

Shortage of Therapy Provision for Disabled Children in Wales

Introduction

As a result of their disability, many disabled children experience delays in development, and can be dependent upon other people. In order to assist in their development and maximise independence, many disabled children receive therapy provision.

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.

Range of Therapies Available

There are many therapies available that a child or young person could benefit from. Probably the three most well known therapies are :-

- 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 the main three therapies described – other therapies available include :-

- Play therapy – which is a mode of therapy that helps children to explore their feelings, to express themselves and to make sense of their life experiences;
- Music therapy – which is the prescribed use of music and musical interventions in order to restore, maintain and improve emotional, physical, physiological and spiritual health and well being;
- Sand therapy- which is used as a medium for children who have been sexually abused;
- Behaviour therapy and psychotherapy which can be particularly be used for children and young people who are on the autistic spectrum disorder:
- Art therapy this offers an opportunity to explore intense or painful thoughts and feelings in a supportive environment. It involves using a wide variety of art materials to create a visual representation of thought and feelings.
- Drama therapy which has as its main focus the intentional use of healing aspects of drama and theatre as the therapeutic process. It is a method of working and playing that uses action methods to facilitate creativity, imagination, learning, insight and growth."

All of the above therapies can be used to benefit disabled children but it is the lack of provision of speech and language therapy, physiotherapy, and occupational therapy which causes huge concerns for parents / carers and disabled children and young people alike. In many parts of Wales there is a shortage of therapy staff who work in all of these areas.

This paper will examine this issue in more detail and look at how the shortage of therapy provision impacts on children who use voluntary sector services. 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 the disabled children known to them has been adversely affected by the shortage of therapy provision. Provision of each of the three main therapies will be discussed individually. This will be followed by a summary of the main issues, and recommendations as to how the situation can be improved.

Speech and Language Therapy Provision

There has been a lack of speech and language therapy provision in many 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, collaborative working.

However many felt 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. “

Even if there is staff available – there is often a long waiting list for assessment and ongoing therapy. This issue has been highlighted by a member of the Powys referral scheme 'Pawb Ynghyd' which supports disabled children to access local playgroups. She highlights the case of a child who attends one playgroup in Powys. The child has complex needs and had been assessed as needing speech and language therapy. To avoid waiting months, her parents decided to pay for her to have private therapy at a cost of £50 a session.

Staff from SNAP – The Special Needs Advisory Project, who support children with special educational needs, experience the same situation. The Projects representative on the Children in Wales Disabled Children's Forum reports that there is a lack of speech therapists in most parts of Wales. She adds “although the Local Education Authority “buy in” a specific amount of therapists time – cover is rarely provided by health if the therapist is off. There is also a long wait for children/young people to be assessed and usually another wait for intervention whether by the therapist or the implementation of a programme in a school setting. Community therapy is in blocks, the child usually having to go back on the waiting list after completion of one block.”

Welsh Language speech and language therapy

Another issue is the non-existence of Welsh speaking therapists, thus causing children accessing Welsh medium education having to have therapy through the

medium of English. This raises the question of how does the therapist assess the needs of the child if they themselves are not bilingual?

This in turn has a knock on effect with parents who had originally chosen to opt for Welsh medium education changing to English because they felt that their child would not get the support through the Welsh medium stream.

Occupational Therapy Provision

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 Ceredigion has no health occupational therapist. The Team Manager of the Family Support Team in Ceredigion has raised concern about this situation, which has been ongoing for years, on many occasions. The Local Health Board believes that it is the responsibility of the Health Trust to provide the service and vice versa. As a result the issue has been passed back and fore between the two bodies and no service has been provided. 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 also 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. “

The Barnardos scheme in The Vale of Glamorgan in its responses also make reference to the shortage of Occupational Therapists and the long waiting lists.

“In my experience there are a shortage of OT's for disabled children and referrals for this service take a very long time to action. In one case I have known provision of specialist OT support re: sensory integration for an autistic child. The work is being done in conjunction with a behaviour specialist. While this input has been extremely valuable, the therapists have not had enough time available to them to make this work as intensive as required and it has also proved impossible to access this provision for other children who would benefit from it. “

The Barnardos scheme in Cardiff also raises the view held by some that an occupational therapists should be provided by the provider agencies:-

“In addition, there is a 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 only asking to access the assessments that have already been carried out. This seems to be a reflection of the amount of work OTs are already being asked to do, they are overwhelmed by demands.”

Physiotherapists

The paediatric physiotherapy services are often highly regarded by parents. Responses were received from professionals working with disabled children in Gwynedd and Monmouth who reported that parents had high praise for the physiotherapy services in each authority.

However physiotherapy case loads across Wales are much higher than the 30 recommended and in some schools 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. Also because of the deteriorating nature of most of the disabling conditions that physiotherapists deal with, we can't have waiting lists, or discharge children disabled children stay open for the whole of their childhood. This is not recorded by waiting list stats. There are just hidden waiting lists of extended reviews and tasks to do. In addition paediatric physiotherapist are notoriously bad at being able to say no to new referrals particularly if they believe that the longer a problem is left, the harder it will be to resolve later.

General issues

An issue with the provision of all therapies arises because the Education Act 1996 does not impose an absolute duty on Health Trusts to comply with requests from the LEA for children with SEN whom it does not consider to be a priority. The issue of primary and ultimate responsibility further complicates the matter whereby the responsibility for providing therapy services primarily sits with Health Trusts, provision under the Education Act sits legally with the LEAs. This creates major conflicts particularly in situations where Tribunals direct that therapy be written into Part 3 of a statement for a child who is considered to be low priority (based on clinical need) for an individual therapy service. LEAs in such situations have to buy in therapy at great cost. A change in legislation may be the only way to resolve the primary and ultimate responsibility anomaly and begin to align aspects of the resources with those who have the legal responsibility for service provision.

As highlighted earlier, the lack of therapy provision not only has an impact of children known to the statutory sector but those 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 up here.

Many Professionals also believe that with the highlighted attention on the rights of the child and young people, there is renewed pressure for appropriate access to therapies. Until now paediatric care has not had a high profile and in terms of finding there is no access to initiatives such as waiting list or emergency pressures moieties.

Example of Good Practice

An example of good practice highlighted by many professionals and parents alike is the Bobath Children's Therapy Centre Wales. Babath 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, 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. Local authorities sometimes however find that after a child has been assessed at the Centre, there is a lack of therapists on the ground to follow through any programme.

The Way Forward

When working with disabled children – it is vital for health, social services and education to work together. Clarity of role is also needed with all professionals understanding each other's roles and having a respect for the skills that other professionals bring. All services should have a focus on the child and family and open communication between agencies is also vitally important.

There also needs to be a far greater integration of acute and community services than exist at present. Also some professionals in the field feel that the purchaser provider issues produce unnecessary complications.

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". He continues, "they must be seen as a resource along with the community paediatrician."

Some local authorities have come up with their own solutions. Eg Bridgend LEA employ some speech therapy assistants to deliver programmes to children in school but are unable to fund sufficient to meet demand. A child is assessed by a therapist and has regular updates of their programme, This method of delivery ensures that a child isn't kept waiting for therapy sessions with the speech therapist, doesn't have to leave school and the programme is delivered within the context of his/her learning environment and the onus to attend a clinic is taken away from the parents.

Providing therapy to children within the school environment in this ways also leads to a decrease in the numbers of children who miss therapy appointments. Reasons why parents are unable to take their child for therapy in a clinic include the lack of transport, appointment times being set too early or too late which means that the parents are unable to take or collect siblings from school, literacy difficulties, two appointments being set in differing departments but at the same time and parents being fearful of therapists response following missed appointments. All the situations described above can be overcome, but to achieve this parents and professionals need to work together for the benefit of the child.

Conclusion

This paper has highlighted the wide variety of therapies that are available to meet the needs of disabled children and young people in order to assist in their development and maximise independence. Difficulties in the provision of occupational therapy, speech and language therapy and physiotherapy have been given, examples of good practice highlighted and suggestions made for the way forward.

These arguments have all been rehearsed over the years but the situation still has not improved. This must now change. Professionals, parents, children and young people have all had enough as the following remarks testify.

“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” –quote from a professional working with disabled young children

Therefore for the benefit of todays and future generations of disabled children and young people, the provision of therapy needs to be reviewed and changed – urgently.

Catherine M. Lewis
Children First Development Officer (Disabled Children)