Pwyllgor Iechyd, Gwasanaethau Cymdeithasol a Chwaraeon
Health, Social Care and Sport Committee
HSCS(5)-27-18 Papur 6 / Paper 6

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Leading the way in Children's Health

Evidence submitted by the Royal College of Paediatrics and Child Health (RCPCH) to the Autism (Wales) Bill Consultation, September 2018

About the RCPCH

The RCPCH works to transform child health through knowledge, innovation and expertise. We have over 500 members in Wales and over 17,500 worldwide. The RCPCH is responsible for training and examining paediatricians. We also advocate on behalf of members, represent their views and draw upon their expertise to inform policy development and the maintenance of professional standards.

Summary: RCPCH's position on the draft Bill

We welcome calls for increased resource to support children with Autism Spectrum Disorder (ASD) and their families and welcome also opportunities to explore changes to improve outcomes for children and young people with ASD or being referred into neurodevelopmental (ND) disorder pathways. The RCPCH shares the aspiration to make provision for meeting the needs of children with ASD in Wales and protecting and promoting their rights. However, RCPCH members in Wales have expressed concerns about possible unintended consequences of the proposed legislation. In particular, members have expressed concerns about:

- The risk of parents seeing an ASD diagnosis as a requirement for accessing services and the potential for increased numbers of children and young people being inappropriately diagnosed with ASD
- The risk of adopting an approach that is not child-centred because it is based on diagnosis rather than need
- The risk to provision of all community paediatric services including ASD if demand increases without sufficiently increasing resource
- The risk to non-ASD community paediatric services such as disabilities or safeguarding if existing resource is allocated on the basis of legal requirement rather than clinical need
- The risk that legislation that will not improve outcomes for children and young people with ASD

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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;

We are concerned that the proposed legislation will not meet the needs of children with ASD in Wales. Our concerns are based partially on the experience from other parts of the UK: evidence from the introduction of Autism Acts in England (2009) and Northern Ireland (2011) suggests that legislation is not leading to improved outcomes for people with Autism Spectrum Disorder. In Scotland, proposals for an Autism Bill were rejected at Committee stage.

Evidence of the experience from other parts of the UK is set out in the briefing we have produced jointly with the NHS Confederation and the Royal Colleges of Psychiatrists, Speech and Language Therapists and Occupational Therapists, which we will re-submit to the Committee with this response. Since then, the Welsh NHS Confederation has produced a detailed briefing looking specifically at this issue, which we encourage Committee members to note.

The first joint briefing also discussed a number of areas of policy and legislation that will have an impact on the evolution and delivery of ASD and ND services in Wales, so we will not repeat the detail here. However, we would urge the Committee to consider the impact and need for evaluation of these areas of work ahead of making recommendations as to whether legislation is the best way to improve outcomes for children and young people with ASD. These include:

- The Social Services and Well-being (Wales) Act 2014
- The Together for Children and Young People programme
- The National Integrated Autism Service
- The Additional Learning Needs and Education Tribunal (Wales) Act 2018

This list is not exhaustive and given the links with mental health, education and trauma, other programmes and policy areas with which there will likely be interaction include ACEs, the First 1000 Days programme and any developments in children and young people’s mental health.

Unintended consequences arising from the Bill

RCPCH members in Wales are concerned that in linking resource to a diagnosis – whether autism, ASD or a given definition of ND disorders - there is a risk that families will feel that their best opportunity to access the support they need is by securing that diagnosis. This is not child-centred, because children presenting with a range of issues or symptoms that may be similar to or overlap with ASD but where ASD is not an appropriate diagnosis, may then be excluded from a pathway to receiving the appropriate care and resources.

RCPCH and our members believe that policy, legislation and services should meet the needs of all individuals with traits similar to ASD or ND, that impair their everyday social, psychological and intellectual functioning - whether or not they meet a diagnostic criteria. Otherwise we risk alienating vulnerable populations who have no diagnosis and a weaker voice to advocate for themselves. These issues were raised by RCPCH member [redacted] during the Children, Young People and Education Committee's inquiry into the mental and emotional health of children and young people:

"A child could have a specific learning difficulty, a child could have a specific motor problem with dyspraxia. But, functionally, that child is struggling. The problem is at the moment that maybe we are driving our resources towards a specific diagnosis, and therefore that leads to frustration and challenge on the part of parents if they do not receive that diagnosis. They may well have got an accurate description of their child's needs, but they cannot secure the support they need or the resources they need."[1]

Another potential consequence of this is drawing resources away from people who do not have ASD or ND but require Community Paediatric services, or from other areas of work such as safeguarding. As one RCPCH member in Wales told us, "an Autism specific Bill may improve services and provisions for children with ASD, but without further resources in all sectors, existing resources are likely to be focused on children and young adults with ASD and away from others with ND disorders or learning disabilities who may have on an individual basis a lesser or greater need".

All of this risks creating additional (and sometimes inappropriate) demand on community paediatric services where this is seen as the 'gateway' to diagnosis without a commensurate increase in resource. Community paediatricians have told us that they are already struggling to meet demand. We also know that there are gaps in the community paediatric workforce and a need for more community paediatricians. Further investment would also be required into the associated services and other professions working as part of multidisciplinary teams to meet any additional requirements and would therefore be key to delivering improved ASD services without risking unintended consequences for other services.

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

As previously stated, the biggest barrier to implementation would be a possible increase in demand on Community Paediatric services, along with Psychiatry and a range of other services including Speech and Language Therapy and Occupational Therapy. Many services are already operating at capacity, or have waiting lists, or have workforce shortages placing additional pressure on existing staff who have to cover gaps. Provisional analysis of the 2017 census (please note: these figures are unpublished and we may need to revise if we receive further data) suggests that:

- The number of community career-grade doctors in community child health in Wales has reduced from 87 in 2015 to 81 in 2017.

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[1] http://record.assembly.wales/Committee/4529#A40906 item 388. See also items 386 and 369.

- There are five vacancies for community paediatric consultants in Wales according to the 2017 census, up from two in 2015. As a proportion of total vacancies in Wales, 50% were community posts in 2017 (5/10) and 29% were community posts in 2015 (2/7).
- The career-grade community paediatric workforce in Wales is increasing in age, with no evidence of replacement doctors for those nearing retirement.
- 74 individuals, trained in Wales, achieved their CCT or CESR between 2011 and 2017. Of those, only 4 specialised in Community Child Health.

Community paediatricians are therefore under pressure and any additional demand could have an impact on services if there is not an immediate and commensurate increase in resource.

Another potential barrier is around waiting lists to access assessments. Due regard needs to be placed on current and future demand to diagnose children with autism. Many referrals are not appropriate and this needs to be addressed with education for referrers on what the other potential solutions or diagnoses could be other than autism. Waiting times could be reduced if mental health and community paediatric services were accessed appropriately, consistently.

We stress again that whether a person has a formal diagnosis or has identified needs but not a formal diagnosis, a timely multiagency commitment must be established to ensure that these children and their carers have their concerns addressed and support initiated. The resources to support identified needs do not necessarily rest with the diagnostic teams. This has implications for both children's social care and education in addition to health services. Legislation on waiting times may therefore not improve 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).

The Explanatory Memorandum says that "The regulation-making powers in this section allow the Welsh Ministers to make regulations, by which include, for the purposes of this Bill only, other neurodevelopmental disorders in addition to the WHO International Classification of Diseases definition of 'autism spectrum disorder'" and "the affirmative procedure is appropriate given that these regulations may significantly extend the scope of the disorders to which the Bill will apply".

Classifications will change and no matter how much this is emphasized in small print this may contribute to confusion for non-specialist individuals. Further discussion and agreement would be required to define what is meant by ND in the context of the legislation - there is considerable variation among professionals and families in their use and understanding of this term.

The inclusion in future of other ND would also create challenges in terms of service delivery as it represents a change from ASD specific services – this would have significant implications. Extending the scope and remit of the proposed legislation to cover conditions beyond ASD could have implications and impact different to that intended by the introduction of condition-specific legislation for autism.