



**DOWN'S
SYNDROME
ASSOCIATION**
A Registered Charity

12 August 2004

FEEDBACK FROM THE DOWN'S SYNDROME ASSOCIATION

ON

**'IMPROVING THE LIFE CHANCES OF DISABLED PEOPLE'
ANALYTICAL REPORT**

The Down's Syndrome Association is the main UK charity dealing with all aspects of living with Down's syndrome. A copy of our most recent Annual Review is enclosed.

In recent years, the Down's Syndrome Association has carried out three pieces of research into areas where people with Down's syndrome are disadvantaged.

All three reports give evidence of discrimination against people with Down's syndrome. They also make recommendations for change and would repay detailed study for the purposes of this project.

To follow is a summary of issues to be taken into account when proposing strategies to improve life chances for people with Down's syndrome. These are:

- Evidence of the problem
- Identifying the barriers
- Priorities for change

1. EVIDENCE OF THE PROBLEM

Summaries of the key findings of the reports carried out by the Down's Syndrome Association into the provision of health, education and benefits are as follows. Full copies of the report are enclosed and are also available on our website www.downs-syndrome.org.uk under 'campaigns' in the 'information' section,.

1.1 WELFARE BENEFITS SURVEY – Benefits agency fails one in three people with Down's syndrome (2000)

- 89% of people with Down's syndrome in the survey get Disability Living Allowance.
- 32% of people have had problems getting the correct rates of Disability Living Allowance or getting DLA at all.

- 53% (370 cases) of the problems with getting Disability Living Allowance are problems with the initial claim when the child is very young.
- If people pursue their claim for Disability Living Allowance, through the review/appeal process, then they are likely to be successful.
- The overall rate of success at appeals where the outcome is known is a staggering 80%.
- Only 66% of people over 16 are said to claim Severe Disablement Allowance and/or Income Support.
 - How likely you are to have problems in claiming DLA depends to some extent on where you live. There seems to be a post code lottery in claiming DLA.

1.2 ACCESS TO EDUCATION – A report on the barriers to education for children with Down’s syndrome (2004)

A third (32%) of parents of children with Down’s syndrome have experienced discrimination or prejudice from education professionals

51% of parents reported a lack of specialist knowledge and skills amongst education professionals, with a further 40% of parents feeling that schools lacked appropriate materials and resources for teaching children with Down’s syndrome

Two thirds (66%) of parents find state provision of essential speech and language therapy is inadequate for their child’s needs

One third (33%) of parents found getting a statement of special educational needs difficult with 43% making representations or going to tribunal to get an acceptable statement agreed

1.3 “HE’LL NEVER JOIN THE ARMY” – People with Down’s syndrome denied medical care (1999)

28 per cent of respondents indicated that they had experienced some degree of discrimination when seeking health care for their child with Down’s syndrome. Evidence of discrimination in various forms, is provided by the parents’ testimony included in the report.

Comments from parents included the following:

“The consultant obstetrician, directly after Sarah's birth, commented to two junior doctors in my hearing that, "Perhaps ante-natal testing should be insisted on so that Down's babies weren't born ". Mother of an 11 year old.

"Our only criticism relates to a female doctor who continually referred to Aymee as a 'Mongol'. This we found to be totally unacceptable, plus her total putting down of Aymee having any chance of leading a near normal life."

Tom is now 13; when it was discovered that his eyesight was very poor, the ophthalmologist said, "We won't bother with glasses as he's not what you would call university material."

"When Daniel had his first heart operation he was in a lot of pain. We were told by staff when we asked for pain relief, "Oh, he has Down's syndrome; they don't feel any pain."
Daniel is now 8 years old.

Our son was described by a Senior Physician as "an unacceptable burden on resources medically, socially and educationally."
Father of an 8 year old boy.

2. IDENTIFYING THE BARRIERS

2.1 Attitudes and discrimination

The research carried out by the Down's Syndrome Association has the common theme that the biggest barriers to opportunities for people with Down's syndrome are ignorance and discrimination caused, in the most part, by a lack of knowledge of the condition and by adherence to myths or outdated stereotypes.

2.2 Lack of co-ordination in services

Other barriers include lack of co-ordination between services e.g. education and health, with resulting failure to make timely provision of e.g. speech and language therapy which is frequently passed from 'education' to 'health' and back, being disowned by both when budgets and resources fail to provide. There is a particular tendency for service providers in all areas including health, education and social care to want to refer to a non-existent and non-essential "learning disability expert" failing to see that the provision of their services is the key issue, not the presence or otherwise, of a disability.

2.3 The disability profile

Unlike the majority of disabled people identified in the analytical report, physical disability, with its accompanying physical barriers to inclusion, is not generally part of the disability profile of someone with Down's syndrome.

The common factor is a degree of learning disability. In addition to this, health problems which are more common in people with the condition may lead – avoidably - to further disability if health care is inadequate.

The degree of learning disability, and the presence of associated aspects of disability such as autism or poor health, cannot be homogenised. It is essential that each person with Down's syndrome is assessed and provided for as an individual. It would be unwise to be overeager to define 'disability types' in a one-size-fits-all approach.

2.4 Empowering people with Down's syndrome

The Involvement of service users in decision making is acknowledged to be a vital part of provision of choice. For people with Down's syndrome, the emphasis should be on provision of differentiated and accessible information and also of advocacy where required.

3. PRIORITIES FOR CHANGE

The following issues require urgent attention and are the Down's Syndrome Association's priorities for improving the life chances of people with Down's syndrome:

- Provision of awareness and attitudinal training for at least a basic level of understanding of Down's syndrome amongst ALL service professionals e.g. health, education and social care, who are likely to encounter people with Down's syndrome through their work.
- Provision of special more in-depth training and information on specific issues relating to Down's syndrome for professionals who are likely to encounter specific needs e.g. Down's syndrome and dementia for psychiatrists, Down's syndrome and its unique learning profile for education professionals who have children with Down's syndrome in their schools, etc.
- Provision of accessible Direct Payments for people with learning disabilities. Currently, a tiny minority of adults with Down's syndrome have the support they need to design and purchase their own care package via Direct Payments.
- Provision of appropriate age-related health checks for people with Down's syndrome. These include proper cardiac evaluation at birth to identify and treat the 40% of babies with Down's syndrome born with a heart defect, and awareness of the signs for the 40% of people with Down's syndrome who will develop early on-set Alzheimer's disease. These health checks should include regular screening for conditions more common in people with Down's syndrome, such as depression and thyroid disorders.
- Provision of joined up early intervention across all care disciplines from birth.
- Provision of adequate Speech and Language Therapy through an urgent increase in funding, plus the training of existing Therapists in Down's syndrome and the recruitment of new therapists.
- Provision of coherent transition services followed by appropriate and tailored care, employment and accommodation options for adults with Down's syndrome.

Submitted: Thursday 12th August