

- 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?

Autism is a spectrum of conditions. The way it effects autistic people is diverse. Some people with autism will have disabilities, mental health issues and other developmental issues alongside their autism. As a result the effectiveness of the arrangement will vary from person to person. To create specialist services that fit all autistic people probably impossible even undesirable. We feel that services are not the whole answer. We feel that inclusion, equality, acceptance, fairness and understanding need to have parity in any strategy for autistic people.

In Torfaen we are making progress improving the lives of autistic people and their carers/families through our multi agency Stakeholder Group, parent/carer support groups, our awareness mission and much more. We accept that there is more work to do and that we have face ongoing battle for resources that has been compounded by austerity.

We have had the support of the National Development Team. Their well-regarded work has improved responses to autism throughout Wales. In Torfaen we actively use ASD learning and improvement networks (LIN) and regional groups, the Integrated Autism Service and the website.

We have confidence in the refreshed plan and leadership of the national team. Some stakeholders support an Autism act in continuing to drive improvement and consistency in autism services and giving autism a priority and weight. Others feel there is a danger in poorly and hastily constructed legislation which may give rise to ambiguities and may create further inequalities. Other feel it simply unnecessary.

To legislate for the details of a national strategy with legislation is ambitious. On the whole we would be more in favour of broad principles and values complimenting those contained within the Wellbeing of Future Generations act and Social Services and Wellbeing Act.

Consultation, involvement even coproduction is already enshrined sufficiently in legislation. We are not sure that additional legislation would add any value. It may even cause confusion and inequality.

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 strategy is regularly reviewed and refreshed.

We think it would be a good idea for governments at all levels to be transparent about what support is available and how successful this has been. We do not feel this approach should be restricted to autistic people and their families.

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

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

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?

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.

We also feel waiting times for diagnosis should be in the public domain.

j) 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?

Yes but this should be included in the overall Population needs assessment – separate legislation is not required

k) 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?

As above

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?

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

Training for key staff is developing rapidly the national team have pioneered and driven the uptake of excellent training programmes. There is however no room for complacency. Adult care is in crisis in Wales and is unlikely to improve. Recruitment and retention are significant issues in the sector and as a result training is often not prioritised.

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.

If legalisation is to oversee the training requirements of key staff it would need to be seamless with the standards set by CSW, CSSIW and Estyn. In addition to the corresponding legislation

p) 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)?

1. An expectation on large businesses that they will report on the proportion of disabled/autistic people they employ, at different levels.
2. Every tender exercise included attention to the social value of employing disabled/autistic people (alongside other types of social value) then the Government could seriously leverage its influence – going beyond mobilising the goodwill of those companies already converted to the cause of disability confidence
3. If Government employers could demonstrate progress in employing disabled people at all levels (alongside the FTSE 250 companies), and improving scores on key indicators like levels of harassment at work, or trust in the performance management system, then Government could genuinely adopt the mantle of exemplar. It could approach other employers to show – not just tell – them how to improve disabled people's employment opportunities. There is learning from the USA: from 2011 to 2015, the Federal Government recruited 109,000 people living with health conditions/disability– through Presidential leadership, outreach to

Departments and Agencies, action plans, advice and support.

4. Improve skills, apprenticeships and traineeships by flexing both entry criteria and timespans for apprenticeships irrespective of type of impairment
5. Make it easier for disabled people to be entrepreneurs or self-employed. Ensure that disabled people have fair access to business loans and research grants; and that the rules on what constitutes a viable business – which govern national insurance and eligibility for Access to Work – do not disadvantage people who need time out of their business for impairment-related reasons.
6. Outreach and engagement with individuals who have been out of work for a significant period can be a challenge. Many autistic people and those with health conditions may not be on out of work benefits and thus may not naturally gravitate towards Jobcentre Plus. Referral pathways utilising primary and secondary health care providers, plus social care settings, are often therefore more useful, although there is an ongoing challenge to increase the knowledge and ability of health and social care professionals to refer to employment support channels. The increased focus by NHS England to open up these referral pathways, based on quantifying benefits to the health service of increasing numbers in work, are therefore very welcome. Good examples of this are APM's work linking in with IAPT services in the West Midlands, helping them to engage with specific cohorts when they fell below their targets for referrals, and the Stroke Association's Back to Work Project, working with NHS clinicians across 20 London boroughs to help pool resources to support individuals who had suffered strokes to re-enter employment.
7. Having a disability or health condition does not, of course, mean being low skilled or having low aspirations. However, evidence exists that aspirations by schools and careers services remain too low for young people with disabilities and health conditions. Some good localised examples of employment support existing, including the Leonard Cheshire- run scheme Change 100 aimed at providing career pathways for disabled graduates and the Royal Mencap scheme of supported internships run in partnership with colleges and the local authority in Oxfordshire.
8. Easing access to services is also helpful – locating employment support professionals in health settings and vice versa has proved particularly helpful, as shown by Remploy's work with GP surgeries in Islington. Condition management techniques, including group based techniques, are also widely used, with some

organisations, such as Intraining, part of Newcastle College Group, providing open ended access to counselling. Underpinning such techniques, however, sits the need for well trained and supported employment advisers. Employment support works best when the individual jobseeker has a long term relationship with an adviser they trust, thus removing the need for repeated assessments of need that can dog parts of the public sector.

Co-location and partnership working between different services, generally, is shown to have a real impact on the quality of services. By drawing together a range of different services under one roof, it offers a 'one-stop shop' for the individual and eliminates the need for multiple appointments in different locations (thereby relieving the claimant of a travel and time burden). Additionally it allows different services to communicate with one another more effectively and take joint responsibility for an individual's needs. A prominent example of this would be the Shaw Trust's Community Hubs pilot in London, which draws together employment, debt, benefits, health and other services to offer wrap-around support to service users. The hubs model was found to increase positive outcomes for users, while also having measurable positive impacts on staff and claimant morale and wellbeing.

And above all use evidence based methods of employment support only!

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?

No comment

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?

By giving a particular condition special legal status there is a risk that other conditions are somehow demeaned. This could create inequality. Imbalance in provision and clamour for specialist services over inclusion.

It could be a charter for specialist services rather than focussing on better lives for all.

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

Without doubt the act would have a cost before delivering any benefit.

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.

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

No – very unlikely

Questions: Other Issues

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

Within Torfaen, 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.