

PROPOSAL TO DEVELOP A TRAINING NETWORK FOR SPEECH AND LANGUAGE CO-WORKERS FOR CHILDREN AND ADULTS WITH DOWN SYNDROME

1. Introduction

- 1.1 Current research and empirical evidence from practitioners, indicates that people with Down syndrome have a predictable profile of speech, language and communication difficulties. This profile includes the existence of sensory disturbance and eating and drinking difficulties.
- 1.2 Research conducted in Belgium, indicates that there are some individuals with Down syndrome who have a typical profile of communicative competence.
- 1.3 The experience in this country is that all children present with a disordered profile of communication skills albeit individuals may be differently affected.
- 1.4 Despite a dearth of evaluative studies, it is clear to clinicians practising with people with Down syndrome that the identified profile of speech, language and communication may be assisted and to some considerable extent remediated, through the provision of targeted intervention of a specialist nature.
- 1.5 Parents and carers of people with Down syndrome are not concerned with the achievement of perfect speech, but they are concerned to ensure that their relative with Down syndrome is given every opportunity to develop their own personal potential.

2. Current Position

- 2.1 People with Down syndrome are entitled to support to develop their speech, language and communication through the provision of speech and language therapy services.
- 2.2 The provision of such services at the pre school stage is the responsibility of the NHS. The service is part of primary care services and as such, children have no statutory right to this service. The provision of speech and language therapy services varies widely across the country. Provision depends upon local identification of need, community priorities and resourcing levels.
- 2.3 At school age, the provision of speech and language therapy services more commonly and properly, rests with the Local Education Authority. Parents who have fought, often through to tribunal, to ensure that provision is available, are too often disappointed to then receive services that are delivered by inexperienced therapists with little knowledge of the needs of children with Down syndrome.
- 2.4 The lack of speech and language therapists is a serious factor. There are approximately 8,000 practising Speech and Language Therapists in this country to

meet the needs of hundreds of thousands of people with communication difficulties.

- 2.5.1 Speech and language therapists treat clients with all forms of disabilities, including people with head injuries, stroke, physical disabilities, learning disabilities and children with developmental disorders, fluency and speech disorders. People with Down syndrome are but one group of individuals requiring speech and language therapy.
- 2.5.2 There are approximately 20,000 children with Down syndrome under the age of 16 years in this country. When we consider the numbers of adults that number more than doubles. Each speech and language therapist would need to hold a caseload of 5 clients with Down syndrome, in addition to all other communication-impaired clients.
- 2.6.1 In addition to recognising the particular communication difficulties experienced by people with Down syndrome, we are also aware of the particular models of service that most effectively meet their needs. Children and adults with Down syndrome learn at an accelerated rate and sustain that learning most effectively, when they receive specialist intervention in a group setting coupled with opportunities to engage in a language rich environment. Children and adults do well in an atmosphere of high expectations and realistic goals.
- 2.7 Across the UK there are few services that offer intervention in the way described above. Increasingly, NHS services are beginning to emulate these models of good practise, but currently these remain few and far between.
- 2.6.2 Within Symbol UK Limited the services provided to children and adults with Down syndrome are delivered via a team of experienced and highly trained speech and language therapists. Services are delivered via regular therapy in group situations. Where children are of school age, a school-based programme backs up their service.
- 2.6.3 For older children entering the programme we adopt a 'functional approach', which addresses their communication needs as they present in their every day life. A central component of the therapy plans for adults is the development of clear speech programmes in order to develop their everyday competence at speaking.
- 2.6.4 We are currently able to meet the needs of some 200 children across the south of England. This is a very small number and represents a deep inequality in provision. We plan to extend our provision in 2003/2004 to increase our group provision by 6 sites that will increase our provision to a further 120 children.
- 2.6.5 These services are privately funded although many are supported by charitable donation. Some groups have acquired statutory funding and in some cases Local Education Authorities have picked up the funding responsibility e.g. Buckinghamshire Education Authority where Symbol is funded to provide a county wide school support service for children with Down syndrome and Bromley Primary Care Trust who fund a service to all adults with Down syndrome in the London Borough of Bromley.

3. Meeting the Need

- 3.1 Quite clearly the current situation requires a radical and innovative solution. We cannot expect the answer to lay in the future provision of speech and language therapy services. The limited specialist resources need to be employed in the most efficacious manner to meet the needs of the maximum number of people with Down syndrome.
- 3.2 The development of an extensive education and development programme for professionals in health and education services is an important component to any plan to meet needs but will not in itself, be sufficient. It will not meet the needs of children awaiting services today.
- 3.3 The Down's Syndrome Association and Symbol have developed a plan to meet the communication needs of children and adults with Down syndrome across the UK. It is ambitious and exciting, capable of achieving radical change and securing the support of professional organisations such as the British Paediatric Association and the Royal College of Speech and Language Therapists.
- 3.4 It is our expectation from preliminary discussions that the government agencies of Health and Education would support our programme.
- 3.5 We would like to set up a network of services for people with Down syndrome delivered by trained co-workers recruited from a range of backgrounds across the country.
- 3.6 This training network would be characterised by:
 - The recruitment of a network of personnel with an interest in enabling the development and life opportunities of people with Down syndrome, working under the direction of specialist speech and language therapists', providing targeted, evidence based intervention to our population;
 - The development of an accredited training programme consisting of a modular programme aimed at the remediation of the speech, language and communication needs of this population;
 - The development of a supervision network staffed entirely by speech and language therapists and specialist teachers;
 - The use of video conferencing and internet ready approaches for assessment and target setting;
 - The development of a practice manual available in hard copy and on CD Rom.
- 3.7 Our aim would be to have 36 co-working personnel offering services across the UK within one year from the commencement of the programme. This would increase the provision to an additional 1,000 children and adults in one year. This programme would increase numbers year on year.

- 3.8 The Down syndrome Association are seeking funds to commission Symbol to develop this programme and to achieve a self-financing service within five years.
- 3.9 The initial budgets require funding in Year 1 of the programme of £140,000 with additional funding of £40,000 per annum in Years 2 to 5

4. Timescale

- 4.1 The Down's Syndrome Association and Symbol are in a position to commence work on this programme as from April 2004. A detailed plan of work would be prepared at that time and reporting requirements agreed. We recommend that we approach Professor James Law from City University to provide independent evaluation of this programme.

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