

## European Down Syndrome Association news

### United Kingdom Down's Syndrome Association UK



**Internet:** [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

**Founded:** 1970. Membership led organisation

**Chief Executive:** Carol Boys

**Members:** 19,000

**Finances:** Members pay fees. Funds are obtained from Grant making trusts, companies, national funding bodies (lottery etc.), donations, literature sales, training, legacies and some small amounts of government funding

#### Main goals

The Down's Syndrome Association UK is an information and support organisation. The Trustees of the organisation are made up of people with Down's Syndrome, parents/carers and professionals with an interest.

The aims of the DSA are to provide information, support and training through conferences, seminars and the publication of journals and literature. The DSA supports applications to research funders from academic establishments and has in the past funded research from its own funds.

The DSA is also a major campaign organisation in the UK in the field of Down's syndrome and learning disability.

#### Services

- counselling
- rehabilitation
- seminars, courses

- library
- family days, leisure activities

#### Publications

The DSA publishes the *'Journal'* four times a year. Other information: the DSA has a large selection of information leaflets and resource materials for people with Down's syndrome their parents/carers, siblings, teachers, medical professionals and anyone with an interest in Down's syndrome

Other: Every year the organisation produces a calendar of images of children and adults with Down's syndrome and in recent years we have held a photographic exhibition as a launch pad for Down's Syndrome Awareness Week in June.

#### Awareness campaign

The DSA holds an Awareness week every year in June. This is usually accompanied by a campaign on an issue that may be current in the UK.



**Carol Boys, Chief Executive**

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The organisation has successfully campaigned for the rights of children with Down's syndrome to be included in ordinary schools and it has carried out major health and welfare campaigns over the years.

### Projects and campaigns

Our main projects in the next years:

The DSA works with and funds the Down's Syndrome Medical Interest Group in the UK and they have produced Medical Surveillance Guidelines for medical professionals working with people with Down's syndrome.

There are a number of research projects underway at the moment including a triple blind study of 160 babies from birth to 18 months and Vitamin and Mineral supplements. There is also research into ageing, Alzheimer's Disease and speech and language production in children with Down's syndrome.

The Association works with families who have been given a pre-natal diagnosis and has contributed to government documents that are available in maternity hospitals around the UK.

### General information

Most new parents of children with Down's syndrome are referred to the DSA UK by their medical professionals and others obtain information from our web-site. The DSA has recently collaborated with The Down Syndrome Educational Trust and the Department for Education in the UK to produce Early Support materials for families of children from 0-3 years old.

### Numbers

In the UK, about one baby in 1,000 is born with Down syndrome, resulting in about 600 births each year.

### Situation of babies and toddlers under 4 years

Medical care, physiotherapy and early intervention is good. Speech and Language therapy is still not as readily available as we would like it to be, but most children with Down's syndrome in the UK have access to a therapist, however infrequent that might be.

### Situation of schoolchildren

There are no firm statistics of the placements of children in schools at the moment.

Generally speaking, most children with Down's syndrome can now go to mainstream schools but it is still not easy to get funding for the right level of support in the classroom for them. Some parents still choose the special school option.

### Situation of adults

Adult services are less than satisfactory in the UK and good college opportunities are not so readily available.

There are more organisations setting up to provide work and housing for people with learning disabilities but there is still a long way to go. Some people with Down's syndrome work in supported employment (in their local supermarket, restaurant or in farming and horticulture) but many will be at home with daily visits to an adult training centre.

The UK government has a strategy in place called 'Valuing People' which was meant to revolutionise adult services for people with learning disabilities in the UK, but things have not happened as quickly as we would have liked and the stumbling block is, as usual, funding. The DSA is a member of a campaign group to monitor the progress of the strategy.

The typical situation for adults with Down's syndrome, if they were lucky enough to get the funding from their local government authority, would be to live in supported housing projects together with approximately six or seven other people.

DSA Awareness Week • News • Survey Update • Adults in Employment • PMS • and much more...

## JOURNAL

NEWS AND VIEWS FROM THE DOWN'S SYNDROME ASSOCIATION

