

## Brief background to who we are:

Tracscare is a private health and social care provider that has been operating in Wales since 1985. We also operate in England. We currently run 40 different services across Wales that mainly support people with a learning disability or mental health issues. Within those services we have twenty individuals with an autism diagnosis and more that would be eligible for one. We also operate twelve residential autism specialist services in England, plus supporting many individuals on the spectrum in supported living and in a therapeutic health care setting. This response has been coordinated by Sue Hatton – Autism Advisor for Tracscare.

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## The Need for an ongoing Autism Strategy.

### Questions

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

There is no doubt that awareness has been raised and Wales has been at the forefront of this with the initial All Wales Strategy for Autism, but momentum has been lost and without legislative teeth it has been difficult to maintain the kind of development that is required to meet the needs of autistic people and their families.

*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?*

We think this would be a positive step forward but there would need to be some elements of compulsion within the legislation and this would mean funding being made available to ensure certain things can happen. Funding that we believe would reduce the overall costs in time as the right kind of services and support could be offered prior to a crisis or a deterioration into mental ill health for individuals with autism and / or their families.

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

As said within the consultation document the detail cannot be too great as needs are varied across Wales but there should be enough to ensure things really do

happen and that there is a right to redress if services fall short of what the legislation requires.

*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?*

It can be time consuming to consult but worth while if done efficiently with clear time frames and outcomes. It should include autistic people and family members as well as professionals from the different sectors. It will need to be steered by someone with clarity of purpose and the authority to ensure things happen. Once again finance will need to be made available to support the process.

*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?*

Yes, three yearly gives time for things to actually get underway and for results to be seen and evaluated.

*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?*

A board made up of some of those involved in the consultation process that is answerable to the Welsh Government whose purpose is to monitor progress is one idea. This is also something that could be undertaken by an academic Institution with a history of research in the field ie Cardiff University. It would need to be funded.

Clarity on Pathways to Diagnosis.

Questions

*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?*

This is a real challenge as the current strategy has led to an increase in demand for diagnosis and some people are waiting a very long time. It might be helpful to have a triage system as a first stage towards getting on the diagnostic pathway. The major challenge is having enough trained and qualified professionals to be involved in the diagnostic process as it is not a simple one. It takes time and a

range of observations as well as fact finding to give a clear diagnosis with some kind of follow up so people do not feel abandoned post diagnosis. The follow up is crucial to ongoing health and wellbeing.

*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?*

It would be helpful for people to be able to look up the information on the diagnostic pathway so they know where to go and what to expect, but as suggested above some kind of triage system to this process may be helpful.

## Delivery of Services.

### Questions

*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 feel this is very poor and are seeking to develop our own and better knowledge and understanding within our LD and MH services as well in order to be able to work effectively with those who have a co-morbid diagnosis.

*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, 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.*

Yes and this needs to be trained and qualified professional in relation to Autism

*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.*

There are lessons to be learnt from the problems in England around excluding people on a basis of their IQ. It was hoped that the Act in England would prevent individuals falling between mental health services and LD services, but this has not really worked. Often it is a matter of time before mental ill health occurs long after support has been sought for, but with an IQ higher than 70 has been denied. Our feeling would be that the LD services need to be resourced to deal with those with autism who do not have mental health problems and well before they get them. All autistic people have a learning disability in a way because they are living in a neurotypical world, but the LD services would need guidance to work with those who do not have an obvious LD though are Autistic. It can be really hard without the right training and experience to understand why someone with a good degree in physics needs support. However, a degree does not mean they know how to make friends and it is often social isolation and an inability to understand how other people work that excludes and isolates more able autistic people. They often need much more support than is initially evident and without good understanding of autism this is just not seen.

*iii. Planning in relation to the provision of relevant services to people with autistic spectrum conditions, as they move from being children to adults.*

A really important area and especially for those who currently do not fit in the MH or the LD category. They may well have received support in school for their additional needs but seeking help and support post compulsory education is key in the prevention of mental health difficulties at this very stressful time. The introduction of EHC plans up to age 25 in England is a good idea BUT at 18 the children's and adult services split happens and adult care has to take over from children's services and this is often when they fall between LD and MH adult team structures. A transition process that has clarity and statutory requirements would ensure the feeling many families speak of as their son or daughter with autism becomes 18 (It is like falling off a cliff) would not happen.

*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?*

The numbers need to be known and data kept up to date in order to plan to effectively meet needs. Once diagnosis has happened keeping a check on where these individuals are and what services they are receiving should not be too difficult if the process is begun centrally and the maintenance is allocated.

*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?*

Diagnosis is the starting point and then a joint data base for people with autism whether they receive any ongoing health input following diagnosis or LA input

Training.

Questions

*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?*

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

It would be good to have clear outcomes for different stages. Within our structures we have the concept of autism awareness – that is required for all staff and can come from an E Learning module or a half day training session. For staff working directly with autistic individuals we then put staff onto a whole day with the hoped for outcome of them learning to work in more autism friendly ways. Across the company we also train “autism champions” and they work towards a CPD certificate in Good Autism Practice that is awarded by Coventry University and gives what we hope is the outcome of staff who can work in an autism intelligent way – really able to “think autism” to quote the follow up on the English Strategy. Within each of those stages we have specific outcomes and this really does make it more likely that people learn, retain their learning and are able to put theory into practice.

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

We think this is very much what we have done across the company – recognising that everyone needs a certain level but you really need a good spread of people with a much more in-depth knowledge and understanding – hence the concept of autism champions across the company who can guide and advise. Autism leads in each authority and health board would be an idea and echo something of the English pattern, BUT the level of training required for this title would need to be specified.

## Employment.

### Questions

*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)?*

Making reasonable adjustments within the remit of the DDA is much more difficult to address for people with autism so it would be good if an Autism Act could make that link and state exactly what a range of reasonable adjustments would look like when employing someone with autism. ie giving them a quiet space to work in or to go to if an open plan office has a large number of visitors in a day. Good notification period of changes to take place in the staffing structures and / or the environment to give two examples.

*Please explain your answer if possible.*

## Definition of Autism.

### Questions

*q) 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);*

Not sure why a definition is required – it is either a diagnosis someone has or not....the definition lies in the diagnostic criteria that does get reviewed and does alter from time to time ie recently in relation to Asperger Syndrome.

- be included in an autism strategy;*
- be included in guidance; or,*
- not be stated at all?*

*Please explain your answer if possible.*

## Unintended Consequences.

### Questions

*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?*

*Please explain your answer if possible*

**see below for an overall answer re costs and savings.**

### Costs.

### Savings.

### Questions

*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?*

*Please explain your answers if possible.*

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

Perhaps a better way of looking at this is, can we afford not to have the legislation that ensures more readily needs are met. If this happens then the mental health difficulties that individuals and their families often deteriorate into would hopefully not occur and not cost the government money. If the needs were being met

adequately more autistic people would be supported into employment and again savings would be made. If staff were well trained to work with autistic people in autism friendly and autism intelligent ways then the difficulties and struggles that autistic people experience would be much better ameliorated and again money would be saved in terms of the level and amount of support required.

## Other Issues

### Questions

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

England has had an autism act since 2009 and we think it would be very valuable to consult with people like the National Autistic Society and some of the key Autism Research centres in England ( Cambridge University / Birmingham University / Discover Autism Research Network) to learn from the pitfalls and the positives of the last eight years in England.