

European Down Syndrome Association news



Germany Deutsches Down-Syndrom InfoCenter



Internet: www.ds-infocenter.de

Founded: 1987

Present director: Cora Halder

Members: 400 in the association, plus 4500 families and professionals as associated members

Finances: membership fees; donations; selling books, information and educational material

Main goals

To improve the life quality of individuals with Down syndrome. Our work is based on the values and principles of edsa.

Our mission is:

- to promote the well-being of persons with Down syndrome in all aspects of life, health, education, personality, autonomy and integration in the society
- to support families
- to promote inclusion
- to inform professionals and society by disseminating up-to-date information on Down syndrome
- to promote a positive image of persons with Down syndrome

Services

- counselling
- seminars, courses
- library
- family days/weekends, leisure activities
- leisure time for teenagers (dancing, cooking courses etc.) We also offer discussion groups for young adults
- a whole range of books about Down syndrome can be bought directly from the centre.

Publications

Our journal *Leben mit Down-Syndrome* has been published for 18 years and there are three issues a year.

We have published a range of information flyers, brochures and books, as well as one video.

For many years we have produced posters and postcards as part of our awareness campaigns.

We sell educational material, like signing cards (GuK) and the early intervention program "Kleine Schritte" both publications of the InfoCenter.

Awareness campaign

The German Down Syndrome Weeks have been held in October since 1996. This was an initiative of the InfoCenter. Many groups throughout Germany organised local events and the InfoCenter designed posters, postcards, cinema spots, advertisements etc. to use during the campaign.

On World Down-Syndrome Day, 21st March 2006, we initiated and supported the nationwide Do-it-yourself-Poster-Campaign with the slogan "Lass mich mal machen" (Just let me do it!).

Also on World Down Syndrome Day we started the medical clinic for children with Down syndrome in the Children's Hospital of Nürnberg (cooperation between the InfoCenter and the hospital; this project has a role-model function in Germany).

In the future we will not celebrate our awareness weeks in October, but will focus on the 21st March. It is not possible to organise two main campaigns, because of lack of finance and staff.

Projects and campaigns

Our main projects in the next year will be:

- the organising of World DS Day. On this occasion we will honour one person with and one without Down syndrome, both for their outstanding work. Both awards (the golden Chromosome and the Moritz) have been granted regularly for several years.



Cora Halder, mother of a 21 year old young lady with Down syndrome, is the director of the German Down-Syndrom InfoCenter



Some of the InfoCenter's publications

European Down Syndrome Association news



Marco Huber, winner of the "Golden Chromosome 2005" award

- From 21st March onwards there will be an exhibition of art by three painters with Down syndrome in Nürnberg.
- We will also organise another Do-it-yourself-Poster-Action.
- We are planning several new publications (e.g. about nutrition and other topics).
- In cooperation with a publisher we will translate and publish the book "Mental Wellness in Adults with Down Syndrome" by McGuire and Chicoine.

A successful campaign in the last year was:

- the poster campaign 2005 with some prominent German actors. Posters were displayed all over Germany, mainly in buses, trains and in the main train stations. At the same time they appeared as advertisements in many magazines.

We have many useful project tips for other edsa-members:

- producing a first information map for new parents, and distributing this to all hospitals. Many parents tell us, that this information was the best they experienced in the first days after the birth of their baby.

- Our flyer about "breaking the news" as information for professionals has been distributed to all hospitals and to many gynaecologists and paediatricians. At the same time the content was published in the two main professional journals.

- With a yearly award for a person with Down syndrome (for outstanding artwork etc.) and one without Down syndrome (a professional in a special area connected to DS) you can draw the attention of the media and the public.

- our poster series were always very successful. The posters were not only used during the awareness

weeks but decorate medical clinics, schools, libraries etc. for many years.

General information

The main problems for persons with Down syndrome in Germany are:

- lack of mainstreaming in schools
- lack of good medical and psychological care for adults
- lack of inclusive workplaces
- lack of housing options for adults who want to live more independently instead of in group homes

Before these things can be changed the whole attitude towards inclusion must be changed. Inclusion starts in ones mind! Also expectations about what individuals with Down syndrome can reach are still very low, therefore they do not get enough opportunities to develop to their full potential.

Numbers

We estimate the approximate number of children born with Down syndrome in Germany per year to be between 1000 and 1200.

The total number of persons with Down syndrome living in Germany is approximately 50.000

Situation of babies and toddlers under 4 years:

The situation for babies and toddlers under 4 years is sufficient, good or excellent. This depends on the area the families live in.

Medical care is good. Medical doctors should be more informed about how children and youngsters with Down syndrome develop, how they live and what goals they can reach.

Physiotherapy and speech therapy are mostly very good and are available for all babies and toddlers.

Early intervention is on the whole very well organised and available for all children. In some parts of Germany pedagogues visit the children on a weekly base in the first 3 years.

Occupational therapy, horseriding, music therapy and many other therapies are available but must mostly be paid for by the parents.



One of the posters from the 2005 poster campaign

European Down Syndrome Association news



Situation of schoolchildren

The situation for children up to 6 is good – about 90% go to their local kindergarten.

The number of children between 6-12 years old in mainstream primary schools is dramatically low. It varies from 2% in the southern part of Germany to perhaps 25 -35% in cities like Hamburg or Berlin.

The total number of children between 12-18 years old who attend mainstream secondary schools is even lower and varies between 0-5%.

Most children with Down syndrome in Germany still attend special schools. As the special school system is very established, it will be very difficult to change this situation.

Situation of adults

All adults with Down syndrome work. About 90% work in sheltered workshops, where they are involved in a range of (sometimes very mechanical) tasks. However, nowadays the workshops offer a lot more other working options as well, like gardening, pottery, woodwork etc.

A small percentage of young adults work in the mainstream work place, often assisted by a job coach service.

Younger adults live mostly in group homes (40 to 50 persons), some in small units with 6 to 8 persons. But there are still some very big institutions in Germany with up to 1000 individuals with a mental disability living there, among them many mostly older persons with Down syndrome.

Some adults stay with their parents, some live in special villages (anthroposophic-based), and very few live on their own, with a friend or as a couple, with as much support as needed.

The number of persons with Down syndrome over 50 years old is approximately 3000. We do not have exact numbers.

They mostly live in the big institutions, where they still have the option to work in a sheltered workshop as long as they are able to do this.

Medical and psychological care is insufficient as there is not enough knowledge among medical staff about the special problems they might have when getting older.