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A snapshot of specialist autism education provision in Wales

A report into our research findings by the Cross Party Autism Group in the National Assembly for Wales Chaired by Janet Ryder AM

Liz Withers March 2009

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Overview of our findings

From the responses we have received it would seem that Specialist autism education providers are dissatisfied with local co-ordination and planning at a local level and are concerned that Further Education is not meeting the needs of young people on the autism spectrum in Wales.

Our findings told us that:

- 75% of schools feel there is a lack of adequate local provision for the young people they support (this links to short breaks, wrap around services etc)
- 46% reported that they found local cooperation difficult
- 58% of schools did not feel there is adequate FE provision for young people on the autism spectrum in Wales

Autism and Education

Autism¹ is a lifelong developmental disability that affects the way a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share three main areas of difficulty (difficulty with social interaction; social communication and social imagination) their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist care. People with autism may also experience some form of sensory sensitivity or under-sensitivity, for example to sounds touch, tastes, smells, light or colours.

According to NAS Cymru figures, around 29,000 people in Wales have autism. Of these around 6,000 are children and young people aged under 18. A lack of appropriate provision for children with autism in schools can have a detrimental impact on children with autism and their families, and impacts on society in general.

Background to this paper

The aim of this paper is to highlight key issues of concern for specialist autism education providers in Wales. The research for this paper was carried out by the Cross Party Autism Group in the National Assembly for Wales (CPAG)². The group is chaired by Janet Ryder AM. This research was conducted following specific concerns regarding the organising and funding of appropriate education provision for young people with autism in secondary and post 16 education in Wales, raised at the April 2008 meeting of the

¹ We use the term autism here to cover all people on the autism spectrum, including autism, Asperger syndrome and other diagnostic terms used for autism spectrum conditions.

² The National Autistic Society Cymru provides the secretariat for the Cross Party Autism Group in the National Assembly for Wales. The group brings together Assembly Members, professionals, people with autism and parents and meets at the National Assembly for Wales in Cardiff Bay. Its aim is to raise awareness and promote the interests of people with autistic spectrum disorder, their families and carers.

CPAG. To investigate some of these issues, and to try to create a picture of specialist autism provision across Wales, questionnaires were sent to schools in Wales with an autism specialism. These included statutory and independent special schools, as well as mainstream schools with autism resource bases. 24 responses were received, of these there was a fairly representative sample from across Wales. Just under half of respondents were from special schools and 88% of schools who took part were state funded institutions. Two responses were received through the medium of Welsh³.

As a result of the data we received back from schools in November 2008, questionnaires were also sent out to further education (FE) providers in Wales to enable some comparison of views to take place. 9 responses were received, all from mainstream colleges. Evidence gathering took place between September and March 2009. This is the final report of the key findings from the research.

Key Findings

Autism Spectrum Disorder (ASD) Action Plan-out of action?

In April 2008 the Welsh Assembly Government launched the Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales to drive improvements across services for children, young people and adults in health, social services and education. Central to the plan, is the notion of joint working and agencies coming together to plan for better access to services and support for people with autism and their families. The CPAG supports the plan.

In line with the plan, local agencies should come together through a local stakeholder group and be working to develop a local autism plan. The plan will be informed by data gathered at local level on the numbers of children and young people with autism in their area and a mapping exercise identifying current provision and gaps in services and support locally.⁴

Our research told us that only 46% of schools feel autism *is* a priority for their Local Education Authority (LEA). Of the remaining schools, many feel their LEA could do more to prioritise autism and 20% feel their LEA does not prioritise autism at all. There is clearly a disparity here between the commitment shown by the Welsh Assembly Government to autism and the levels of awareness and mainstreaming of information about the plan and its implications at local level.

The issues raised by specialist providers were not solely related to education provision. In terms of the main areas of concern in supporting children, young people and their families, schools are clearly aware of the barriers that parents face in accessing a whole range of support. In fact, 75% of schools feel there is a lack of adequate local provision for the young people they

³ The questionnaires to schools were sent out bilingually

⁴ There is an expectation by WAG that this work will include adults also

support. Specifically, almost half of respondents told us that access to short breaks and parental support during out of school hours was hard to come by.

'Many parents have difficulty obtaining respite care'

- Teacher in an autism centre attached to a mainstream primary school in South East Wales

We know that access to short breaks provision for young people with autism in Wales is extremely patchy, in fact, according to Shared Care Network, children with autism spectrum disorders are amongst those who wait the longest for short breaks⁵. Despite the availability of generic short breaks provision within authorities, mainstream provision can often find it very difficult to cope with the needs of children and young people with autism, which can mean parents, find it almost impossible to access appropriate support.

The Cross Party Group believes that local authorities should be using a proportion of their recurring allocation from the Assembly Government for supporting children and young people with autism, specifically on short break services⁶. The group also recommends that the Health, Wellbeing and Local Government Committee in the National Assembly for Wales look into the issue of access to short break services for children and young people with autism and their families.

The CPAG believes that local agencies and the local named lead in particular need to be engaging with specialist education providers in the local area who are in a unique position to inform the current picture relating to services and support, particularly gaps in service. However, in light of the evidence provided in this paper, the **CPAG also believe that access to wrap around services for young people with autism, including short breaks should be considered as a priority in local autism plans.** The CPAG supports ESTYN's recommendation that, 'local authorities should strategically plan services in partnership with others to provide effective non-educational support in conjunction with school based support, for pupils with complex special needs and their families.'⁷

Local and regional co-operation

The importance of cooperation cannot be overstated in ensuring that a young person with autism has easy access to a wide variety of services and support in their area. Despite an increase in structures to aid co-operation, 50% of schools reported that they still find cooperation to plan for local and regional provision for children and young people with autism, difficult.

⁵ Shared Care (2007) Still Waiting: Families of Disabled Children in the UK waiting for Short Break Services

⁶ Since 2007 the Welsh Assembly Government has made ± 1.7 million available to local authorities in Wales through the revenue support grant for children and young people with autism. ± 0.7 of this allocation is for social services

⁷ ESTYN (October 2008) Local authority placements of pupils with additional learning needs in independent special schools with linked 52-week residential provision p.7

'The Unlocking Potential Plan has promoted things in the educational system, but we need a lot more organisation between education, health and social services.'

- Teacher in a Welsh medium specialist school in Anglesey.

'Sometimes far too many people (are) involved (and) nothing gets completed.' - Teacher in a special school in North East Wales

This is of particular concern; since local agencies must work together to deliver on the plan at local level, but also there will now be more opportunities for agencies to come together to plan for low incidence, high cost services at regional level. This planning will be supported by regional co-ordinators housed by the Welsh Local Government Association. As part of the ASD action plan, the WAG aims to issue guidance to Local Education Authorities (LEAs) on the development of regional provision of goods and services for children and young people across Wales. However, this is not autism specific.

The CPAG believe that local agencies would benefit from greater autism specific guidance on commissioning services and support for young people across Wales both at local and regional level.

Disparities across the sector

Children and young people with autism have often very complex educational needs which can require myriad learning aids, support staff, speech and language therapy and sensory stimuli resources in order to ensure that they fulfil their academic potential. However, many specialist state schools who responded to our survey feel that they simply do not have the finances to provide these resources to every student.

'[we need] more psychological and psychiatric support needed. Level of speech therapy support is farcical... [WAG need to] encourage purpose built, autism friendly and carefully thought out provision. Facilities in private sector can be jaw dropping.'

- Special School for pupils with profound multiple and complex difficulties and autism in South Wales Central

Access to support through the medium of Welsh was also highlighted as an issue, both in terms of access to appropriate educational provision, but also in terms of in school support.

'There are enough communication problems without also having to come to terms with an unfamiliar language' - A special school in North West Wales

57% of those state schools who completed the questionnaire admitted that they feel out competed by the independent sector. Most specifically in terms of resources, access to speech and language therapists, occupational therapists and training opportunities for support staff. When asked what more the Welsh Assembly Government should do to support the development of local provision, 54% of schools felt that it should increase funding.

'Across Wales there needs to be agreement on levels of support to ensure that there is a standard of service accessible to all. Should be monitored by the WAG'

- Special school in South Wales Central

The Cross Party Autism group believes that all young people with autism should be able to access local education provision appropriate to their needs. The Cross Party Autism Group also recommends that the WAG makes available more schemes for specialist education providers such as Unlocking the Potential of special schools (2006). In cases where this funding has been made available, schools have highlighted it as beneficial.

Troubled Transition

Transition can be a particularly difficult time for young people with autism, as due to the nature of their condition, they can find change hard to cope with. They can also find it difficult to visualise things beyond their routine, what they would like to do in the future for instance. For these reasons effective and early planning around transition is essential.

Despite this, 50% of schools have experienced problems with their young people moving onto further education.

'We have never been able to place a child in FE because they cannot provide the individual support a child needs.'

- Teacher in a Special school in South Wales

We also asked colleges about their experiences of transition. All the colleges who responded to the survey agreed that support could be improved for young people at transition from school to college.

25% of schools who have experienced problems at transition highlight a lack of training and knowledge of autism amongst FE staff as the main reason for these problems. 4 out of the 9 (44%) colleges agreed that there was a lack of staff awareness and training in autism and they required greater expertise.

'Being kindly disposed and interested is not enough; committed staff need committed training which will improve the quality of provision overall.' - Mainstream FE Provider North East Wales

In order to improve transition, suggestions from colleges included more 'taster days' and 'schools links programmes'.

We have close links with feeder schools with college staff attending school reviews when possible. Feeder schools have a programme of visits to the College in the spring term with in some cases students spending time in

College with their support staff. In July the college holds a 3 day induction course for all new learners in the department. This allows the students to get to know the college environment, try some lessons and to meet the other learners.'

- Mainstream college

Funding for Specialist College placements

The issue of the funding process in terms of applying for Specialist College placements is a major issue for families and something the group would like the Assembly Government to take urgent action on. Schools and colleges have highlighted the importance of a planned transition and opportunities for taster days and a chance for a young person to get to know their new environment, whilst the staff can understand more about a young person's individual support needs. However, the group understands that currently parents are not able to apply for funding for a specialist college placement until the end if January, where the student is due to start at the college that September.

'I know several parents of severely autistic young people who have had under a week between a decision on funding and their child starting college. Disastrous for young people with this level of need. It makes a nonsense of having transitional annual reviews from the age of 13/14years at school'. - Parent of a young man with severe autism

The CPAG believe this delay in being able to apply and receive decisions on funding is unnecessary and has a detrimental impact on the young person with autism, the family and the placement college. We would like to see the Welsh Assembly Government change policy in this area as a matter of priority.

Specific issues for young people with Asperger syndrome

75% of schools think there are specific issues for young people with Asperger syndrome in accessing ongoing support in college. Examples of such issues include preparation for and support into employment, lack of support outside college and losing friends when moving out of their county for placements. In general the colleges agreed that providing tailored support for young people with Asperger syndrome was often difficult. Colleges reflected the recognition that young people at the higher end of the spectrum will need social skills and life skills support but they often struggle to be able to provide these types of support to young people.

'We have a lot of experience in supporting learners who have severe learning difficulties alongside their autism, but are increasingly taking learners who have moderate learning difficulties but extremely poor social skills. The difficulty here is in meeting their learning needs as well as their social and life skills needs'.

- Mainstream College South West Wales

This seems to be largely due to a lack of access to funding and not meeting the criteria for support.

'There is a distinct lack of services for people with ASD, particularly for those at the higher end of the spectrum. For example, to be eligible for assistance from the Community Teams for Learning Disabilities, a service user must have an IQ of less than 70. This precludes many of our students who still will require a high level of support to achieve a degree of independent living, and most importantly the help and support they require to access employment.' - Mainstream College in west Wales

'There are difficulties for all learners accessing support post College but for learners with Asperger's it is particularly difficult as the services for people with learning difficulties are not available and often work is not a viable option.'

- Mainstream College

The CPAG believes that the Welsh Assembly Government needs to take specific action to address the gap between services for young people with Asperger syndrome to better enable them to access support.

Social skills support highlighted by both schools and colleges in their responses is also the most commonly requested support by adults according to NAS Cymru. In light of this, the CPAG believes that FE providers should also consider how they can best support the development of social skills in their young people with ASD who often find break time and other non-contact time difficult. Some students find themselves so unable to cope that they actually drop out of FE.

The CPAG welcomes the work the WAG is undertaking to respond to the Education and Lifelong Learning Committee recommendations around transition. The group would strongly support the notion of a support plan, (or a statement) being carried with a young person through into college. We also feel that if an Assembly Measure around transition was to be drafted, there are specific areas where the group feels specific reference to autism and young people with social and communication difficulties should be made. Examples of this might be mandatory training in autism for staff supporting students through transition and in post 16 environments and a greater focus on broader support, beyond that of an academic focus, such as life skills and social skills support, to enable young people to be better prepared for the next stages for their lives.

Is FE provision for children and young people with autism fit for purpose?

According to our survey, 58% of schools do not feel there is adequate FE provision for young people on the autism spectrum in Wales with some reflecting the lack of appropriate FE placements available in Wales felt by some parents.

'My son will be leaving education soon; we are having to look for a college in England. There is nothing suitable in South Wales for him to go (post 16) so we are having to look in England for places that aren't too far away.' - Parent of a young man with complex autism.

'I am aware of some children who have to go outside Wales for FE.' - Teacher in an autism resource base within a mainstream primary school in South East Wales

According to Welsh Assembly Government statistics, the number of students with autism in Wales whose further education provision was funded by the Welsh Assembly in 2007/08 was 38, with 16 of these attending specialist residential colleges in England. Clearly, there is a problem with access to appropriate further education provision in Wales. It is important that young people are able to access provision as close to home as possible.

In regard to FE provision that *is* available in Wales, many schools reported that they would like to see more autism awareness training within those FE institutions.

Courses are there but the understanding of how ASD children learn is not. - Teacher in an autism resource base within a mainstream secondary school in South East Wales

From a college perspective, of those that responded 6 out of 9 felt that they provided good support to those on the autism spectrum, with 2 considering that their support 'needed improving'. However all of the colleges had difficulties in supporting young people with autism. All colleges agreed with the schools that autism awareness and training was important to successfully support students with autism. This includes the need to have an understanding of a young person's sensory needs and practical techniques and coping strategies.

'Autism is a hidden disability. Raising awareness amongst all college personnel is of vital importance to ensure that students are treated appropriately and equally.'

- Mainstream College in south west Wales

'There is a need for more in depth training for those staff immediately involved with ASD students. But also there is a need for greater all-college staff awareness since many problems occur outside the classroom, within the wider college community.'

- Mainstream College

Meanwhile the remaining college highlighted difficulties in meeting the social and life skills needs as well as learning needs. The CPAG would like to see WAG supporting colleges to access autism training, as well as social and life skills support 8 out of the 9 colleges who responded agreed that they thought that Wales would benefit from a state funded FE college, especially for those with severe autism.

'Excellent idea because it could provide all other life skills areas alongside curriculum-social skills, applying for jobs, interview techniques etc. It could teach independent living'

- Special school for young people with variety of complex needs, including autism in South West Wales.

'We are under pressure to accept applicants with particular complex needs but we are unable to meet their needs. Those who make referrals often acknowledge this but cite lack of alternative as reason for making the referral anyway'.

- Mainstream College

'Although we have a number of learners with autism there are always some learners for whom it is felt that the College environment is not the most suitable placement. These learners could benefit from the specialist environment that a residential college would offer.' - Mainstream College in south west Wales

Even those schools who answered no to this idea agreed that FE has to adapt

Even those schools who answered no to this idea agreed that FE has to adapt in order to better meet the needs of young people on the autism spectrum in Wales.

'It would have to be residential which is expensive. Perhaps that funding could be put into a number of strategically placed regional centres attached to existing colleges. Getting the right mindset and staff is key to success.' - Special School for pupils with profound multiple and complex difficulties and autism in South West Wales

'Young people with autism can successfully access courses, provided there is someone on site to advise, monitor and support' - Mainstream school with an autism base in South East Wales

Possible suggestions included, training up FE lecturers to improve knowledge and understanding of autism and increasing efforts to engage youngsters in FE inclusion practises.

The CPAG believe that FE institutions should review the support they have in place for people with autistic spectrum disorders and produce a strategy to address gaps in support. Furthermore, in order to inform future planning of FE provision; it would be helpful if the WAG could start collecting data on the destinations of young people with autism when they leave school. We believe that this short research project, has uncovered some major issues in the FE sector relating to the access of support for young people with autism in Wales. We therefore recommend the Enterprise and Learning Committee undertake a short review to further investigate the barriers to appropriate support in FE for young people with autism.

Summary of key recommendations

The Welsh Assembly Government should:

- Consider mandatory training in autism for key staff making assessments and supporting students in post 16 environments.
- Provide guidance to enable a greater focus on broader support for students with autism within post 16 environments, such as life skills and social skills support.
- Develop autism specific guidance on commissioning services and support for young people across Wales both at local and regional level.
- Make available more schemes for specialist education providers such as 'Unlocking the Potential of special schools' (2006).
- Improve data collection on the destinations of young people with autism when they leave school.
- Support colleges to access autism training and social and life skills support.
- Review their funding policy for young people with autism applying for specialist college placements as a matter of priority to ensure that young people and their families are not disadvantaged by delays in funding decisions.
- Take specific action to address the gap between services for young people with Asperger syndrome to better enable them to access support.

Further Education institutions should:

- Consider how they can best support the development of social skills and a more rounded curriculum for young people with autism spectrum disorders and provide greater opportunities for support during breaks and other non-contact time difficult.
- Review the support they have in place for people with autism spectrum disorders and produce a strategy to address gaps in support.

Local authorities should:

- Involve specialist education providers in helping to identify gaps in local provision when completing local mapping to inform the development of local autism plans.
- Use a proportion of their recurring allocation from the Assembly Government for supporting children and young people with autism, specifically on short break services.
- Consider access to wrap around services for young people with autism, including short breaks as a priority in local autism plans.

The Health, Wellbeing and Local Government Committee should:

• Look into the issue of access to short break services for children and young people with autism and their families.

The Enterprise and Learning Committee should:

• Undertake a short review to further investigate the barriers to appropriate support in FE for young people with autism.