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National Assembly for Wales

Children and Young People Committee

Education (Wales) Bill : Stage 1

Response from : National Autistic Society Cymru (NAS Cymru)

### **About Us**

The National Autistic Society Cymru [NAS Cymru] is Wales' only member-led charity for people affected by autism<sup>1</sup>. The National Autistic Society was founded in 1962 by a group of parents who were passionate about ensuring a better future for their children. In Wales, since 1994, we have been providing local support, services and actively campaigning so that people with autism get to lead the life they choose.

Across Wales we have nearly 1000 members and 12 local branches. We provide:

- Information, advice, advocacy, training and support for individuals and their families;
- Information and training for health, education and other professionals working with people with autism and their families;
- A telephone helpline, free to use;
- Specialist residential, supported living, outreach and day services for adults;
- Out-of-school services for children and young people; and
- Employment training support and social programmes for adults with autism.

The NAS Cymru's outreach and student support services help people in Wales get the most out of school or college. Our Education Rights Service provides information, advice and support to around 2,000 callers every year, including support for families taking cases to the Special Educational Needs Tribunal, Wales [SENTW]

NAS Cymru believes that the right support at the right time makes an enormous difference to the lives of those affected by autism and we are committed to ensuring that their voices are heard.

### **About autism**

Autism 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, their condition will affect them in different ways. The three main areas of difficulty are:

- difficulty with social interaction. This includes recognising and understanding other people's feelings and managing their own. Not understanding how to interact with other people can make it hard to form friendships;
- difficulty with social communication. This includes using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice; and

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<sup>1</sup> The term autism is used throughout this document to refer to all people on the autism spectrum including Kanner autism, Asperger Syndrome and high-functioning autism.

*Accept difference. Not indifference.*

*Gwahaniaeth. Nid difaterwch.*

- difficulty with social imagination. This includes the ability to understand and predict other people's intentions and behaviour and to imagine situations outside of their own routine. This can be accompanied by a narrow repetitive range of activities.

Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist support. People with autism may also experience some form of sensory sensitivity or under-sensitivity, for example to sounds touch, tastes, smells, light or colours. Asperger syndrome is a form of autism.

Autism is much more common than people think. Research has shown that more than one in 100 people have autism<sup>2</sup>. By applying the one in 100 figure we estimate that over 30,000 people in Wales have autism. Together with their families, they make up over 100,000 people whose lives are touched by autism every single day.

## **1. General Comments**

NAS Cymru is pleased to be given the opportunity to respond to this Bill. We also note that the National Assembly for Wales' Children and Young People Committee has included NAS Cymru in its list of those invited to contribute to the consultation.

Our response considers issues that specifically relate to people with autism, their families and carers. In developing our response, we drew on research from an NAS survey: 'The Life We Choose: Shaping Autism Services in Wales.

We note that these proposals relate to specific areas and that further, wider reform of SEN is underway. We urge the Government to continue to work closely with NAS Cymru in developing its proposals to transform support for learners with additional needs, for the benefits of pupils with autism in Wales.

## **2. Provision of post-16 educational and training needs**

For most parents, getting the right educational provision for their children is a priority.

With the right support, every child has the opportunity to succeed. But, because autism is a spectrum condition and affects each person in a different way, a single type of provision will not meet the educational needs of people with autism. This means that the right provision has to be suitable for the individual involved.

NAS Cymru believes that parents and young people should be able to access more information so that they can make informed decisions about which educational establishment would best support them to meet their potential.

In 2011 we published the results of the largest ever survey of experiences of people with autism and their families in Wales. The report 'The Life We Choose' shows that of the parents with children with autism who took part in our research, only a third [34 per cent] felt that they had enough support and information to make the right choice in terms of their child's education.

NAS Cymru believes that the Bill offers a clear opportunity to address this by putting clearer duties on local authorities to develop a local statement of what is available post-16 for young people with special educational needs and making arrangements to publish and publicise this information widely. A new clause could be inserted after clause 40 O to this affect.

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<sup>2</sup> Brugha, T et al (2009) *Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007* London: The NHS Information Centre for Health and Social Care

In addition, we also believe that Welsh Government and local authorities should work together to ensure:

- there are sufficient resources available for Parent Partnership Services across the country;
- the need for a range of educational provision locally is reflected in local autism action plans; and
- local needs assessments are carried out in every local area, in consultation with relevant stakeholders, to plan for sufficient placements

### **3. Education Workforce**

There are currently more than 6,000 children and young people of school age with autism in Wales. This means that every teacher should expect to teach children with autism during their career, and all school staff who will come into contact with, or make decisions about, pupils with autism should have an understanding of the condition.

Our survey for the Life We Choose report showed that secondary school subject teachers were a particular group of teaching staff who needed better training in autism. Less than half of parents who responded to the survey [47 per cent] said that they were satisfied with secondary school subject teachers' knowledge of autism.

The section on the education workforce offers an opportunity to ensure that all teachers are incentivised to develop their understanding in autism and other special educational needs. In particular, we believe that the induction standards should include specific experience and training in teaching staff on autism and other disabilities so that they can be fully equipped to support all learners with and SEN.

To ensure this happens we recommend that the Bill is amended so that:

- in developing the induction standards the Welsh Government has to consult with parents of children with a disability, as well as young people themselves and other stakeholders; and
- a new clause is inserted setting out that induction will cover the specific needs of children and young people with a SEN

### **4. Assessment of post-16 educational and training needs**

For young people with autism, who, because of the nature of their condition can find dealing with change difficult moving from childhood into adulthood can be a period of great uncertainty and can be particularly challenging.

Providing long-term support and effective transition for individuals with autism is therefore essential for their educational and social development.

The transfer of responsibility for assessing young people with SEN from Careers Wales to the local authority has the potential for providing greater consistency for young people with SEN in Wales.

However, in order to ensure that local authorities are fully equipped to do this effectively and to ensure that the education priorities outlined in the Welsh Government's Programme for Government can be met, we believe that as this Bill is taken forward it must be clear that local authorities are:

- properly resourced to assess the post-16 educational and training needs; and
- provided with autism awareness training, especially for those who are making assessments around the educational and training needs of people with autism

We also hope that the change in responsibility for assessments can help speed up the process for assessment and funding decisions. In 2010, following work by the Cross Party Autism Group on autism provision in further education, the National Assembly's Enterprise and Learning Committee undertook an

inquiry into this issue and subsequently published its report 'Specialist provision for young people with autism in further education'.

A key recommendation of the Committee around transition into further education was that all funding decisions on Further Education placements should be made by 31 March each year.

Welsh Government statistics obtained by one of our Cardiff and Vale branch members under a Freedom of Information request showed that the majority of funding decisions aren't made until as late as the beginning of the new school term in September, and that this has been an ongoing trend over the past five years. The figures show that in March 2009, only three funding decisions had been made while 32 were taken in September 2009. In March 2012, only one decision had been made with 35 decisions being made in September 2012.

NAS Cymru recommends that in order to give pupils and parents certainty about their education placements in good time for the start of the new term in September:

- the Bill is amended to put a duty on local authorities to make funding decisions by 31 March each year; and
- funding for specialist colleges and other further education provision should be ring-fenced.

Parents of children with autism have also shared with us their concerns at the lack of choice facing them in terms of further education and that local provision doesn't necessarily provide the right level of support.

NAS Cymru firmly believes that the Bill should:

- place a duty on local authorities to ensure that a range of provision, is available locally so that young people with autism can access the right support at local level, whether that is in mainstream or in specialist settings, as appropriate.

## **5. Extending the remit of the SENTW**

NAS Cymru strongly welcomes the proposal in the Bill to extend the right of appeal to the Special Educational Needs Tribunal Wales [SENTW] to those who are between 16 and 25 years age. This will give all pupils receiving education and/or training in Wales the same statutory provision and protections and will enable more effective post-16 transition.

NAS Cymru notes, the Welsh Government's proposal to replace statements with an Integrated Development Plan [IDP] that covers both health and social care that as part of the wider reform of SEN.

NAS Cymru believes that in order to fulfil the Welsh Government's aspiration of a 'full partnership between the education, health and social services' a single point of appeal is crucial to ensure complete accountability. Without this, parents and learners will continue to battle the system on multiple fronts, with social care and health bodies' complaints procedures notoriously difficult to navigate.

NAS Cymru would therefore seek assurances from Welsh Government that it is committed to:

- creating a simpler, joined up system for parents and pupils with SEN that is person centred and places equal duties on education, health and social services;
- providing a single point of resolution so that parents and pupils would then be able to appeal all parts of the IDP to the SENTW, making it easier for parents and young people to hold multiagencies to account; and
- ensuring that individuals on SENTW have the relevant experience across education, health and social services to provide the necessary expertise

**For further information please contact:** Meleri Thomas, External Affairs Manager, Wales