, job integration service

European Down Syndrome Association news

- Seminars, courses for teachers, for parents, for doctors, for persons with Down syndrome.
- Library specialising in all disabilities including Down syndrome
- Family days, leisure time: Lectures for families, leisure promotion for persons with Down syndrome
- Down Syndrome Medical Center

Publications

Our regular journal is called: "SD. Revista medica internacional sobre el sindrome de Down" (DS. International Medical Review on DS.) It is published 3 times a year in Spanish, Catalan, and in English on the web.

We have published the following brochures, information flyers and books:

- Brenchin, A. and Swain, J., Cambio de relaciones, Spanish, FCSD and Milan, *Diseños de integración*, 4: 1987.
- Brown, L., iterios de funcionalidad, Spanish, FCSD and Milan, *Diseños de integración*, 1: 1989.
- Edwards, J.P. and Elkins, T.E, *Nuestra sexualidad*, Spanish, FCSD.
- Martínez, I. El desafío de la Integración, Spanish, FCSD and Milan:, *Diseños de integración*, 3: 1990.
- FCSD, *El adolescente y el joven con SD, Resumen III Jornadas psicopedagógicas*, Spanish and Catalan, FCSD: 1991.
- FCSD, Para llegar a ser una persona autónoma, *Resumen IV Jornadas psicopedagógicas*, Spanish and Catalan, FCSD: 1992.
- Coleman M. and Rogers P., *Atención Médica en el Síndrome de Down*, Spanish, FCSD:1994.
- FCSD, La relación con el otro en la construcción de la identidad, *Resumen V Jornadas psicopedagógicas*, Spanish and Catalan: FCSD: 1995.
- FCSD, Proceso hacia la vida adulta de las personas con SD, *Resumen VI Jornadas psicopedagógicas*, Spanish and Catalan, FCSD: 1995.
- Montobbio E., El viaje del Sr. Down al mundo de los adultos, Spanish, Masson and FCSD, *Diseños de integración*: 1995.
- Montobbio E., La identidad difícil. El falso yo, Spanish, Masson, *Diseños de integración*: 1995.
- FCSD, Síndrome de Down. Aspectos médicos y psicopedagógicos, Spanish, Masson *Diseños de integración*: 1996.

FCSD, Avances Médicos y psicopedagógicos, *Ponències de les II Jornades Internacionals*, Spanish and Catalan, FCSD: 1998.

Cunningham, C., *Guías para padres, SD. Introducción para padres*, Spanish, Paidós: 1999.

Kerr, D., *Síndrome de Down y demencia. Guía práctica*, Spanish, FCSD: 1999.

Canadian Down Syndrome Society (CDSS), *Sexualidad, las relaciones y yo. Libro de sexualidad para jóvenes y adultos*, Spanish, FCSD, 1999.

FCSD, Llegar a ser adulto, *Resumen VII Jornadas psicopedagógicas*, Spanish and Catalan, FCSD: 2000.

FCSD, *Services and methodology*, (2a edició), English, Catalan and Spanish, FCSD: 2004.

FCSD, Síndrome de Down. Construyendo el futuro. Interrogantes de hoy, respuestas para mañana. *Resumen VIII Jornadas psicopedagógicas*, Spanish. Edición digital programada por Espintime. FCSD: 2005.

Peralta, M., *Mírame con otros ojos*, Spanish and Catalan, FCSD: 2005.

Sierra Fabra, J. and Caruncho, I., *¿Qué será cuando sea mayor?*, Spanish-catalan-gallego-vasc, Edebé, and FCSD, 1st edition: 2003.

Sierra Fabra, J. and Caruncho, I., *Mis hermanos y yo*, Spanish-catalan-gallego-vasc, Edebé, and FCSD, 1st edition: 2005.

Sierra Fabra, J. and Caruncho, I., *Soy especial para mis amigos*, Spanish-catalan-gallego-vasc Edebé and FCSD, 1st edition: 2003.

FCSD; *Aspectos médicos actuales.*, Spanish, Masson: 2005.

Awareness campaign

There is no regular Down Syndrome awareness campaign so far. But we have proposed that the organisations celebrate the 21st March.

Projects and campaigns

Our main projects in the next years are:

- celebrating the 20th Birthday of our DS Medical Center (end 2007)
- preparing our next International Conference on Down Syndrome for 2008.



European Down Syndrome Association news

- new publications: a book about Diet and Sports and another for new parents

Our most successful projects in the last years were:

- the organisation of the Medical International DS Congress in 2005
- the publication of "*Síndrome de Down Aspectos Médicos Actuales*"

A useful project tip for other EDSA members could be to collaborate with other medical publications.

General information

The three main problems in our country for persons with Down syndrome are:

- there is no pension provision for early retirement from work
- we have not enough inclusive jobs
- the idea of independent living with support needs more promotion

These things should be urgently changed:

- Pension for early retirement from work will become a big problem soon
- further quality training for old people who can not work or who have never been integrated
- housing, there are no options, and those promoted by the government are too crowded (residences and group homes)
- to have a house of one own is difficult for most people, because of their financial situation.

Numbers

In Catalonia between 20 and 25 children with Down syndrome are born per year, (that means 1 of 3000 children born alive.)

We have no official numbers of the persons with Down syndrome living in Catalonia.

Situation for babies and toddlers under 4 years

The services of our Foundation work very well. The Foundation is one of the Governmental Sectorised (since 1998) Early Intervention Centres and therefore public and free. Children with all kinds of disabilities or difficulties (not only Down syndrome) from birth to age 6 from a specific area of Barcelona city can attend the foundation.

Medical care is generally good. We have a Down syndrome medical centre that promotes a Down syndrome Health Programme to help families and other doctors.

The Foundation has also a physiotherapy service for those children who need it. Other therapies for toddlers are speech therapy and psychological counselling.

Situation of schoolchildren in Catalonia

- Approximately 19% of children up to 6 are in mainstream kindergarten. However, many children do not go to kindergarten, but remain at home or go to a mainstream nursery. We do not have specific data.
- 60% of children (6-12 years old) attend mainstream schools.
- Approximately 21% of youngsters (12-18 years old) are in mainstream secondary schools.

Children who are not in mainstream school settings attend special schools.

Situation of adults

Most adults go to special workshops. Some others work in an integrated work situation. The Foundation has a programme for integrated work.

Adults live with family or in residences. The Foundation has started an independent living programme with support where the person can choose with whom and where he is going to live. Adults living on their own in their own place happens more often nowadays.

If adults do not live with their families, the options are: institutions, residences, or group homes.

Most of the big institutions have the whole continuum organised, from the special schools, sheltered workshops, special leisure time and residences or group homes.

We do not know how many persons with Down syndrome over the age of 50 live in Catalonia.

In the data base of the Down Syndrome Medical Center of the FCSD, with a total of 1800 persons, we have between 75 and 80 elderly individuals.

They live mostly in residences or remain inactive at their family home.