

## Questions: Strategy

- a) What are your views on the effectiveness of the current arrangements for improving autism services in Wales?
- 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?
- c) To what degree of detail do you think the content of a national autism strategy should be defined in legislation?
- 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?
- 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?
- 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?

In Monmouthshire we feel that we have been able to put in place effective arrangements for improving autism services through our multi agency Stakeholder Group, parent/carer support groups, our awareness mission and much more. However, we do accept that there is less consistency across Wales.

We have always welcomed the support of the National Development Team and feel that it has and, will continue, to drive towards improved services throughout Wales, via the ASD learning and improvement networks (LIN) and regional groups, the Integrated Autism Service and the website.

Given this, we feel positive about the current infrastructure guided by the refreshed Action Plan in delivering improvement. However, when consulted,

Monmouthshire parents and carers have seen the merits of Wales wide legislation in continuing to drive improvement and consistency in autism services and giving autism a priority and weight.

If Welsh Government is going to develop a new proposed National Autism Strategy, a public consultation could be required. Over the last few years the National Development Team has produced a wide variety of public consultations and surveys and information arising from these could be used to inform future direction and prevent duplication of work. It is important that such guidance is regularly monitored and reviewed with a suggested 4 to 5 year refresh date.

### Questions: Pathways to Diagnosis

- a) What are your views on how easy it is to access a diagnostic assessment where you live?
- b) What key challenges around how the diagnostic process works would you like legislation to address?
- c) 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?

Access to diagnostic assessments for children and young people is provided by Aneurin Bevan University Health Board through the Integrated Service for Children with Additional Needs (ISCAN) into the neurodevelopmental service. Families tell us that this system is relatively easy to access with support and information available from the children centres.

The new Integrated Autism Service is a positive development that will provide diagnostic assessments for people without a learning difficulty or mental health.

In terms of key challenges, parents, carers and some professionals tell us that some GPs are not aware of who or how to refer for diagnostic assessments. Also, people in the criminal justice system and the secure estates find it difficult to access diagnostic assessments.

Another challenge to be addressed, is ensuring the availability of clear published information regarding pathways to diagnosis.

## Questions: Delivery of Services

- a) What are your views on the sufficiency of services currently provided to meet the needs of people with autism spectrum conditions in Wales?
- b) 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, I would like to know your views on which requirements the guidance should place on local authorities and Local Health Boards.

The following is a list of the areas which I believe should be included in the statutory guidance for local authorities and Local Health Boards. Please indicate:

- whether you agree that these should be included, and,
- any other areas that should be included.
  - 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.

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?

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?

Should legislation be forthcoming we would expect it to be accompanied by the relevant guidance. Certainly, the issues raised in the list I to v should be considered for inclusion. However, there may well be other key areas which would benefit from guidance and we would suggest that an inclusive process involving stakeholders from across Wales is undertaken to ensure the robustness of the process of drawing up guidance.

Our own experience would suggest that data collection around numbers and needs of children and adults with autism spectrum conditions is somewhat problematic as there is little consistency and one often encounters systems issues. We feel that this situation will improve with the advent of the new Integrated Autism Service that will be working across boundaries and collecting consistent data across Wales.

### Questions: Training

l) 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?

m) Do you believe that legislation should specify outcomes that training should achieve, thereby providing greater flexibility around the delivery of such training? An alternative approach would be for legislation to specify that key staff working with people with autism spectrum conditions should undertake autism training.

We feel that a real success of the current approach is the development and implementation of training. The National Development Team has rolled out a number of packages across Wales with positive results. An example is the development of a suite of Learning with Autism tools that is in its early stages of implementation and will be rolled out across early years, primary, secondary and further education settings across Wales.

Locally, over successive years we have provided a range of autism training programmes ranging from basic awareness to specialist support. A good example is the specific training we have delivered to the secure estates in Monmouthshire.

Whilst we feel that any legislation should highlight the importance of training, we feel that any further detail or compulsion would remove the flexibility that has

been so important in developing training to respond to the needs of children and adults with autism spectrum conditions over the years. Any specific detail on training might be more appropriate in guidance.

### Questions: Employment

l) 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)?

We are aware that there remains scope to improve the rates of employment of people with autism spectrum conditions.

However, we do not feel that this is the purview of legislation. Rather, we feel that the situation could be improved by Welsh Government giving a profile to the issues experienced by people with autism spectrum conditions and working with national government, other agencies, employers and public bodies to change systems, improve understanding, create opportunities and introduce better employment support.

### Questions: Definition of Autism

l) 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?

Having listened to Monmouthshire parents and carers there is no discernible view on where such definition would be lodged. We feel that the focus of discussion should be on the provision of support for people with autism spectrum conditions rather than one of definition.

### Questions: Unintended Consequences

r) 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?

There is a concern that using legislation to cement an autism strategy and services in Wales could create a culture of 'entitlement' with challenges being taken through the courts.

Autism legislation as well as having accompanying guidance is likely to need an infrastructure to support its delivery and those accessing services through it.

### Questions: Costs

s) 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?

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

- i. producing a national autism strategy;
- ii. placing duties on local authorities and NHS bodies to act under guidance;
- iii. creating and maintaining data collection practices on the numbers and needs of adults and children with autism spectrum conditions; and,
- iv. providing training for key staff?

s) 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?

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

There will be undoubtedly be costs arising from the introduction and implementation of legislation.

Over recent years Welsh Government has made resources available to support the development of services and support for people with autism spectrum conditions and this level of financial support would need to be at least continued, and possibly increased, were legislation to be introduced.

### Questions: Savings

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

At this early stage it is difficult to identify overall savings opportunities. However, were legislation to move forward we would expect a more detailed analysis to be undertaken of potential savings opportunities.

### Questions: Other Issues

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

Within Monmouthshire, agencies, support groups and individuals have worked hard to ensure that people with autism spectrum conditions benefit fully from the opportunities that the current system of support offers. This has yielded very positive outcomes. We are committed to working together to continue to support people with autism spectrum conditions into the future and will ensure that that they benefit within any future arrangement.