



(North Wales) Limited

Community Support for Autism in Wales

Cymorth Cymunedol Awtistiaeth Cymru

Enterprise and Learning Committee

EL(3) 04-10 (p3) : 11 February 2010

Report by Catherine Thompson:
Project Officer for C-SAW Ltd, North Wales

C-saw has received numerous enquiries regarding transition support in Denbighshire. In 2008 C-SAW came to the decision that a small booklet would be of benefit to parents and carers. A booklet on Transition outlining what parents/carers should be receiving, was produced by C-SAW and was distributed to young people with an LD in the schools in Denbighshire.

Pam Roberts, the family support worker for C-SAW continued to receive telephone enquiries stating that there was no transition support for people with an ASD in Denbighshire.

Testimonies from Parents:

Our daughter was a pupil at Brondyffryn from the age of 7 to 16, and is now aged 19, and a student on a mainstream course at College. Throughout her childhood she had a designated social worker, although we only ever met him once. Social services provided us with two hours respite, weekly at first, and then fortnightly. Once our daughter became an adult we had a visit from a social worker who told us that she no longer qualifies for any support from them. She is deemed too able to need help. Our daughter attends Barnardo's activities, although she will very soon be too old to qualify for these, and she also goes to activities organised by CSAW.



Our daughter falls between two stools. She is considered to be not disabled enough for support from social services, but is too disabled to cope without help. The support she receives now is limited to social activities, but as far as the important things go there is nothing. There are questions that we train ourselves not to think about, but which need answers. Questions such as;

Will our daughter always have to live with us? She needs support to live away from us. What support is available in Denbighshire?

She cannot continue in college forever. She needs support to find a job with an employer who would understand her strengths and be sympathetic to her difficulties. What support is available in Denbighshire?

Our daughter is mixing in the mainstream world. Because of her Asperger's syndrome she is vulnerable, but has the same desires as any teenager. What if

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she were to fall pregnant? She would need a lot of support to cope with a baby. What support is available in Denbighshire?

And the biggest question of all. What will happen when we die? Our daughter has a limited understanding of the value of money. She will not be able to look after herself without help. What support is available in Denbighshire?

We do not allow ourselves to think about these questions because all the enquiries we have made in the past have told us that there is no support available. Providing social activities has had a very positive impact on our lives, but it does not go anywhere near enough to deal with the realities of supporting an adult with ASD.



We are writing to you today due to the frustration of our current urgent situation regarding our sons funding for residential college. There seems to have been a catalogue of errors leading up to the current position resulting in the transition process failing at so many levels.

Boy 1 attends Ysgol Plas Brondyffryn & his 12 years at the school have been of an exceptionally high standard & the teachers are first class. No one knows more than us how much the school (both day & residential facilities) has improved over that last 10 years & he is lucky to have attended such an establishment

He started 2 nights residential at YPB in Sept. '05 & although it has been very beneficial for Boy 1; it certainly hasn't been easy for him to adjust to staying away from home. But his time in hostel was preparation for residential college, which we were advised was the best & most appropriate way to prepare him for adult life. Most importantly he needs to develop his independent living skills. There is a strong argument to be made in terms of life long planning for Boy 1, which will inevitably include at some point living separately from our family. It has had to be a gradual process as due to ASD he copes badly with any changes in his routine.

Since 2005 we have been extremely active visiting a selection of residential colleges all over the country, but for a variety of reasons Derwen seems the most appropriate. Eventually in March 2007 he was offered a place at Derwen College starting Sept 08 & we felt relieved a place (allowing for funding) had been secured. In January 08 Careers Wales sent his application off to DCELLS department in Cardiff.

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Boy 1's application for funding has been considered by DCELLS & they have written to xxxxxxxx in connection with the application, to confirm the level of involvement that the department has with Boy 1 & to consider whether or not Social Services should make a contribution to the funding. As DCELLS have not received a response to date they have sent another letter.

We believe the officers at DCELLS are hindered in their decision making process waiting for important information from other agencies, & presume that is the case. We find it alarming that the transition officer at DCC Adult Social Services knew nothing about Josh until she met with us earlier this week. Boy 1 seems to have been over looked in this period.

The transition period is such an important phase for any young person with SEN & it appears important strategies have been neglected by Education, Children's & Adult Social Services. It is now nearly June & this lack of preparation is extremely exasperating for families. We require an early decision on the funding giving us time, if necessary, for an appeal (such as has happened with another child who lives in Cheshire).

In Nov 2003 we were sent 'Denbighshire Information Pack- Directory of services for disabled children & young people'. Section 5 deals with transition & lays out the schedule for this process, with clear time tables for procedures. What actually happened for Boy 1 contravenes these rules.

I have lived in Ruthin Denbighshire all my life.

I have two daughters, the eldest went to main stream school then college, and now runs her own business.

My youngest daughter has an Autistic Spectrum Disorder ASD.

The only help that I have had for her since she was diagnosed at the age of two and a half is through the special autistic school she attended at Denbigh.

I have enquired on many occasions about a social worker for her, or a project worker to the local authorities. Only to be told that she was not considered a special needs case. Her intelligence is supposedly above the percentage that Denbighshire social workers need to act upon, and she was not at any risk.

The school was a great help, with their vast knowledge of autism My daughter did improve.

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The year of her transition a Careers Wales Officer attended the school twice that I am aware of.

On both these occasions I had to convince/persuade her that going to a university to become a veterinary nurse or an RSPCA officer would not be possible for her although she would be able to work with animals in many other ways.

The lack of knowledge that this person had about autism and my daughter did anger me.

Once again I enquired about a social worker and a career adviser to attend her transition reviews, which she was entitled to.

They did not.

I have since learnt that Denbighshire did not have this facility for the whole of the county.

C - S.A.W. is an organisation that we found out about through the school.

They have provided us with information on colleges and placements that may have been suitable for her.

They have talked to my daughter in a realistic way about her career and what she can achieve, giving her great confidence to move on.

C - S.A.W. does as it states it supports children, young people, adults and their families in many different ways.

It has been a fantastic life line of information that is there when you need to tap into it.

C - S.A.W. have many groups

The group my daughter attends is the young persons social group 16 to 25. They meet at least twice a week with varied activities.

These activities are planned in advance so the person who attends knows what to expect and there are no hidden surprises or shocks that can and do affect each individual with autism, many do not like changes.

This is not the last group that the young people can attend at C - S.A.W, they are certainly not considered too old after 20. There is yet another group for the 25+ who socialise in chosen activities.



Barnardos on the other hand stop the young people attending at the age of 20 they are considered too old to attend. Leaving a big gap for parents to fill.

I myself have found that the parent information sessions held by C - S.A.W. a great source of help.

I have been given names and contact numbers of many people to help sort out which college was the most suitable for my daughter.

Something that a proper transition should have provided.

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C - S.A.W also provide a siblings group, who meet twice a year. This enables brothers and sisters to talk about their own experiences of having an autistic sibling.

My eldest daughter thinks that this a great idea and that it would of helped her a great deal with her confidence knowing that she was not the only sibling in the world who had to take second place on many occasions.

Denbighshire LEA did not supply my family/me with the information of a transition officer/adviser on the transition of my child it was left up to us to find an organisation that I could access.

My daughter attends every C - S.A.W group meeting that she can. She really enjoys it as there are many who attend that she has become friends with, which is not easy for some one who has ASD.



I am most grateful that she has this group to go to as after Barnardos stops she will only have her friends at C - S.A.W who she will be able to relate to and get sound information from for a long time to come I hope.

She also attends Barnardos. She attends the over 14's group. Once a young person has reached the age of 20yrs old they are no longer able to take part. They are considered too OLD.

I am expecting a letter to inform me that she will not be included in any more activities during this summer as she has reached the age of 20.

Although she is able to attend college she does not interact with any of her peers, She goes to college, comes home, goes to C - S A W twice a month and to Barnardos when she can as the times are very early for her to attend 5 - 7 am but not for much longer

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