

Committee	Care Scrutiny Committee
Date	September 13th, 2018
Cabinet member	Councillor Dilwyn Morgan
Subject	Autism Services for Children

1.Introduction

1.1 Derwen (Integrated Team for Disabled Children)

A members will be aware, Derwen is an integrated service for disabled children based on a formal Section 33 Agreement under the National Health Service Act (Wales) 2006 - Partnership Agreement.

1.2 The integrated team consists of Clinical Psychologists, Community Nurses, Social Workers, Duty and Customer Care Offices, and support services who all work with disabled children, including a high number of disabled children who have autism.

2. Autism

2.1 Over recent years there has been a strong emphasis on the needs of children and adults with autism in Wales. This is positive for this group, but it is important to note that there is a large number of other children who are receiving services, where there is not the same emphasis or resources allocated for their needs, but where their needs can be as intensive. It is critical when the needs of disabled children are discussed, that the whole spectrum, of needs are recognised, and to not focus on one group specifically.

2.2 (i) Neurodevelopmental Service

Over the last three years, there has been a lot of emphasis on establishing the Neurodevelopmental service for autistic children across Wales. The purpose of the development was to ensure consistency of services for children who were being referred to disabled children's services and to CAMHS (Children and Adolescent Mental Health Services) for assessment, to bring the waiting list down and to offer some intervention. Due to a lack of resources that came as a result of this development, it is not possible to see the expected consistency across North Wales. Unfortunately, waiting lists are longer, some resources were transferred for disabled children's services to the new service which has an impact on Derwen, and any intervention is based on short term grant funding. On a positive note, it does mean that all referrals for autism go to the same service and they are referred on to Derwen if they are disabled. In the past, all children under 5 were referred to Derwen for an assessment, but if they did not have a learning disability, they did not remain open to the team, and at times this led to complaints. In relation to the neurodevelopmental service, one deficit is that it consists of seconded health board staff only and very limited capacity is available form education. There is no social

worker attached to the team which means that families do not receive a carers' assessment for example.

2.2 (ii) Integrated Autism Service

This is another development that has stemmed from a different department from within Welsh Government, and has been developed mainly to respond to adults' needs, and also to offer information and advice to children and their families. The service is in its' early days and it is therefore difficult to state clearly what the effect will be on children and families. There was very little consultation with the neurodevelopmental service when it was being established.

2.3 Changes over the years.

From extensive experience of working in this field, autism is becoming more identifiable and therefore there is an increase in the demand. It is not unusual to have a family where there are two, and sometimes three children who are assessed to have autism and a learning disability. Some of these children and young people have other extremely challenging behaviours and related conditions, such as PICA, which increases the complexity in relation to care.

3 Developments and intervention via Derwen

3.1 The team's core services

Families with autistic children who are referred to Derwen can expect the same services to be offered to them as to any other families open to the team by the various professions within the team.

3.2 Duty and Customer Care Officer

Initially this officer will undertake an assessment of needs, undertake a carers' assessment, will lead and support the family through the Initial planning process in order to form an Initial Individual Support Plan, and will refer to the professionals within the team. If there is a waiting list, the role of this officer is to keep in contact with the family whilst they wait and provide them with information and advice, and to support them as needed.

3.3 Clinical Psychologists

Prior to establishing the neurodevelopmental service, a child where autism was raised would be referred to the psychologists for an assessment. The team developed the PACT (Pre Autism Communication Therapy) intervention through using grant monies from Families First, and positive reports were received from families who utilise the intervention with their children. As a result, a pack called 'Ga i ymuno â chdi?' was developed by a member of the team. It is a bilingual pack which is available to families and front line staff to help to understand and develop their communication skills with children. The pack won an award in the Welsh Health and Care Awards. The PACT intervention along with Interactive Music Therapy is funded through a small team – IMPACT – under ICF funding (Intermediate Care Fund)., and is available to families open to Derwen and to the neurodevelopmental service. This year the team has moved forward by using the Families First grant to

work with disabled young people (including a number with autism) to look at their individual skills in relation to their development, and to form groups for the Incredible Years ASD course and Speech Delay for parents. A small number of Derwen staff are being trained to help to run the courses. Furthermore the psychologists will be working individually with children, young people and their families and will be advising, training and supporting staff from a number of agencies.

3.4 Children's Community Nursing

The nurses work with children offering interventions in areas such as sleep, feeding, play, development and growing up on a one to one basis and in groups. If there is a child protection matter in a case that they are involved with, they will become part of the Child Protection process.

3.5 Social Workers

Social workers respond to the statutory duties in relation to children's services and work with each element related to disabled children, including children with autism. They assess in relation to support needs such as support services and short breaks, offer advice and information to families, undertake safeguarding responsibilities, court work and contact work. The social workers work with looked after disabled children and provide information for statutory reviews and arrange contact between children and their families. This element can take the worker far afield as there is a lack of regulated placements for disabled children. All of these duties include responding to children with autism.

3.6 Support services

Following an assessment by a professional worker within Derwen the referrals that come to the service can request input from a Youth group or summer scheme, to a few hours of support worker service on a one to one basis, to an intensive support package. Over recent years, a number of children with autism and extremely challenging behaviour have been supported to remain at home by the service. In order to do this, specialist training is needed along with specialist equipment and a large package of support. In the last year, for example, three cases cost the service £ 43,993. Family support workers have also been developed as part of intervention to develop specific measurable outcomes.

4. Short breaks.

4.1 Hafan y Sêr

The unit was opened during the year. It is a step forward in the process of meeting the demand for short breaks that have been under resourced for a long period. A number of disabled autistic children are receiving short breaks at the unit, and a number are on the waiting list.

4.2 Family care.

This resource is extremely scarce, but there is a joint piece of work ongoing with Anglesey at the moment to develop and raise awareness of the need of shore break

carers for disabled children. This will include children with autism and a learning disability.

5. Challenges

5.1 Meeting the needs of autistic children who do not have a learning disability.

As mentioned, the needs of disabled children who have autism and a learning disability are assessed and partly met by Derwen along with assessing their parents' needs. However, where there is no learning disability, at this point in time there is no intervention or direct series other than an assessment for a diagnosis, education and intentions available through grant funding for these families. There is a clear need to establish a process to assess the needs of carers and to offer supportive intervention.

5.2 Clinical Psychology time

As the resource is so limited within the Health Board and the assessment element depends on them as professionals, the waiting lists can be over 12 months. This is not acceptable to families of very young children who are concerned about their children's condition.

5.3 Short Break resources

Alongside what has been stated, some support service and Direct Payments are used, but there is a clear resource issue to be able to develop further. The service has already had less money following the Her Gwynedd process and this has had an effect on what can be offered to disabled children, including children who are autistic.