

Date: 6 February 2002
Venue: Committee Room 3, National Assembly for Wales
Title: Response from the Downs Syndrome Association

Ms Claire Morris
Deputy Clerk
Social Services Committee
National Assembly for Wales
Cardiff Bay

18 December 2001

Dear Ms Morris

Health and Social Services Committee review of health and social care services for children with special health needs

The Down's Syndrome Association is the lead voluntary organisation representing the needs and interests of the estimated 5,000 people with Down's syndrome living in Wales.

C.A.R.I.S. data for 1999 showed that there were 127 reported cases of Down's syndrome in the 12-month period (1998-9), resulting in 62 births of babies with the condition across Wales. The DSA provides information, advice and support to many of these families.

Support is provided across the whole age range, but as might be expected, much of this advice and support is most needed during the earlier stages of life and during childhood.

The majority of families of children with Down's syndrome have very positive experiences of the health and social care services they receive on behalf of their child. This is increasingly apparent through the greater understanding of and therapeutic treatment of some of the health problems over-represented in children with Down's syndrome (for details of these conditions, please refer to the enclosed document *Basic medical surveillance essentials for people with Down's syndrome*). Although the majority of

families are broadly satisfied with the health-care services provided, a major survey of our members in 1998 demonstrated that 28% (426 families) reported a high level of dissatisfaction (see the enclosed DSA report "*He'll never join the army*"). This report suggests that despite a decade of government commitment to the health care of people with learning disabilities - *The Health of the Nation: a strategy for people with learning disabilities* (Department of Health 1995), change seems to be very slow.

The DSA welcomes the review of the health and social care services for children with special health needs. We have hopes and expectations that this review will lead to changes and improvements in the services provided for children with Down's syndrome. At this early stage of requesting evidence on key issues that will inform the review process, the DSA is keen to highlight the following areas of concern:

(taking key headings from the Assembly's letter)

1. The early identification and diagnosis of special health needs. Obviously, as Down's syndrome is a genetic condition diagnosis is usually confirmed within the first few days of life (and in some cases pre-natally). In addition, babies and children with Down's syndrome may have a number of associated health problems related to their heart, hearing, vision, growth and thyroid function, where diagnosis may not be possible until later in the child's life. Accurate and up-to-date knowledge of these associated health problems together with appropriate clinical surveillance is therefore essential. For a breakdown of the recommended surveillance essentials please refer to the enclosed document on Basic medical surveillance essentials. With regard to the issue of pre-natal screening, the DSA accepts that pre-natal testing for Down's syndrome is now a routine part of ante-natal care. However, we strongly believe that any programme of testing for a genetic condition **must** be accompanied by non-directive counselling. Those associated with a pre-natal testing service must also recognise that identification of Down's syndrome during the pre-natal period should not necessarily lead to termination - a pregnant woman and her partner should be supported in exploring the options available to them. The provision of accurate and balanced information (examples of DSA booklets enclosed) is vitally important.

2. The provision of information to parents/guardians. Access to good quality information resources can be particularly helpful to families of children with Down's syndrome. The Association produces a range of information booklets, leaflets, videos and internet resources and frequently publicise or make available copies to maternity units and children's centres across Wales. We know that in many cases this information does not reach those who need it most. It can be particularly difficult and frustrating trying to reach new families of babies and children with Down's syndrome, as we have no way of contacting them directly. A referral to us by a paediatrician, mid-wife or health visitor is one effective way of ensuring that a new family receives the information and support they need.

3. The co-ordination of care. This is an area, that in many cases, can be fraught with difficulties, as there can be significant challenges for families in ensuring their child receives all the care they need. Due to the fact that health and social care services are typically organised on a local (Health authority / Unitary Authority basis) it can be particularly difficult for an organisation like the DSA to provide advice. For example, a family living in one area may be provided with a portage worker, whereas in a

neighbouring area this service might not be provided, or it may be called something different. Some families have an excellent relationship with their paediatrician or specialist health visitor, while others may find themselves apparently lacking one named individual professional to co-ordinate the health services their child receives. Parents can very often be frustrated by a lack of communication between the 3 agencies of health, social services and education. This can be particularly evident at the stage where their child receives a Statement of Special Education Needs. Problems can arise in the process of obtaining reports and evidence needed by officers producing a statement or in the review process. There are also frequent problems associated with the funding of services that are traditionally regarded as a health authority responsibility e.g. speech therapy and other allied therapies such as physiotherapy.

4. Availability of care and treatment. The DSA would like to register a very strongly felt concern about the availability of speech therapy services in Wales. The current provision is woefully inadequate and we fear that the development and learning ability of children (and thus the overall potential for independent living of adults with Down's syndrome) is being severely compromised. This is due to the insufficient (and in many cases absence of) speech therapy services across Wales. There are particular additional problems for children who attend Welsh-medium schools or who live life bi-lingually. We are aware of some areas in Wales where there have been vacant speech therapist posts for a number of years. The recruitment and retention difficulties of some health trusts needs to be addressed as a matter of urgency.

5. Support for families and other carers. There appears to be a very ad-hoc basis to the funding of respite care or family sitting services across Wales. Some families have access to a very high quality and flexible service, while others (in the majority) have no provision. We are increasingly aware of the support needs of teenagers with Down's syndrome who need support in accessing integrated leisure activities away from their parents. Equipping young people with Down's syndrome with the necessary life and social skills to be independent in adulthood is a prime objective of many families who feel they are given little support in helping their children in this very important area. We know that the needs of siblings of children with Down's syndrome are often overlooked and are aware of some projects that offer examples of good practice e.g. Merthyr Sure Start, Ceredigion Family Support Team.

6. Children with special educational needs. We are aware of a number of children whose placement in a mainstream school has been jeopardised because of a lack of understanding, or in some cases a refusal of teaching or support staff to have any involvement with even basic health / personal care needs of a pupil with Down's syndrome e.g. supervision of medication / monitoring of a catheter and alerting parent if a problem arises during the school day. We appreciate that this is a matter of concern to the training / professional bodies / unions representing education staff and will be affected by the policies of these bodies and the relevant Education Authority. Under this section, we would again draw your attention to our comments about speech therapy.

7. Good practice. The Association has a team of specialist advisors and information officers (including medical advisors, educational advisors and a speech and language advisor) that can contribute to or disseminate examples of good practice. The DSA is well advanced with a web-based training package for health professionals, which will be formally launched in the spring.

In conclusion, I would record the points raised are initial areas of concern. They represent ideas compiled of the Wales Regional Office of the Association in consultation with Officers of the DSA and members of the All Wales Committee of parent members. We are happy for our comments to be shared with a wider audience.

We would particularly welcome the opportunity to give further oral evidence in February or March. This will give us further time to consult with our membership on a wider basis.

Yours sincerely

Julian Hallett
Regional Manager Wales