

The Royal College of Psychiatrists is pleased to respond to your consultation around an Autism Bill for Wales. The Faculty of Child and Adolescent Psychiatry and the Faculty of Intellectual Disability have been consulted and their collective views are represented on the following pages.

In short, the College feels that an Autism Act will not necessarily drive good practice and could lead to a push for higher diagnosis rates rather than focus on meeting the needs of the individual. The need for diagnosis in order to push for resource will only artificially increase diagnosis rates for the wrong reasons.

Autism Spectrum Disorder (ASD) is a complex condition that presents differently in different individuals, which is in part why it is difficult to diagnose. No two persons' needs will be the same. Similarly, there are many children with neurodevelopmental differences (ASD like traits, learning disability, ADHD) who may not meet the criteria for a diagnosis but the sum total of their difficulties is what creates the impairment and affects the quality of life. Support and treatment should be tailored through the needs of the individual through a formulation that is based on a multi factorial understanding of each case, not through their diagnosis and not prescribed through legislation.

The College feels that progress in this area has been made already through wider legislation and specific policies around ASD, and we would recommend that time is allowed for these policies to embed before considering introducing further legislation.

- The Social Services and Wellbeing (Wales) Act 2014 places a duty on public bodies to assess and address the needs of individuals. This legislation effectively covers the needs of children and adults with autism. Under the Act, Regional Partnership Boards must ensure that there are integrated care and support services to meet the need of people in their area and we understand that autism has been identified as one of their priority areas for integration. Regional Partnership Boards will provide annual progress reports to Welsh Government on their outcomes in relation to the National Integrated Autism Service.

- The Together for Children and Young People Programme, Neurodevelopmental Work stream has focussed specifically on neurodevelopmental disorders (ASD and ADHD) and has invested funding in this area. We are pleased that this investment is already resulting in improvements in the quality of service delivery and that there is now an integrated all-Wales neurodevelopmental pathway.
- The refreshed Autistic Spectrum Disorder Strategic Action Plan, and the Delivery Plan also seek to improve existing services. An Implementation Board will review the delivery of the Action Plan and produce annual reports on its progress. The Plan has also established a National Integrated Autism Service, which will see dedicated specialist teams to assess and diagnose adults and support families of children and young people in all regions in Wales by 2019. There will be an independent review of the Service.

Finally, we question if passing legislation in this area would result in a push to legislate in other areas of health.

## The need for an ongoing Autism strategy

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

The current arrangements are not yet fully effective in improving ASD services and provision is patchy across Wales, but autism has been seen as a priority and there have been changes in policy and law seeking to address meeting the needs of people with autism.

The Together for Children and Young People Programme (T4CYP) Programme has recognised that quality of service delivery is dependent on shared practices, joint pathways, good communication, multi-disciplinary approach supported by solid financial investment. The investment of £2m is already resulting in major improvements. The T4CYP work stream on neurodevelopmental disorders which includes children and young people with learning disabilities, has developed the all-Wales neurodevelopmental diagnostic assessment pathway with a single point of entry and quality standards for audit, a clinical peer support group and a Clinician Toolkit. There is currently ongoing work on an All-Wales Intervention Pathway to promote multi-agency working.

Once these initiatives are fully adopted and applied, we believe that these arrangements will be effective in improving autism services.

**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?**

At this point in time, we do not believe that this should be enshrined in legislation. In Wales, we have a coherent clinical national strategy supported by the National Integrated Autism Service and T4CYP. What we need is to ensure that mechanisms for monitoring progress are robust and there is continued financial investment to develop and strengthen services. We agree that the services are currently limited in size and function; however, with the national approach it will be possible to allow assessment of impact over time and to see where the gaps in service are, and allow sharing of good practice through the T4CYP community of practice events.

We worry that passing an Autism Act would prompt other disadvantaged groups to seek support for producing more legislation. The Social Services and Wellbeing (Wales) Act 2014, if properly implemented, should cover all individuals regardless of disability, particularly those with complex needs.

We would urge decision makers to look at England's experience in setting this in statute. The Autism Act has been largely ignored. In addition, Think Autism has statutory authority as the current implementation guidance for the Act but this is not usually followed. On a positive note, where in England the money for health and social care is squeezed and as other services that used to cover gaps are closing, the fact that it is statutory is leading to the Act gaining more traction. Statutory bodies are now under pressure to take action.

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

Again, we do not believe that legislation is appropriate in Wales at this time.

**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?**

See answer to question c).

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?

See answer to question c).

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?

Under the Act, the Regional Partnership Board must report progress to the Welsh Government. The new National Integrated Autism Service will be independently reviewed. We would recommend that a progress report is submitted to Welsh Government annually. The Implementation Board of the new Strategy will also publish annual reports.

## Clarity on pathways to diagnosis

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

Access to assessment is still patchy across Wales but there have been improvements in waiting times for assessment and in the assessment process overall. This is particularly true for children.

Many individuals with ASD have co-morbid mental illness or substance misuse problems, which can cloud their diagnosis and complicate pathway options, with patients potentially falling between services.

Community Learning Disabilities Teams support diagnostic assessments for adults within their services; however, there is a recognisable gap in provision of adult diagnostic assessments for those who do not fit the criteria for learning disability or mental health service provision.

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

We do not believe that legislation will drive best practice. The unintended consequence of such an Act is that diagnostic processes could improve at a pace and legislation would only prove to restrict advances.

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?

Yes, they should be providing children and adults information on the pathway to diagnosis. For children, this integrated, national pathway is already publicly available. We would like to see similar for adults.

## Delivery of services

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 concerned that cuts to local authority budgets have impacted on the quality of services that it provides for people with ASD. The health service restructuring and changes in provision lead to shortage in staffing and resources for diagnostic assessments and eventually delays in access to assessments.

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.
- 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.

If we were to have an Autism Act, it would require statutory guidance

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?

Local Health Boards and Local Authorities are already required to collect data on the needs of their populations. We believe that if health boards and Local Authorities met the requirements of existing legislation this would address this issue.

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?

## Training

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?

Multi-agency training is crucial for delivering quality services, and adequate resources must be allocated.

Many people with ASD with have co-morbid psychiatric disorders such as anxiety, depression and bipolar disorder so will often present in adult mental health services. The College has written [Good practice in the management of autism \(including Asperger syndrome\) in adults \(CR191; Sept 2014\)](#) primarily for psychiatrists other than those in the specialties of intellectual disability and child and adolescent psychiatry.

More trained professionals are needed to enhance current service provision for the diagnostic pathway implementation.

o. 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

## Employment

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)?

When collecting data, attention should be paid to those with ASD in further and higher education. It is common for pupils to leave early if they are unable to cope with the social skills and self-help required. Data should be collected on the number of pupils with ASD completing their education. This should be done with or without legislation.

## Definition of autism

q) Do you believe that a definition of autistic spectrum disorder should: difficult to change in the future);

- 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 believe that this is best placed either in the Autism Strategy (as it currently is [2016]) or in guidance, but not legislation.

## 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?

Autism Spectrum Disorder is a disorder that has gained national prominence through a strong and successful lobby of influential third sector organisations with high profile campaigns. Whilst it is welcomed that ASD gets the attention that it deserves, there are many conditions, illnesses, and diseases that hold a lower profile. If this Bill is passed, it could be argued that we should legislate for good practice in other areas, such as ADHD.

The Mental Health (Wales) Measure 2010 has not resulted in driving quality mental health service provision. We would urge that you look at the unintended

consequences that have arisen during the implementation of this piece of legislation.

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