

Executive Summary

The Royal College of Speech and Language Therapists (RCSLT) Wales welcomes the opportunity to comment on the proposed Autism (Wales) Bill. Speech and Language Therapists (SLTs) are integral members of the multi-agency teams that provide support to children and adults with autism spectrum disorders.

We have developed our response in consultation with our members who advise on, manage and deliver autism services. We have divided it into a number of key themes namely

- effectiveness of the current arrangements for improving autism services in Wales and whether we believe there is need for legislation requiring the publication of a national strategy and guidance,
- the diagnostic process,
- statutory guidance including data collection,
- training,
- unintended consequences
- costs

Key points raised within the response

RCSLT Wales believes that the policy objectives of the proposed Autism bill are laudable. However we would caution that protections and provisions for people with autism spectrum disorders are not considered in isolation from those with other neurodevelopmental conditions. We also recognise that there have been several recent, important developments with regard to autism services such as the introduction of the Integrated Autism Service and the development of neurodevelopmental services. We are very aware that new developments require time to bring about significant change and believe it may be too early to judge the impact of the new services and decide whether specific Autism Spectrum Disorder (ASD) specific legislation is required.

About the Royal College of Speech and Language Therapists

1. RCSLT is the professional body for speech and language therapists (SLTs),

SLT students and support workers working in the UK. The RCSLT has 17,500 members in the UK (500 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 Therapy manages the risk of harm and reduces functional impact for people with speech, language and communication support needs and/ or swallowing difficulties.

3. SLTs are experts in supporting children and adults with speech, language and communication needs (SLCN) and training the wider workforce, carers and families so that they can identify the signs of speech, language and communication needs, improve communication environments and provide effective support.

The role of speech and language therapist in autism services

4. SLTs help to assess, diagnose and support autistic people. They work to enhance their communication skills, so that individuals with autism can effectively communicate their thoughts, needs and feelings. SLTs involve family members, carers and other professionals so that they can contribute to decisions and implement communication aids and strategies that help to meet a child or adult's needs.

Effectiveness of current arrangements and need for legislation

5. RCSLT believes that there has been significant progress with regard to autism services in Wales since the development of the Autism Spectrum Disorder Strategic Action Plan in 2008 and the refreshed plan in 2016. We particularly welcome the introduction of the 26 week waiting time target and standardised assessment pathway as part of the development of neurodevelopmental services in Wales, within the Together for Children and Young People Programme (TCYP). SLTs are part of a core group of professionals driving change and providing specialist assessment and there is now provision within services across all local health boards in Wales which is a hugely positive development. Members have informed us that the new monies are slowly leading to reductions in assessment waiting times and have significantly improved processes by providing more comprehensive, multi-professional assessments. We understand that assessment waiting times remain too long in many areas but believe that the right systems are now in place to support further improvement and that waiting times will reduce

significantly over time as the neurodevelopmental services bed in.

6. We also believe that the national integrated autism service (IAS), under which new specialist teams will be developed in every region is a very positive step forward with particular regard to ensuring adult diagnosis and support in the community – a longstanding gap in provision. We are pleased that SLT is part of these core teams across Wales. Whilst, we have a number of concerns around the size of the teams funded given the scale of the task in hand, we recognise that this is a new initiative and will need time to develop and deliver.

7. With regard to education, the profession is very supportive of the development of the new system to support children and young people with additional learning needs (ALN). We have been closely involved in the drafting of the code of practice and are hopeful that the new system will bring tangible benefits to children and young people with autism spectrum disorder (ASD) by supporting early identification of additional learning needs and effective interventions to support these needs throughout a child and young person's education. Again, with the legislation yet to become law, it is difficult to assess the impact of the changes and whether further action will be required.

8. As professionals working regularly with people with ASD and their families, we fully understand the concerns and frustrations raised around the inconsistencies in the current provision of services. We do however believe that given the range of new initiatives currently within the early stages of development, particularly the IAS, that it may be prudent to assess the impact of the implementation of these new initiatives prior to the introduction of new legislation. In addition to the question of timing, we think it may be helpful to consider the points raised below. For example;

- Whether such disability-specific legislation would set a new precedent and could potentially risk prioritising the needs of people with ASD above the needs of those with other disorders. The development of the 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. Autism legislation could perversely have unintended consequences for such people who may then struggle to access support.

- Whether primary legislation is the most appropriate vehicle to achieve change in this area. We would be interested to gain further clarification on the recent announcement by the Minister that statutory guidance on autism under the Social Services and Well-being Act would be introduced to underpin delivery of the strategic action plan and that consideration would be given to exploring whether the autism spectrum strategic action plan may be put on a statutory footing.
- We would also question whether the proposed legislation would lead to improvements in services without significant extra funding for staff and resources, particularly with regard to training. Parliamentary consideration of the proposed Autism Bill in Scotland highlighted this as a key issue in its recommendation that the general principles of the bill should not be agreed to.

The Diagnostic process

9. As we have alluded to briefly above, we believe that the development of the neurodevelopmental assessment services and nationally agreed children's assessment pathway is gradually leading to reductions in assessment waiting times and more comprehensive, multi-professional assessments. It is equally very positive that there is growing understanding of co-morbidities in this area. (Evidence has shown that 70% of young people with ASD experience depression and 50% suffer from co-morbid anxiety (Lugnegard et al, 2011) with 70% of young people with ASD living with at least one co-morbid condition and 41% with two or more (Simonoff et al, 2008). Members have highlighted to us that families who have experienced well-conducted assessment and diagnosis process are requiring less support and are demonstrating increased levels of resilience and independence from services.

10. Undoubtedly issues remain with regard to diagnosis. Members have advised us that there is significant variation in terms of the amount of provision funded in each service, the composition of teams, where line management sits and aspects of services delivered. In addition, many SLTs have conveyed to us their concerns that there is insufficient funding to provide specialist pre and post diagnosis intervention. They highlight that the TYCP programme targets focus exclusively on assessment which has a significant knock on effect for other parts of the service such as intervention and training. However, it remains very early days for the developments of the new services and we are not convinced that legislation would

deliver further improvements with regards the diagnostic process without further funding. We would welcome exploration of other options such as consideration being given to autism being listed as a tier one target.

Statutory guidance and data collection

11. As highlighted above, given the existing legislation in place, we would question the need for further duties on local authorities and local health boards without such duties also being extended to education and other sectors. We do however believe that data collection practices could potentially be improved without the need for autism specific legislation. For example, the population needs assessment currently collects combined data on autism and learning disabilities are currently linked together which may miss out those who have autism but do not also have a learning disability. In addition, data is collected on referral, at a stage when people may not yet have been diagnosed, do not fit clearly into diagnostic criteria or where autism is not the primary reason for referral and is identified at a later stage. There is significant scope to refine data collection processes to support a clearer understanding of need.

Training

12. As highlighted within the consultation, there is a great deal of focus currently within both the IAS and neuro-developmental pathways on improving multi-disciplinary training. There are clear efforts to join up training programmes and it is our understanding the regional partnership boards are undertaking training needs analysis. A national training programme and suite of resources is also being developed by the national ASD development team. We are unclear whether legislation is required to promote consistency of training outcomes, particularly whilst evaluation of the IAS and neuro-developmental pathways has yet to take place. Again, we believe other avenues may be helpful to explore such as statutory and mandatory training for all staff around autism as exists for dementia. This would support the upskilling of staff in generic services which is key in ensuring that people with ASD are able to access all services equitably, appropriate to need.

Unintended consequences

13. We have a number of concerns that the bill may have unintended consequences. We question whether disability-specific legislation would set a new precedent and could potentially risk prioritising the needs of people with autism

above the needs of those with other disorders. It is important to consider that 7.6% of children (2 in every class of 30) will start school with a developmental language disorder (Norbury, CF et al, 2016). Prevalence of autism in adulthood is now recognised to be similar to childhood prevalence, at 1.1% (Brugha et al., 2012). The development of the 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. Autism legislation could perversely have unintended consequences for such people who may then struggle to access support.

14. In addition, we sense that the balance of the proposed legislation is heavily weighted on health and social services whereas what we believe is required is a partnership approach with individuals and families to achieve the best outcomes. We would welcome consideration of how services may best support individuals on the ASD to move away from dependence on services in keeping with the spirit of the Social Services and Wellbeing Act and principles of prudent healthcare. The focus of any intervention should be the delivery of outcomes that are truly valued by individual service users, rather than the focus being on the output or activity provided by the professional (Bradley and Wilson, 2014).

Costs and savings

15. 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. We believe that improved autism services would bring a number of savings in terms of wellbeing. For example reductions in hospital admittance, early discharge. However we strongly believe 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 of the comments in the National Autistic Society Push for Action report on the implementation of the Autism Act in England which suggested 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).

References

Bradley, P and Wilson, A (2014). Achieving prudent healthcare in NHS Wales. Cardiff: 1000 Lives Improvement.

Brugha, T. S. et al. (2012). Validating two survey methods for identifying cases of autism spectrum disorder among adults in the community. *Psychological Medicine*, 42(3), 647–656.

Lugnegård T, Hallerbäck MU, Gillberg C (2011). Psychiatric comorbidity in young adults with a clinical diagnosis of Asperger syndrome. *Research in Developmental Disabilities*. 2011;32(5):1910–1917.

National Autistic Society (2013). Push for Action: We need to turn the Autism Act into action. London: National Autistic Society

Norbury, CF et al (2016). The impact of non-verbal ability on prevalence and clinical presentation of language disorder: evidence from a population study. *Journal of Child Psychiatry and Psychology*, 2016;57(11):1247–1257

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 *Journal of the American Academy of Child and Adolescent Psychiatry* 2008 August 47 (8) 921–9 doi: 10.1097/CHI.0b013e318179964f