

a) What are your views on the effectiveness of the current arrangements for improving autism services in Wales?

Ceredigion's Autism Strategy Group was formed in 2008. Original funding allowed the area to fund additional hours for an ASD specific key worker and allowed the translation into Welsh of Wendy Rinaldi's Sulp materials.

From this forum our Social Communication Assessment Team (SCAT) was founded. This continues to be the group of specialist workers which carries out the assessment and diagnosis of autism (in accordance with NICE guidelines) in Ceredigion. For young people who do not receive a diagnosis of Autism as part of this process the SCAT team is able to signpost them to other agencies/ support. In comparison to neighbouring authorities, Ceredigion's assessment and diagnosis of ASD is efficient.

The Ceredigion Autism Strategy was written.

Now the Strategy Group has become the Autism Monitoring Group which meets approximately three times a year.

Ceredigion is committed to improving the understanding of autism in our schools and in developing strategies to enable those pupils to meet their potential:

Ceredigion LA recognised the need for improved understanding and support of ASD pupils and chose to use the ALN innovation fund to support pupils with ASD. The focus for this fund is on transition and in raising capacity of schools to meet the needs of pupils on the ASD spectrum in the mainstream. One of our innovations is to train a member of staff to be a champion for autism within each of our secondary schools and large primary schools. The impact of this project will be evaluated and shared as good practice with others. We are also developing a transition toolkit for pupils with ASD at key transition points.

Learning Services has paid for Intensive Interaction training for support staff and parents of pupils with severe communication difficulties.

We were also a pilot area for Learning with Autism which is being promoted in our schools to encourage all schools to become autism friendly.

Ceredigion invests in early identification and support of communication and socialising difficulties through a Service Level Agreement. This secures a Speech and Language Therapy Service in the early years and in our specialist resource centres.

We promote an inclusive society which is inclusive for all (including people with autism). We do not believe that the status of one category of need should be elevated above those people with other learning challenges.

b) Do you believe Wales should have legislation requiring the Welsh Government to publish a national autism strategy for children and adults and issue guidance to local authorities and NHS bodies on implementing the strategy?

Although we appreciate a national strategy for ASD and the funds that we have received from government which have allowed us to develop initiatives which meet our local needs, we would not appreciate a strategy which does not allow us the autonomy to work in a way which is inefficient for us. One size cannot fit all.

c) To what degree of detail do you think the content of a national autism strategy should be defined in legislation?

The ALN Bill should negate the necessity for an Autism specific bill affecting children and young people. All children, regardless of diagnoses should be treated of equal status in the eyes of the law. There is no proposal for a Down's Syndrome Bill, a Cerebral Palsy Bill or a Dyslexia Bill etc.

d) What (if any) consultation do you think the Welsh Government should be required in legislation to undertake, when developing, reviewing and updating a national autism strategy?

We do not believe that Welsh Government should elevate the status of Autism above other needs and feel that the ALN Bill will ensure that children and young people with autism are recognised and have their individual needs assessed and met.

e) Do you believe that legislation should define how often a national autism strategy should be reviewed and updated? If so, how often should it be reviewed and updated?

We do not believe that legislation is appropriate for an individual diagnosis.

f) Do you have any views on how Welsh Government should monitor what

progress is being made and how public services should be held accountable for how they support autistic people and their families?

No more than for any other children and young people identified as having additional learning needs.

g) What are your views on how easy it is to access a diagnostic assessment where you live?

In Ceredigion we have a SCAT team (as described in response to question a). Our referral process is clear and efficient and can be made by schools in consultation with an EP, by GP through the Paediatrician, Speech and Language Therapists. Children and Young People are discussed at SCAT once a referral has been received. A decision as to the appropriateness of the referral is made and if appropriate the assessment process begins

h) What key challenges around how the diagnostic process works would you like legislation to address?

We do not agree that legislation is appropriate.

i) Do you believe that Local Health Boards and Local Authorities in Wales should be required to publish information on the pathway to diagnosis for children and adults living in their areas?

NICE guidelines are already in place. A leaflet on the SCAT team exists and explains the roles and expertise of those who sit on this team.

j) What are your views on the sufficiency of services currently provided to meet the needs of people with autism spectrum conditions in Wales?

We are aware that children and young people with high functioning autism, who have received support throughout their school years, can leave school and find that there are no support mechanisms available. There is some support for those pupils who have a greater degree of learning difficulty.

We feel for example that the key worker role could be expanded to offer support. This is a valuable service but insufficient funds mean that this service cannot offer the level of support that all families require.

The issues in supporting pupils with ASD, as with all pupils with ALN, are a problem because of lack of funding not lack of legislation.

k) The legislation I am proposing would require the Welsh Government to issue statutory guidance that would put duties on local authorities and Local

Health Boards on how they should be delivering services for autistic children and adults and their families.

Do you agree that legislation should require statutory guidance? If so, does the following list cover the right areas to be included under the duties on local authorities and Local Health Boards?

- i. The provision of relevant services for the purpose of diagnosing autistic spectrum conditions in children and adults.
- ii. The fact that assessment of the eligibility of children and adults for relevant services cannot be denied on the grounds of the person's IQ.
- iii. Planning in relation to the provision of relevant services to people with autistic spectrum conditions, as they move from being children to adults.
- iv. Other planning in relation to the provision of relevant services to children and adults with autistic spectrum conditions.
- v. Local arrangements for leadership in relation to the provision of relevant services to children and adults with such conditions.

We do not believe that legislation is appropriate for an individual diagnosis.

l) Do you believe that Local Health Boards and Local Authorities in Wales should be required to establish and maintain new data collection practices around the numbers and needs of children and adults with autism spectrum conditions so that local areas can plan services accordingly?

Ceredigion's SCAT team collects this data.

m) Do you have a view on how data can most effectively be gathered, on the numbers and needs of children and adults with autism spectrum conditions in different Local Health Board and Local Authority areas in Wales?

The most effective way is through the diagnosis and assessment teams.

n) Do you have a view on the current scope and effectiveness of training in Wales for key staff working with people with autism spectrum conditions?

The Learning with Autism materials provided by Welsh Government have given an opportunity for training a wide number of people. It is doing a good job at raising awareness of the challenges for people with autism.

An all Wales training programme would require significant additional funds. In education, for each teacher (a 'key member of staff') trained an additional teacher

(supply) needs to be paid for. Training within education is particularly costly.

o) Do you believe that legislation should specify outcomes that training should achieve, thereby providing greater flexibility around the delivery of such training?

We do not believe that legislation is appropriate for an individual diagnosis.

However, we believe that people should take ownership of their own Continuous Professional Development as 'forced training' is rarely effective.

p) An alternative approach would be for legislation to specify that key staff working with people with autism spectrum conditions should undertake autism training.

Welsh Government should make mandatory training on all areas of ALN as part of initial teacher training.

q) Do you have any suggestions for additional action that could be taken through legislation to improve the rates of employment of people with autism spectrum conditions (bearing in mind that the National Assembly for Wales does not have the power to make changes to employment law)?

Certainly, young people with autism should be encouraged to develop their strengths which reflect their abilities to undertake tasks in the workplace. Employers need to be made aware of the young person's strengths and the value the individual may be able to bring to their workforce. However, to legislate for this group alone discriminates against other young people with learning differences.

r) Do you believe that a definition of autistic spectrum disorder should:

- be included on the face of legislation (which makes it more difficult to change in the future);
- be included in an autism strategy;
- be included in guidance; or,
- not be stated at all?

We do not believe that legislation is appropriate for an individual diagnosis.

However, we agree that a definition should be included in the Strategy and phrased in such a way as to encompass the potential strengths and talents of individuals with ASD.

s) Can you identify any possible unintended consequences which could arise as a result of this legislation? If so, what steps could be taken to deal with them?

Any legislation which elevates the status of one category of people over others who experience difficulties will naturally create inequality.

Any legislation which provides statutory obligations for one group over another will lead to a drive for diagnoses in order to attain preferential services. This will lead to a significant rise in requests for diagnoses placing increased demand and pressure on diagnostic assessment teams. This will of course slow down the assessment process for all.

Parents of children and young people who do not receive a diagnosis may be disappointed at the prospect of not receiving additional resources/services. This may lead to increased appeals to local government and health boards.

Nobody would object to increased awareness and services for people with ALN. However, the provision of services should be needs driven not diagnosis driven.

Increased legislation leads to increased litigation and is at odds with what the Welsh Government is legislating for through the ALN Bill (increased co-working and planning for the futures of all children with ALN and a less adversarial process).

t) Do you believe that the proposals in this consultation would give rise to any substantial costs, in addition to the cost-areas already noted in this consultation? How can such costs best be mitigated?

By giving rights to one group of people over others and providing mandatory services for those with ASD, those not receiving a diagnosis will be disappointed and this will likely give rise to appeals and requests for compensation.

Increased legislation leads to increased litigation and is at odds with what the Welsh Government is legislating for through the ALN Bill (increased co-working and planning for the futures of all children with ALN and a less adversarial process).

All litigation impacts massively on the workload of officers of the LA who would otherwise be working directly with children and young people to support the individual needs. This, in turn, reduces the effectiveness of actually meeting needs.

u) What would the impact or costs be in terms of:

i. producing a national autism strategy;

Local Strategy groups meet without additional cost

ii. placing duties on local authorities and NHS bodies to act under guidance;

If additional duties are placed on local authorities, someone will need to be employed to undertake those duties. This may be a new employee or an existing employee but either way the funding pot will remain the same...meaning a reduced service for someone.

iii. creating and maintaining data collection practices on the numbers and needs of adults and children with autism spectrum conditions; and,

Data is maintained on numbers in Ceredigion. The pupils' individual needs are recorded in their Individual Education Plans and One Page Profiles at school. There may be no additional cost if the current data collection is sufficient. However, if there is an expectation that increased data or information is required and that this needs to be centralised, this will have significant administrative impact and cost.

iv. providing training for key staff?

Any training of teachers is particularly costly as supply cover is necessary when teachers are out of class. This is prohibitive.

v) Do you envisage any other additional administrative and regulatory costs as a result of this legislation and if so, how can any such impacts be mitigated?

There is always a risk that providing rights in law for some citizens over others may lead to litigation and compensation claims.

Increased bureaucracy is associated with a decrease in the actual hands on planning and good practice.

w) What factors should be measured to determine the cost-benefit analysis of this legislation should it become law?

The benefits to those with a diagnosis of ASD will be increased at the expense of

those who do not have a diagnosis or who have other diagnoses.

The bureaucracy is a threat to spending appropriate time with pupils who require their needs to be met

x) Do you have any views on how savings that might arise from this legislation can most effectively be identified and calculated?

We have no views on this.

y) Do you wish to make any other comments on my proposals?

The number of people in the population who are recognised as having ASD appears to be rising. Further academic research needs to be explored on whether there is an *actual* rise in the number of people with ASD in the population or whether we are better at diagnosing/ over-diagnosing this condition.

If there is an increase in numbers then research should identify the factors so that appropriate support can be delivered. We believe this to be a better focus than legislation.