



Royal College of Paediatrics and Child Health (RCPCH) consultation response, Feb 2019: Code of practice on the delivery of autism services

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.

Code of practice on the delivery of autism services

RCPCH welcomes attempts to improve services for children with Autism Spectrum Disorder (ASD) and accepts much of the content of the draft Code. We recognise that the Code covers both children and adult services, but we will focus on issues affecting children, young people, their families and paediatricians.

We are pleased that the Code notes the progress being made through the Together 4 Children and Young People (T4CYP) programme. On a wider perspective we concur that “improvements are being secured for neurodevelopmental services for children and young people as part of the Together for Children and Young people Programme (T4CYP). This programme is improving assessment and diagnostic services for all neurodevelopmental conditions and services are linked at the local level to ensure that there is a strong relationship with the IAS.”

However, paediatricians have raised concerns about separating children with ASD from others accessing services through the Neurodevelopmental Disorders (ND) pathway. Much of this concern is around how we continue to deliver the improvements we’re seeing through the ND and trauma-informed approach being taken by T4CYP as highlighted in the code, if we then adopt an ASD-specific model of practice. The two things could be contradictory, especially in the context of services running at or beyond capacity.

Specifically, our concerns are about:

- Capacity and workforce
- Equity and delivering a child-centred approach
- The need to consider an ND pathway approach rather than an ASD-specific approach

Capacity and workforce

We are concerned that a Code that does not address the question of capacity as a starting point and places no duties on Health Boards to deliver a fully staffed community paediatric workforce risks overlooking a significant barrier to delivery.

Data from our most recent workforce census are being gathered. We will share Wales-specific data with the Welsh Government in the Spring of 2019. However, we know that there are gaps in the community paediatric workforce and have highlighted this in previous reports. For example, in our recent Workforce Winter Briefing, we noted that: “In 2017, the College and the British Association for Community Child Health (BACCH) published *Covering all Bases* which found that there was a need for substantial increase in the number of community child health medical workforce. This is necessary to meet the current and anticipated demand due to a rising number of co-morbidities, long delays in diagnosis for autism and ADHD, and growing safeguarding concerns.”¹

These children thrive best when seen by a multidisciplinary team. It is important to note that there is a lack not only of paediatricians, but of capacity across the multidisciplinary team and that this is not uniform across Wales. Paediatricians may be deployed inefficiently if other skills are lacking in the team. Where there are gaps in the workforce or a lack of capacity, there may also be a tension between meeting diagnostic standards on the one hand and service delivery on the other. As one of our members commented, targets for diagnostic assessment can drive service providers to “allocate limited resources to assessment rather than support”. He noted that in his area, difficulties in securing input from psychologists and behaviour support workers has highlighted this tension.

We recommend that a starting point for improving ASD services for children and young people is for Welsh Government and Health Boards to provide fully staffed multidisciplinary teams and increase capacity in community paediatrics, based on a workforce strategy agreed by Welsh Government and HEIW, in line with the vision set out in *A Healthier Wales*.

We support the proposals in this Code for further training for professionals who deal with diagnosis and management of children and young people with ASD but suggest that this would require further investment, given that services within community paediatrics and CAMHS are stretched. The training pathways envisaged provide a model of how appropriate delivery of ASD training could look.

Equity and developing a child-centred approach

In a context of limited and often stretched capacity, a Code that sets out duties for a group of people with a given diagnosis is potentially discriminatory. It risks negative unintended consequences through focussing on ASD to the detriment of other children with different neuro-disabilities and needs who may require the services of multidisciplinary teams. This is not a child-centred approach because it allocates services based on diagnosis rather than need. This is a concern we raised last year when proposals were put forward for a new Autism (Wales) 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

¹RCPCH, 2018 *Workforce briefing winter 2018*. Available at: https://www.rcpch.ac.uk/sites/default/files/2018-12/state_of_child_health_-_workforce_briefing_winter_2018.pdf p4

resources.”² Community paediatricians have raised these same concerns in the context of the draft Code.

The need for an ND approach

The T4CYP pathway is currently configured around ND rather than ASD specifically. Waiting lists are currently for the ND pathway, rather than ASD. This is usually also how data are gathered. However, the document contains a number of references to the 26-week waiting time standard for assessment. In practice, this could lead to pressure on services to ‘filter out’ and prioritise ASD to the detriment of ADHD, for example. In section 4, the ‘LHBs Must’ box sets out an expectation that Health Boards collect ASD waiting time data. However, what LHBs may actually currently record is ND data. LHBs can attempt to pull out ASD data but that undermines the point of collecting and thinking about ND.

We believe that the pathway should address the needs of all vulnerable and disadvantaged children who require the services of community paediatricians as part of the assessment and diagnosis through the ND pathway and requiring social care services and voluntary organisations for their ongoing support.

Focussing exclusively on ASD even if this is to the detriment of others risks creating an ‘unmet middle’. Often the young people seen for assessment present outwardly with similar difficulties as those with ADHD, sensory processing disorders, Learning Disability (LD) and those who have experienced chronic trauma. These presentations include behavioural issues, inability to access education, difficulties with societal inclusion and difficulty accessing facilities that may be available to them. Many children may not have ND but nonetheless have real need, often similar to and equivalent or greater than children with ASD or other ND. Creating separate waiting lists or service standards is not in the spirit of ND assessment.

Paediatricians are particularly concerned about children who have experienced trauma or Adverse Childhood Experiences (ACEs) and/or LD who come through the ND pathway and are often left with no unifying ‘diagnosis’ to open up equitable resources post assessment.

We recommend therefore that Welsh Government considers how to address these issues, including whether or not an ASD-specific Code is appropriate, or whether the Code needs to be developed further for the ND pathway as a whole.

Specific Issues

Paediatricians have raised a number of specific points and questions about parts of the draft Code.

- On page 26, we’re unsure what is meant by a ‘local children’s team’. The paragraph implies regional variation. Children with LD should access an equivalent level of service.

² RCPCH, 2018, *Evidence submitted by the Royal College of Paediatrics and Child Health (RCPCH) to the Autism (Wales) Bill Consultation*. Available at: https://www.rcpch.ac.uk/sites/default/files/2018-09/rcpch_consultation_response_for_hscs_committee_on_the_proposed_autism_bill_wales_september_2018.pdf p2

- On page 27, we are unclear as to the intention behind the 'Local Authorities and Local Health Boards should' box. It should set out equitable services for children with ASD and/or LD. How will LHBs ensure that all CYP have equal opportunities and access?
- On page 28, 'Health Education and Improvement Wales Should' – we would question whether this consistently ensures appropriate referral. Is there a case, for example, for an ND referral standard to include schools and other referrers? Diagnosis can often be complex. There is a risk that inviting individuals for an initial assessment without relevant supporting information leads to delays in obtaining diagnoses as well as having an impact on the resources of the service provider. We therefore suggest further conversations with GPs and other referrers and with service providers.
- We agree that social care services need to be involved during the assessment and at the conclusion, regardless of whether or not a diagnosis of ASD is given.

Key recommendations:

- Plan the child health workforce. This was the key recommendation in our Winter Workforce Briefing and is the key factor in improving outcomes for children with ASD or ND and their families.
- Ensure that the Code meets the needs of all vulnerable and disadvantaged children that require the services of community paediatricians as part of the assessment and diagnosis through the neurodevelopmental pathway, in line with the acknowledged improvements made through T4CYP.
- Ensure that policy makers have direct engagement with clinicians through holding workshops in North and South Wales specifically for paediatricians, psychiatrists, OTs, Speech and Language Therapists and others involved in the multidisciplinary teams providing diagnoses and services to children with ASD and ND. This would enable policy makers to better understand the challenges faced by clinicians and the real-world implications of any proposed changes. We would be glad to help facilitate this and would be confident of support from colleagues at other relevant Colleges.

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