**Welsh Government Consultation: Code of Practice on the Provision of Autism Services**

This submission is made on behalf of the Royal College of Occupational Therapists (RCOT), the professional body for occupational therapists across the UK.

The submission is made in response to the Welsh Government consultation on the Code of Practice for the provision of autism services. In compiling this response, we have sought the views of occupational therapists with experience and an interest in neurodevelopmental services (adults and children), including occupational therapists who identify as autistic and occupational therapists who are themselves parents of autistic children.

Thank you for the opportunity to comment on the Welsh Government Consultation: Code of Practice on Provision of Autism Services

Please find below comments from RCOT.

**Submission**

**Q2: Do you agree that the Code should focus on autism services or could be expanded to cover other neurodevelopmental conditions?**

RCOT recognises that services for autistic people and their families need to be improved. Too many individuals and families wait too long to access the help they need to enable them to carry out the daily activities, roles and routines (occupations) they want, need or expected to do.

RCOT is concerned however, that adopting a Code of Practice for autism services will have unintended consequences for people with other neurodevelopmental differences, for those who do not reach the threshold for an autism diagnosis and for other groups including people with learning disabilities not related to autism. There is a risk that the Code of Practice will improve services for people with autism to the detriment of others.

RCOT believes that the Code should be expanded to cover other individuals whose needs related to other neurodevelopmental differences. People are complex and rarely fit into neat diagnostic categories. RCOT believe that limited resources, including occupational therapy, should be focused on n eed and directed to where they will have the most impact rather than targeted towards one population group. This approach would be in line with the ethos of existing legislation such as the Social Services and Well-being (Wales) Act 2014 and the Additional Learning Needs and Education Tribunal (Wales) Act 2018. All people with neurodevelopmental differences should be able to ask for the help they need when they need it to prevent their situation getting worse.

RCOT believes that many of the principles included in the Code of Practice could be applied to children and adults with other neurodevelopmental differences. Expanding the Code to improve services for people with a wider range of occupational needs would be welcomed.

**Q3: Arrangements for assessment and diagnosis**

The detail included in the Code regarding assessment and diagnosis of autism is welcome. RCOT agrees that clear referral, assessment and diagnostic pathways should be established and effectively communicated to individuals, families and practitioners (including teachers, health visitors and GPs). This will require more effective communication across sectors and organisations including health, education, social care and the third sector.

However a diagnostic pathway that addresses only one diagnostic group without considering other possible explanations for a person’s difficulties is not helpful. ADHD and Developmental Coordination Disorder (DCD) are more common than autism and need to be identified alongside autism where appropriate so that support can be provided to address each person’s unique profile of strengths and difficulties. Likewise, people who do not meet the criteria for the diagnosis of autism also need clear information about referral/assessment/diagnostic pathways to explore other possible explanations for their difficulties and avenues of support. The individual and their needs should be the centre of any care system.

RCOT is concerned that having a Code of Practice for autism services will encourage people and families to seek an autism diagnosis so they can access the services and support detailed in the Code. Other services may be regarded as less helpful if they are under-resourced. This will increase demand for autism assessment services that are already under pressure and may lead to frustration among people who do not meet criteria for the diagnosis of autism. RCOT believes that a person-centred approach based on need rather than diagnosis is required.

RCOT recommends that the purpose of existing Neurodevelopmental Teams is reviewed and services developed to include people with a wider range of neurodevelopmental differences. Resources should be directed towards the provision of needs-led interventions, rather than prioritising diagnosis. This would ensure that occupational therapy skills and expertise are used to support people with autism and other neurodevelopmental differences to participate in the activities (occupations) that they need and want to do. This is the help that people seek and which makes a difference to their daily lives.

**Q4: Arrangements for Accessing Health and Social Care Services**

Recommendations within this section of the Code are good practice and could be applied to people seeking help for a range of needs including (but not limited to) autistic people. This would include:

* providing relevant, accessible information to ensure people know how to access health and social care services
* ensuring people are equal partners in relationships with practitioners (advocacy)
* timely and appropriate referral to preventative services
* understanding and applying eligibility criteria for referral for social care services, tailored to suit each individual
* Preparing and maintaining a support plan for those who need one
* Planning and enabling positive transitions
* Ensuring social care assessors understand a person’s needs so they can provide appropriate advice and support for parents/carers
* Ensuring people access high quality health care and rehabilitation with appropriate reasonable adjustments
* Provision of training to ensure practitioners recognise and understand the needs of people with a range of neurodevelopmental conditions
* Ensuring people with neurodevelopmental conditions, learning and physical disabilities have access to mental health services and support when they need it

**Q5: Arrangements for Awareness Raising and Training on Autism**

RCOT welcomes the promotion of information and training to promote understanding of autism within mainstream and specialist services. However we believe such training should be expanded to promote awareness and understanding of neurodiversity more generally, covering a broader range of neurodevelopmental conditions protected under the Equality Act.

RCOT believes that as a society we want everyone to participate as valued members of their community, regardless of physical, learning and mental health needs. Raising community awareness of neurodiversity and tools/strategies/adjustments to meet individual need would help to achieve this.

The proposal for a ‘tiered’ approach to the provision of high quality, evidence-based training appropriate to a person’s role and engagement with autistic people and others is welcome. Occupational therapists working with people with neurodevelopmental differences have the skills and expertise to develop and deliver information at different levels in a range of different formats.

RCOT members support the specific inclusion of information/training to help GPs recognise people who may have autism or another neurodevelopmental disorder to enable them to make appropriate onward referrals for assessment and support based on individual need.

**Q6: Arrangements for Planning of Autism Services**

RCOT have previously highlighted that there is a range of new initiatives in Wales currently in the early stages of development including the Together for Children and Young People programme, the National Integrated Autism Service (IAS) and the Additional Learning Needs and Education Tribunal (Wales) Act 2018. RCOT believes that the proposed Code is not consistent with the needs-based approach of existing legislation.

The IAS has ring-fenced funding from the integrated care funding (IFC). This fund is the mechanism to support delivery of various requirements of the Social Service & Well Being Act in that it supports the development of integrated care and support services for individuals with complex needs including people with learning disabilities, children with complex needs and autism.

We note the recent Evaluation of the Integrated Autism Service and the Autism Spectrum Disorder Strategic Action Plan (2019) which identified a number of recommendations that RCOT feel could support better access to services and improved outcome for users. Implementation of these recommendations would promote equity of service throughout Wales and support ISA to consider the scope and ambition of their service delivery.

RCOT believe that current legislation and health policy support the planning of services to take a broader needs-based approach. We are concerned that the proposed Autism Code of Practice would inhibit service planning by diverting resources towards a pathway based on assessment for a single diagnosis rather than need.

RCOT members are also concerned that the proposed Code prioritises assessment and diagnosis with little detail about intervention and support. Occupational therapists have the skills and expertise to support people with a wide range of needs to achieve their potential and participate in the daily activities that matter to them, but their capacity to do this will be limited if resources are focused on assessment and diagnosis.

**Q7:** **Arrangements for Monitoring of Autism Services**

RCOT believes that there should be a greater focus on monitoring and evaluation of services to assess whether services and interventions address needs that are important to people and their families. The focus should be on understanding the impact of interventions/support on people’s daily lives, rather than measures of process.

**Contact**

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