

A31

Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill

Ymateb gan Goleg Brenhinol y Therapyddion Galwedigaethol

Response from Royal College of Occupational Therapists

Royal College of  
Occupational  
Therapists



**Evidence to the Health, Social Care and Sport Committee's inquiry into the general principles of the Autism (Wales) Bill**

Produced by [REDACTED], Professional Adviser for Children, Young People and Families, and [REDACTED], Policy Officer for Wales on behalf of the Royal College of Occupational Therapists, the professional body for occupational therapists across the UK.

**Summary of Position**

---

RCOT supports the need to improve outcomes for people with autism but is concerned that the proposed legislation will not achieve the desired aim.

The College believe that equality of access to occupational therapy should be a guiding principle for everyone, and that access to occupational therapy should be person-centred and based on occupational need rather than diagnosis. Occupational therapists have the skills and expertise to enable people with autism to lead healthy and productive lives. Occupational therapy is however a limited resource and focusing on one population will mean that others miss out.

**Background information:**

There are 1900 registered occupational therapists in Wales (August 2018) working across health, social care, education, the voluntary sector and in other specialist areas.

Occupational therapy is a science-based, person-centered profession, concerned with promoting health and well-being through occupation. Occupational therapists work with people of all ages who are experiencing difficulties through injury, illness or disability or a major life change. Occupational therapists consider the relationship between what a person does every day (their **occupations**), how illness or disability impacts upon the **person** and how a person's **environment** supports or hinders their activity. The primary goal of occupational therapy is to enable people to participate in the activities they want, need or are expected to engage in, including work, social activities and maintaining roles and responsibilities.

Occupational therapists are uniquely trained to address mental health and physical health which means we are able to work with people in a more streamlined way.

NICE (2016) identifies occupational therapists as key members of specialist autism teams for adults and recommends that children should have access to an occupational therapist if one is not included as a core member of their local autism team (NICE 2017).

As members of these teams, occupational therapists contribute to the early identification, diagnosis (where appropriate) and participation of people with autism in activities that are important to them. We enable people's participation and occupational performance by working directly with individuals and indirectly through consultation and collaboration with family members, communities, teachers, employers and other professionals. Occupational therapists identify individual's strengths and abilities as well as the needs and challenges that hinder their participation in meaningful activities. Occupational therapists choose the most appropriate setting in which to work with people with autism, for example at home, in their workplace, at school/nursery/college, in residential settings and at diagnostic/assessment centres. In Wales, occupational therapists meet people with autism through their role as members of a children's occupational therapy team, as independent practitioners and as members of an Integrated Autism Service.

#### **RCOT's Position:**

- **Access to occupational therapy should be based on need, rather than diagnosis.** Occupational therapists focus on health and well-being: "*Occupational therapists are active health enablers, focused on what matters to the person so that they can help them to participate in the occupations they need, want or are expected to do.*" (RCOT, 2016). Occupational therapists do not try to fix or cure the problem, but endeavour to fix 'what matters to the person'. RCOT recognises that people often present with complex needs and occupational therapists rarely work with individuals who fit into neat diagnostic categories. Some people with autism manage very well, while others who don't reach the threshold for diagnosis have great difficulty participating in daily life activities and benefit from occupational therapy. RCOT is concerned that condition-specific legislation may prevent some people from accessing the services, support and resources they need to live happy, healthy and productive lives.
- **Occupational therapy is a limited resource. Focusing the workforce on services for people with autism will mean that others are disadvantaged.** People with a wide range of neurodevelopmental difficulties benefit from occupational therapy including people with developmental coordination disorder (which affects around 5% of the population, Lingam et al 2009), ADHD (which affects around 5% of the population, NICE 2018) and autism (which affects around 1% of the population, NICE 2017). Recruitment to specialist occupational therapy posts (including those for children) can be difficult. If services for people with autism (which represent 1% of the population) are prioritised by legislation, occupational therapists will be diverted from other areas of practice (particularly CAMHS) to the detriment of other populations who would benefit from occupational therapy.

- **Demand for diagnostic assessments will increase.** Diagnosis can provide an explanation for a person's difficulties and is useful in identifying appropriate support and resources. There is a risk however, of individuals and families regarding a diagnosis of autism as a 'passport to services', leading to increased demand for assessments and an artificial increase in diagnostic rates. Clinicians may be required to prioritise assessments rather than intervention, meaning that individuals do not receive the post-diagnostic support they need to live healthy and productive lives. Individuals/parents may also be reluctant to accept an alternative, more appropriate diagnosis and may seek alternative assessments which do not meet the same quality standards as those offered by Integrated Autism Services. RCOT is concerned that an unintended consequence of diagnosis-specific legislation will be increased demand for diagnosis and increased risk of inappropriate diagnosis.
- **An increase in the number of people diagnosed with autism will mean increased demand and expectations for post-diagnostic occupational therapy support.** Diagnosis-specific legislation increases the expectation of individuals and family members that they will receive post-diagnostic support, yet prioritising assessments means fewer occupational therapy resources will be available for intervention. This has been the case for people with dementia in Wales. Despite diagnosis of dementia being identified as a priority, diagnosis rates in Wales lag significantly behind those of the other nations and many people struggle to access support when they need it (Alzheimers Society, 2014). RCOT is concerned that without additional funding and resources, the proposed legislation will not lead to improvements in services for people with autism and their families.

### **Recommendations**

RCOT recommends that services should be commissioned to meet the needs of people with autism and their families, and not driven by legislation or linked to diagnosis. We share the concerns outlined in the joint briefing prepared with the Royal Colleges and the Welsh NHS Confederation that the proposed legislation may not achieve the desired outcome of improving services for people with autism. Instead we recommend that services are commissioned to address local needs, drawing on existing resources and partnerships to ensure that delivery is sustainable and contextually relevant. Further examples of how occupational therapists work as agents of change to improve outcomes across health, education, social care, employment and voluntary sectors are included in our Improving Lives Saving Money campaign reports which can be found [here](#).

### **References:**

Alzheimers Society (2014) Alzheimer's Society view on public health, prevention and dementia. <https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/public-health-prevention-dementia> (accessed 11.9.18)

Lingam, R; Hunt, L; Golding, J; Jongmans, M; Emond, A; (2009) Prevalence of developmental coordination disorder using the DSM-IV at 7 years of age: a UK population-based study. *Pediatrics*, 123 (4). e693-700.

NICE (2016) Autism spectrum disorder in adults: diagnosis and management  
<https://www.nice.org.uk/guidance/CG142> (accessed 11.9.18)

NICE (2017) Autism spectrum disorder in under 19s: support and management  
<https://www.nice.org.uk/Guidance/CG170> (accessed 11.9.18)

NICE (2018) Attention deficit hyperactivity disorder: diagnosis and management.  
<https://www.nice.org.uk/guidance/ng87/chapter/recommendations> (accessed 11.9.18)

Royal College of Occupational Therapists (2016) Reducing the pressure on hospitals: A report on the value of occupational therapy in Wales. Pub: RCOT, London.

### **About the College**

---

The Royal College of Occupational Therapists is the UK Professional Body and Trade Union for over 33,000 occupational therapists, support workers, managers and students. Occupational therapy enables people of all ages to participate in daily life to improve health and wellbeing. They are the only Allied Health Profession trained at a pre-registration level to work within both physical and mental health.

### **Contact**

---

For further information on this submission, please contact:

[REDACTED]

[REDACTED]

Royal College of Occupational Therapists

[REDACTED] [REDACTED]

[REDACTED]

[REDACTED]

Royal College of Occupational Therapists

[REDACTED]