Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill Ymateb gan Goleg Brenhinol yr Ymarferwyr Cyffredinol Response from Royal College of General Practitioners



RCGP Wales response to the Autism (Wales) Bill consultation

- The Royal College of General Practitioners Wales welcomes the opportunity to respond to the National Assembly for Wales' Health, Social Care and Sport Committee's consultation on the Autism (Wales) Bill, and to provide oral evidence to the Committee.
- RCGP Wales represents a network of around 2,000 GPs, aiming to improve care for patients. We work to encourage and maintain the highest standards of general medical practice and act as the voice of GPs on resources, education, training, research and clinical standards.

The general principles of the Autism (Wales) Bill and the extent to which it will make provision for meeting the needs of children and adults with Autism Spectrum Disorder (ASD) in Wales and achieve the aim of protecting and promoting their rights;

- 3. We have concerns that the Bill would lead to diagnosis-based services, instead of services that are needs based and person-centred.
- 4. Autistic spectrum disorder has a broad range of presentations which can make diagnosis difficult. Individuals can fall between mental health and learning disability. The spectrum may be part of a physical disability, meaning patients do not get either learning disability or mental health support.
- 5. Those not diagnosed until they are adults may have greater problems accessing support; there are less services for adults and some preclude those who were not diagnosed as a child. There are difficulties in the transition between children and adult services. Services are limited for children but often there are no services available to move to when they are adults.
- 6. People with learning disabilities, neurodevelopmental disorders or other diagnoses such as attention deficit hyperactivity disorder may not meet the criteria for support under an Autism Bill. Obtaining services and support for these patients can be very difficult; the proposed Bill must not further restrict the support available to those without an autism spectrum disorder diagnosis.

7. We believe support services targeted specifically at those with suspected autism spectrum disorder may be difficult to implement. We have some doubts about support based on legislation or a particular diagnosis; instead we would prefer a needs-based approach which allocates resources and support according to a person's needs.

Any potential barriers to the implementation of the provisions and whether the Bill takes account of them;

- 8. Workforce shortages across a number of professions are likely to be a barrier in improving services.
- 9. We know it is the case with GPs, where severe workforce pressures are having a negative effect on the quality of care GPs are able to give patients. As of September 2017, GP numbers per 10,000 population were the lowest they have been since September 2004, when this figure were first collected¹. While raising data quality issues, a Welsh Government statistical bulletin outlined that the number of GPs in Wales (excluding locums, retainers and registrars) has fallen to 1,926². This is the lowest since 2006/07. We are aware that other professions also face shortages.
- 10. Access to services will depend on the staff working in them. Increased support is unlikely to happen unless there is a boosted multidisciplinary workforce.

Whether there are any unintended consequences arising from the Bill;

- 11. We are concerned that making support dependent on a diagnostic label could exclude others who are equally in need of support. Again, this is a risk of making support diagnosis-based rather than needs-based.
- 12. There may be a risk that introducing diagnosis-based legislation may also lead to calls for specific legislation around other illnesses and conditions. We have doubts as to whether a series of separate pieces of legislation would deliver the best outcomes, as opposed to developing holistic services that are based on need.
- 13. There is a risk around the impact on diagnostic rates, given individuals or families may feel they are most likely to obtain support by securing a specific diagnosis.
- 14. We are aware of a number of existing programmes seeking to improve ASD patient outcomes, and there may be an unintended consequence that new legislation duplicates some of that work. The Social Services and Well-being Act, Together for Children and Young People, the National Integrated Autism Service, and the Additional Learning Needs Bill all contain measures that could improve patient outcomes. These are in various stages of development and implementation and may deliver improvements.

¹ https://statswales.gov.wales/Catalogue/Health-and-Social-Care/General-Medical-Services/localhealthboardcomparisonsofgpworkforce-by-year

https://gov.wales/docs/statistics/2018/180426-general-medical-practitioners-2006-2017-en.pdf

The financial implications of the Bill (as set out in Part 2 of the Explanatory Memorandum);

- 15. We believe additional investment would be better spent on developing needs-based services, rather than diagnosis-based services.
- 16. We note that general practice remains significantly under-resourced. In 2016/17 general practice received 7.30% of Welsh NHS spend; across the United Kingdom that figure was 8.88%. Proposals involving general practice to improve services will need to be backed with a shift in resource if they are to deliver positive outcomes.

The appropriateness of the powers in the Bill for Welsh Ministers to make subordinate legislation (as set out in Chapter 6 of Part 1 of the Explanatory Memorandum).

17. If a Bill is passed we would support flexibility to meet future needs developments, including in definitions to ensure the emphasis on autism does not restrict the support available to those who fall outside of a diagnosis of autistic spectrum disorder.