National Assembly for Wales Health, Social Care and Sport Committee consultation on the general principles of the Autism (Wales) Bill

Executive Summary

- The Royal College of Speech and Language Therapists (RCSLT) Wales welcomes the opportunity to comment on the proposed Autism (Wales) Bill. We have developed our response in consultation with our members who advise on, manage and deliver autism services.
- RCSLT Wales is fully committed to improving outcomes for people with Autism Spectrum Disorder (ASD). The question is whether the proposed bill and whether primary legislation is the most appropriate vehicle to achieve change.
- In scrutinising the proposed legislation, we believe it would be helpful for the committee to consider four main areas, namely:

- whether the proposed bill could drive a focus on diagnosis rather than need
- current new developments in relation to ASD services such as the Additional Learning Needs and Educational Tribunal (Wales) Act, the integrated autism service and timeliness of the proposed legislation
- the potential implications of introducing condition-specific legislation
- learning from other nations where autism-specific legislation has been enacted.

- We also wish to draw to the attention of the committee the briefings on the bill which we produced jointly with the **Welsh NHS Confederation, the Royal College of Psychiatrists, Royal College of Paediatrics and Child Health (RCPCH), and the Royal College of Occupational Therapists (RCOT).**

About the Royal College of Speech and Language Therapists

1. RCSLT is the professional body for speech and language therapists, SLT students and support workers working in the UK. The RCSLT has 17,500 members (650 in Wales) representing approximately 95% of SLTs working in the UK (who are registered with the Health & Care Professions Council). We promote excellence in practice and influence health, education, care and justice policies.

2. Speech and Language Therapists (SLTs) are integral members of the multi-agency teams that provide support to children and adults with ASD and their families and carers. SLTs have a unique role in identifying the social communication characteristics of importance to diagnosis, contributing to differential diagnosis and facilitating identification of retained abilities and co-morbidities. They also have a key role in educating/training others involved in the care of those with ASD, including families, health, education and social care staff.

The general principles of the Autism (Wales) Bill and the extent to which it will makes 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. RCSLT Wales does not object to the general principles of the proposed Autism (Wales) Bill in relation to promoting best practice in diagnosis, strengthening support for families, ensuring that key staff receive appropriate training and strategies are regularly reviewed. The question is whether legislation would be the most appropriate vehicle to achieve the ambitions set out in the purpose of the bill.

4. There are a range of new initiatives for people with ASD currently within the early stages of development in Wales. These initiatives aim to tackle many of the key areas of concern which the legislation proposes to address such as diagnosis, support, data and training. We discuss these changes in more detail here with reference to the key principles of the proposed bill.

- *Prioritisation of ASD* – Under the *Social Services and Well-being (Wales) Act 2014* there is a duty on public bodies to assess and address the needs of individuals. Under the Act, Regional Partnership Boards must ensure that integrated care and support services meet the needs of people in their localities. ASD has been identified as one of the priority areas for integration. The Act also places a legal obligation on Regional Partnership Boards to provide annual progress reports to Welsh Government on their outcomes in relation to the National Integrated Autism Service. We understand that a code of practice on the delivery of Autism services will be published under the Act in 2019.

- *Diagnosis* - Under the *Together for Children and Young People programme,* there has been significant investment in neurodevelopmental services. Nationally agreed neurodevelopmental children and young people's diagnostic pathways and standards are now in place and have been adopted by all health boards. A new 26 week waiting time standard from referral to first assessment appointment has also been introduced.

- *Support* - The National Integrated Autism Service has recently been established with the aim of creating consistent support for people with ASD across Wales. All services are due to be in place by the end of 2018. An independent review of the service will take place in 2019.

- *Education* - The Additional Learning Needs and Education Tribunal (Wales) Act has recently been given Royal Assent and implementation will begin in 2020. It is hoped that the new system will bring tangible benefits to children and young people with ASD by supporting early identification of additional learning needs and effective interventions to support these needs throughout a child and young person's education.

5. Whilst understanding of the frustrations of people with ASD and their families, given the scale of these changes, we believe that that it may be prudent to assess the impact of the implementation of these new developments prior to the introduction of new legislation.

6. Learning from the enactment of autism specific legislation in other nations (England and Northern Ireland) appears to indicate that legislation is not leading to the envisaged improved outcomes for people with ASD. The National Autistic Society Push for Action report on the implementation of the Autism Act in England in 2014 concluded that whilst the strategy has been successful in putting in place the building blocks for better planning and commissioning of services 'for the most part adults with autism and their families are still waiting for the support they need' (National Autistic Society, 2014). This is also supported by a recent detailed report by the National Autism Project (a UK wide initiative which aims to provide authoritative recommendations on autism research and practice) which stated that 'nearly a decade on (from the Autism Act) the needs of autistic people are still unmet' (National Autism project, 2017).

7. Similarly in Northern Ireland, the National Autistic Society Northern Ireland and Autism NI 2016 report on progress since the introduction of the Autism Act in 2011 revealed strong evidence that services had stayed the same or worsened since the enactment of legislation. The survey revealed that 75% of respondents felt that services for children had got worse or stayed the same and 56% of adults felt that services had got worse or stayed the same. The report argued that 'in 2011, the Autism Act and resulting Strategy and Action Plan increased the hopes of autistic people and their families for a better future for them and their loved ones. However the reality is that their life is getting more, rather than less, difficult for them and services are failing to deliver' and challenged the Northern Ireland Government on what they saw as 'broken promises' to autistic people and their families (NAS Northern Ireland and Autism NI, 2016).

8. It is our view that learning from other nations suggests that legislation without significant extra funding and detailed consideration of the impact on the workforce will not deliver the ambitions outlined in the general principles of the bill. We would welcome a review of practice in countries where 'autism-specific' legislation is enforced so that assessments can be made of the effectiveness of such measures.

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

9. We believe that a major challenge to the implementation of the bill would be workforce capacity. Our members have told us that neurodevelopmental services are already under significant pressure to provide assessment and support under referral to treatment time targets. In our evidence to the recent Children, Young People and Education Committee inquiry on emotional and mental health, we expressed concern that given the pressures, SLTs' time is often solely focussed on diagnosis with no capacity to support post-diagnostic interventions (RCSLT, 2017). Significant additional resources would be required to meet the specified time targets within the bill and to offer appropriate post-diagnostic support. We are concerned that this would inevitably impact on the ability of the profession to meet the needs of other populations who have similar needs but a different (or no) diagnosis and prioritise those with the greatest needs first. Current prevalence figures suggest that 1% of children and adults have ASD with 7.58% of children affected by developmental language disorder – a disorder that affects the way they understand and express language. Others conditions which may have associated language disorders include learning disabilities, cerebral palsy, brain injury, sensorineural hearing loss and down's syndrome. We strongly believe that policy and legislation should meet the needs of all individuals with neuro developmental (ND) disorders, including those who may not fit the ICD diagnostic criteria for ASD or other ND disorders specified by Welsh Ministers (and therefore not receive a formal diagnosis) but have traits of these conditions that impair their everyday social, psychological and intellectual functioning.

Unintended consequences arising from the Bill;

10. We believe that the proposed bill may have a range of unintended consequences. Throughout the legislative journey thus far, we have raised concerns that autism specific legislation could potentially risk prioritising the needs of people with ASD above the needs of those with other disorders. We understand that this issue has been considered in the proposed bill. However we do not believe the proposed change to include 'any other neurodevelopmental disorder as prescribed by Welsh ministers' will be possible to support given the current lack of shared understanding of this term amongst professional groups and the fast growing body of research in the area of neuro-disabilities, particularly with regard to classification of sub-groups. We foresee such a change to the proposed bill is likely to result in protracted discussions with regards what is included and excluded from the legislation.

11. We strongly believe that protections should be on the basis of need not diagnosis which would be consistent with the ethos of existing legislation such as the Social Services and Wellbeing Act and the Additional Learning Needs and Education Tribunal (Wales) Act. A needs-based approach is particularly important in improving outcomes for this client group given the high prevalence of co-morbidities for individuals with ASD, with evidence suggesting that 70% of young people with ASD live with at least one co-morbid condition (Simonoff et al, 2008).

The development of the all Wales neurodevelopmental pathway has been very helpful in supporting broader thinking around diagnoses. There is currently a move away from tight diagnostic groupings to ensure that people who do not necessarily fulfil the criteria for autism but require intervention have their needs met. We would not wish to see this shift potentially undermined by legislation and for the needs of people with ASD and/ or included other neurodevelopmental conditions to be prioritised above the needs of those with other disorders.

12. We also question whether disability-specific legislation could potentially set a new precedent and could lead other interested parties, patient groups and third sector organisations to call for the introduction of specific legislation for other illnesses and conditions. We concur with the views of the Welsh NHS Confederation in this regard that '(while) this does not mean that proposals for an Autism Act are unwarranted, it does mean that the evidence base for the introduction of such legislation must be extremely robust and convincing around improving patient outcomes' (Welsh NHS Confederation, 2017). As part of scrutiny, we believe it will be key to consider the fit of this legislation with both the Social Services and Wellbeing (Wales) Act 2014 which already legislates for all individuals regardless of the extent of complexity of patient needs and the Additional Learning Needs and Education Tribunal (Wales) Act 2018.

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

13. We recognise the findings of the National Audit Office that if services identified and supported adults with high functioning autism spectrum conditions then the outlay would be cost neutral (National Audit Office, 2009). We believe that improved autism services would bring a number of savings in terms of wellbeing. For example reductions in hospital admittance and early discharge. However we are strongly of the view that in order for the legislation to address the issues the proposal highlights around inconsistencies in services, significant additional funding would be required to support local authorities and local health boards to fulfil their duties. We are mindful that parliamentary scrutiny of the proposed Autism bill in Scotland considered whether the proposed legislation would lead to improvements in services without significant extra funding for staff and resources. This was highlighted as a key issue in the scrutiny committee's recommendation that the general principles of the bill should not be supported (**Education, Lifelong Learning and Culture Committee Report, 2010)**.

Further Information

1. We would be happy to provide any additional information required to support the Committee's decision making and scrutiny. For further information, please contact:

[redacted]

References

Education, Lifelong Learning and Culture Committee (2011). Report on Stage 1 of the Autism (Scotland) Bill. Edinburgh: Scottish Parliament

National Audit Office (2009). Supporting People with Autism through adulthood. National Audit Office: London.

National Autism project (2017). The Autism Dividend: reaping the rewards of better investment. London School of Economics and Political Science: London.

National Autistic Society (2014). Push for Action: We need to turn the Autism Act into action. National Autistic Society: London.

National Autistic Society Northern Ireland and Autism NI (2016). Broken Promises. National Autistic Society Northern Ireland and Autism NI: Belfast.

Royal College of Speech and Language Therapists (2018). Children, Young People and Education Committee inquiry into the emotional; and mental health of children and young people – written evidence from the Royal College of Speech and Language Therapists. Available at: http://senedd.assembly.wales/documents/s67508/EMH%2006%20Royal%20College%20of%20Speech%20and%20Language%20Therapists.pdf

Simonoff E, Pickles A, Charman T, Chandler S, Loucas T, Baird G (2008). 'Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample' in the Journal of the American Academy of Child and Adolescent Psychiatry 2008 Aug;47(8):921-9. doi: 10.1097/CHI.0b013e318179964f.

Welsh NHS Confederation (2017). The Autism (Wales) Bill - Evidence from Welsh NHS Confederation. Available at: http://www.nhsconfed.org/-/media/Confederation/Files/Wales-Confed/Welsh-NHS-Confed-response-to-the-Draft-Autism-Wales-Bill.pdf