

AEC 49

Ymateb gan: Coleg Brenhinol Pediatreg a Iechyd Plant (Cymru)

Response from: Royal College of Paediatrics and Child Health (Wales)



Royal College of  
Paediatrics and Child Health

*Leading the way in Children's Health*

## **Children, Young People and Education Committee's inquiry into 'Do disabled children and young people have equal access to education and childcare?'**

*September 2023*

### **Summary**

All children and young people have a right to education under the United Nations Convention on the Rights of the Child (UNCRC, Article 28).

Education supports the healthy development of a child, their personality, talents and physical and mental abilities. Education settings provide a haven for children which can deliver appropriate safeguarding and uphold children's rights. However, in practice children and young people with a disability continue to experience discrimination, difficulties with accessibility and bullying which can exacerbate existing mental ill-health and/or present new challenges.

The Welsh Government, local authorities and schools need to ensure schools are a safe, inclusive environment capable of meeting every child's needs.

### **Recommendations**

1. The Welsh Government, via the Disability Rights Taskforce, should champion the Social Model of Disability and ensure it is embedded across all policies, including health and education.
2. The Welsh Government should adopt an asset-based approach to supporting children and young people with a disability which empowers and enables them to thrive.
3. The Committee should consider those awaiting a diagnosis and the 'Missing Middle' (children and young people with disabling forms of distress) within this inquiry, and how education and health settings could better meet their needs.

## Disabled children and young people's right to education

The 2021/22 Health Behaviour in School-aged Children Survey detailed nearly one in five (18%) of young people reported having a long-term health problem or disability that limits their day-to-day activities.<sup>1</sup> Those with less family affluence were more likely to report having a long-term health condition (21% in FAS 1 (low)), compared to 16% in FAS 3 (high).<sup>2</sup>

All children and young people have a right to education under the UNCRC, Article 28. The Equality Act 2010 prohibits direct and indirect discrimination to those who have a disability and specifically references education (Section 6). The terminology and rights-based approach to disability is well established but children and young people with a disability continue to experience challenges.

Welsh Government statistics show that during the last academic year, 18.1% of pupils (ages 5-15) were persistently absent in maintained schools, rising to 34% for those eligible for free school meals.<sup>3</sup> Over two-third (67.6%) of absences were 'authorised' with the most significant reasons for authorised absences being 'illness' (42.7%) with a further 3.6% for 'doctor and/or dentist appointments'.<sup>4</sup> Unfortunately using the current statistics it is not possible to explore the attendance of those with a disability or whether an 'illness' is chronic or a seasonal cold. That said, it is well known that children with disabilities and chronic conditions, both mental and physical, can experience difficulties in attending school, due to their condition, but also due to requiring support to meet their needs.

Despite legislation, children and young people still face challenges that children without a disability do not. An example of this is accessibility. Over a third (38%) of local authorities report not having enough childcare for disabled children in their local authority area.<sup>5</sup>

To overcome this, there should be a prioritisation of the needs of all children and young people. This should take the form of adopting a social model of disability, supported by an asset-based approach to health and care. This will focus on the strengths of both the young person and community which in turn will help empower and enable children and

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<sup>1</sup> <https://www.shrn.org.uk/wp-content/uploads/2023/04/SHRN-2021-22-National-Indicators-Report-FINAL-en.pdf>

<sup>2</sup> <https://www.shrn.org.uk/wp-content/uploads/2023/04/SHRN-2021-22-National-Indicators-Report-FINAL-en.pdf>

<sup>3</sup> <https://www.gov.wales/attendance-pupils-maintained-schools-5-september-2022-24-july-2023>

<sup>4</sup> <https://www.gov.wales/attendance-pupils-maintained-schools-5-september-2022-24-july-2023>

<sup>5</sup> <https://business.senedd.wales/documents/s122062/Report.pdf>

young people to fulfil their potential, be it in education or extra curriculum activities. Conversations regarding the needs of children and young people must include the individual - and advocate as applicable - and where at all possible involve their families or carers.

The social model of disability focuses on what disabled young people can do when barriers, i.e. physical barriers, are removed.<sup>6</sup> For example, a young person using a wheelchair may experience difficulties in participating in an extracurricular activity if the chosen venue is inaccessible, i.e. not fitted with a ramp, sliding doors or a lift. To overcome this and allow for social participate a disability 'friendly' venue would facilitate their involvement.

The Welsh Government established the Disability Rights Taskforce following the Covid-19 pandemic. The taskforce aims to remove inequalities experienced by disabled people in society and is exploring embedding the social model of disability in Wales. Children and young people are a 'workstream' of this taskforce, and education would be central to this. It is important that this work is undertaken without delay, involving those with lived experience, charities and health and education professions and with the fully support of the Government.

To support the social model of disability, an asset-based approach to health and care should be adopted. The approach seeks to build on social, cultural and environmental resources and is based on co-production which looks to combine formal health and social care services with communities and informal networks – whether that's in education, health or social care. At the heart of the asset-based approach is valuing the skills, strengths and successes of individuals and communities, recognising the importance of achieving a balance between service delivery and community building, as well as meeting people's needs and nurturing their strengths and resources.<sup>7</sup>

In Scotland the asset-based approach has been developed over the course of 10 years<sup>8</sup> and has come a long way in sharing, illustrating and embedding the values of this way of working.<sup>9</sup> However, it is recognised that despite much progress, there remains challenges with embedding the approach.

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<sup>6</sup> <https://www.disabilitywales.org/social-model/>

<sup>7</sup> [Asset-based approaches in practice: the Scottish experience | Local Government Association](#)

<sup>8</sup> [Asset-based approaches to health improvement \(iriss.org.uk\)](#)

<sup>9</sup> [Asset-based approaches in practice: the Scottish experience | Local Government Association](#)

The combination of delivering a social model of disability across Wales, supported by an asset-based approach to health and care, could greatly reduce the obstacles in an individuals way and enhance their ability to fully participate and reach their full potential.

### **Recommendation One**

The Welsh Government, via the Disability Rights Taskforce, should champion the Social Model of Disability and ensure it is embedded across all policies, including health and education.

### **Recommendation Two**

The Welsh Government should adopt an asset-based approach to supporting children and young people with a disability to empower and enable them to thrive.

## **Obtaining a diagnosis**

Once a formal diagnosis of a disability has been established, the rights of children and young people are protected in legislation. However, it is also well documented that waiting times are extensive. Obtaining a diagnosis can be a complex and time-consuming process which is often delayed. This is in part due to professional capacity, lack of resources and guidance and more recently the Covid-19 impact. Even getting onto a waiting list can prove challenging in itself.<sup>10</sup> So what support and protection is provided for a child or young person in the interim?

For example, the wait time for a child referred for an assessment for autism and/or ADHD is extensive. In March 2023 an FOI revealed that the wait time for an assessment ranged between 47 weeks to 166 weeks across Wales.<sup>11</sup> If support is not provided due to the absence of a formal diagnosis, or the inability to join the waiting list this could have a significant impact on a child's education.

While a child or young person is awaiting an assessment and a potential diagnosis, be it physical or mental, it is imperative that evidence-based

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<sup>10</sup> <https://senedd.wales/media/dfqbfajl/cr-ld15079-e.pdf>

<sup>11</sup> FOI data published in Health Board disclosure logs. Betsi Cadwaladr did not hold this data. Some Health Board separate wait times for ADHD and Autism, others do not.

interventions and support are put in place. The support should focus on empowering the individual towards increasing autonomy, independence and agency. This should include ensuring the individual and their families and carers understand their options and how to navigate appropriate services.

Support for a child or young person should not necessarily be linked with them receiving a formal diagnosis (covered by the Equality Act 2010) but rather what is required to meet their needs at any given time.

The Welsh Government, local authorities and schools need to ensure schools are a safe, inclusive environment capable of meeting every child's needs.

## **'The Missing Middle'**

The Committee should consider 'The Missing Middle' within this inquiry. Those children and young people whose health is impacted by a multitude of factors causing distress - often *disabling* but not necessarily diagnosed as a *disability*.

The Missing Middle is predominately defined for those with mental health difficulties, but it equally applies to young people with physical health manifestations. The Missing Middle can have physical and mental health disabilities, which would be covered under the Equality Act 2010, or disabling pain and/or health conditions, which may not be.

These young people have distress, often a disabling form of distress, attributable to a multitude of factors, but who do not have access to the guidance or support they need. These factors, often undisclosed or unrecognised, may include adverse events and experiences, neurodiversity, carer roles, attachment disorders, family discord, bullying, unhealthy sleep patterns and diets, and adverse thoughts and behaviours. They often occur in combinations and result in a loss of agency, of schooling, physical activity and routines. In turn this can lead to impacts on physical health, such as obesity, social isolation, disrupted family life and a potentially spiralling decline with further effects on sleep, anxiety, depression and withdrawal. Simply put, this population's needs are not well met.

“As clinicians, in order to break the cycle and empower the young person and family to self manage, this starts with time and a

sensitivity to their confounding factors, a confident and sometimes collaborative assessment, and effective explanations and signposting...this early intervention stops the spiral of decline, avoids embattlement and prevents excess referrals within a conventional system that cannot cope.” **Dr Nick Wilkinson, RCPCH Officer for Wales**

To support the missing middle there needs to be more of an emphasis on embedding the NEST framework<sup>12</sup> and improving the integrated system of accessible support within health, social care, education and justice.

### Recommendation Three

The Committee should consider those awaiting a diagnosis and the ‘Missing Middle’ (children and young people with disabling forms of distress) within this inquiry, and how education and health settings could better meet their needs.

### About RCPCH Wales

The RCPCH works to transform child health through knowledge, innovation and expertise. We have over 500 members in Wales, 14,000 across the UK and over 17,000 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. We are grateful to the Health and Social Care Committee for the opportunity to help inform scrutiny of the Welsh Government’s plan to Transform Planned Care Service and Reduce Waiting Times.

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<sup>12</sup> <https://www.gov.wales/next-framework-mental-health-and-wellbeing-introduction>