

Therapy Provision for Disabled Children in Wales.

Children in Wales wish to raise concerns on behalf of the Voluntary Sector in relation to the provision of therapy services for disabled children. . Members of The Children in Wales Forum on Issues for Disabled Children and Young People have provided the evidence presented and many feel that the development of some of the disabled children known to them has been adversely affected by the shortage of therapy provision.

The provision of a range of therapeutic interventions is key to assisting disabled children in their development and maximise independence. The decision for a child to receive therapy provision is usually made following an assessment of a child's needs by a paediatrician. Following this assessment the child or young person is referred to the therapists that can meet their needs. Therapy services are highly valued by parents and carers as they are by children and young people.

There are many therapies available that a child or young person could benefit from, these include: -

- Occupational therapy – which aims to maximise potential for independence in activities of daily life (for children these include play, school and social skills),
- Speech and language therapy – which aims to maximise a child's potential to communicate (including eating and drinking skills which require the same postural background needed for speech and non verbal methods of communication) and
- Physiotherapy – which uses specific handling techniques and activities to maximise potential of posture and movement for function.

In addition to these three therapies, other therapies available include: -

- Play therapy.
- Music therapy.
- Sand therapy.
- Behaviour therapy and psychotherapy.
- Art therapy.
- Drama therapy.

All of the above therapies can be used to benefit disabled children but it is the lack of provision of, and difficulties in accessing, speech and language therapy, physiotherapy, and occupational therapy, in particular, which is currently causing concerns the voluntary sector in Wales.

There has been a lack of speech and language therapy provision in parts of Wales for many years. This situation has been recognised by the Welsh Assembly Government who in 2003 published a consultation document entitled "Working Together – Speech and Language Services for Children and Young People" which made 17 recommendations around patterns of need and provision of service, Welsh medium and bilingual therapy, training, recruitment and retention of speech and language therapists and collaborative working.

However many in the Voluntary sector feel that the situation still has not improved. Julian Hallett – Director of the Downs syndrome Association reports that "One of the biggest issues for many of the families that we support is an absence of speech and language therapy. I have been in this job for 9 years – it was a real problem when I started and has got worse. Speech and language Therapists are working flat out,

they have ridiculously large caseloads and in many cases have a backlog of many months just to do the assessment and then can't follow this through by monitoring a language programme because they haven't the staff. "

Where staff are available, there is often a long waiting list for assessment usually another wait for intervention whether by the therapist or the implementation of a programme. Community therapy is in blocks, the child usually having to go back on the waiting list after completion of one block.

For those families who seek to access services through the medium of Welsh there are additional challenges as there is a very severe shortage of Welsh speaking therapists. As a result children accessing Welsh medium education have to have therapy through the medium of English. This can result in parents, who had originally chosen to opt for Welsh medium education changing to English because they felt that their child could not get the support through the medium of Welsh.

An All Wales Survey of Community NHS Occupational Therapy Services for Children with Disabilities / Developmental Problems was undertaken by the All Wales Network of Children's Occupational Therapists in March 2004. The report raises serious questions in regard to equity of access to occupational therapy services across the whole of Wales and concerns that there must be whole groups of disabled children being denied services due to a scarcity of resources. The report also identifies that Ceridigion has no health occupational therapist. Voluntary sector providers and statutory partners have raised concern about this situation on many occasions.

Other areas of Wales are also under resourced given the numbers of children who receive a service and those who are waiting to be seen. The Manager of the Barnardos short term breaks service in Monmouth highlights the lack of resources for occupational therapy provision and the long waiting lists.

She adds: - "We know from our requests for OT assessment and support that the one half time OT (Local Authority) is not adequate. Waiting lists are lengthy and we sometimes are unable to provide support with foster carers and other carers because the OT service cannot respond. It is substantially under resourced. "

Some voluntary sector providers are challenged with the view that provider agencies should provide their own OT input in order to support services for children with a physical impairment. Providers cannot afford this with already limited budgets, and are also keen to work within the identified therapy plan, rather than ask the child to be reassessed. One Voluntary sector partner who reported this issue felt that it was a reflection on the amount of work Occupational Therapists are already being asked to do, and the fact that they are overwhelmed by demands.

The paediatric physiotherapy services are highly regarded services, however physiotherapy case loads across Wales are much higher than the 30 recommended and in some settings there are no appropriate facilities that can be used for therapy and physiotherapists give examples of having to carry out programmes of treatment in toileting areas or bathrooms.

Due to the deteriorating nature of most of the disabling conditions that physiotherapists deal with, disabled children's cases stay open for the whole of their childhood. This is not recorded by waiting list statistics. There are hidden waiting lists of extended reviews and tasks to do. In addition paediatric physiotherapist are keen to be responsive in the belief that the longer a problem is left, the harder it will be to resolve later.

The lack of therapy provision impacts directly on children who receive a service from the voluntary sector also. This is highlighted by the following response from the Manager of Viva in RCT.

“I am aware of the lack of therapeutic interventions that would help the children and young people we work with enormously. Parents decry the lack of speech therapy where it should be available at an early age, and they don't get to see a speech therapist for up to 2 years after referral. We know the help that drama therapy gives young people with behaviour problems - the project occasionally buys it in but it is very expensive for us as a charity with very little core funding. Art and music also have calming effects on behaviours - but these are impossible to access here.

An example of good practice highlighted by many professionals and parents alike is the Bobath Children's Therapy Centre Wales. Bobath therapy is a concept of treatment pioneered by Dr and Mrs Bobath. It is an interdisciplinary approach to the care of children with cerebral palsy and involves physiotherapists, occupational therapists and speech and language therapists. Parents and child are consulted to help decide on the specific goals for the child during the therapy period, which involves intense therapy sessions over a short period of time. Bobath is a registered charity and no charge is made for the service, which can cost over £2,000 for a two-week therapy block.

The Dyscovery Centre provides a similar service for those who have development coordination disorder, dyslexia, dyspraxia, ADHD and Aspergers. Here the Team of professionals also includes a medical advisor, educational psychologists, and psychiatrist in addition to a speech and language therapist, occupational therapists and a physiotherapist. Unlike the Bobath Centre, the Dyscovery Centre is a private company and carries out assessments for the NHS and parents at a cost. However there are concerns that after a child has been assessed at the Centre, there is a lack of therapists on the ground to follow through any programme.

For some professionals the question of therapy provision is not as simple as do we need more therapists? One Community Paediatrician argues that what is needed is “therapists working within multidisciplinary teams in an evidence based way. They must be seen as a resource along with the community paediatrician. “

These arguments in relation to difficulties in the provision of occupational therapy, speech and language therapy and physiotherapy have all been rehearsed over the years but the situation still has not improved. Professionals across the sector are both frustrated by the current situation, and concerned for the children and young people that they support. As evidenced by two quotes from members who contributed to this report.

“Sorry about the diatribe - but this is a subject I feel very strongly about. Early interventions - especially in speech and language can make such a profound difference to a child's progress and development”

“I apologise for being on my soap box but this is an issue that needs to be addressed as my own son had this problem 21 years ago”

Lynne Hill
Policy Director
Children in Wales.