

Cyflwynwyd yr ymateb hwn i'r [Pwyllgor Plant, Pobl Ifanc ac Addysg](#) ar gyfer yr ymchwiliad: [A oes gan blant a phobl ifanc anabl fynediad cyfartal at addysg a gofal plant?](#)

This response was submitted to the [Children, Young People and Education Committee](#) for the inquiry: [Do disabled children and young people have equal access to education and childcare?](#)

AEC 73

Ymateb gan: Coleg Nyrsio Brenhinol Cymru

Response from: Royal College of Nursing Wales



About the Royal College of Nursing

The Royal College of Nursing is the world's largest professional organisation and trade union for nursing, representing over 500,000 nurses, midwives, health visitors, healthcare support workers and nursing students, including over 29,500 members in Wales. RCN members work in both the independent sector and the NHS. Around two-thirds of our members are based in the community. The RCN is a UK-wide organisation, with National Boards in Wales, Scotland and Northern Ireland.

The RCN represents nurses and nursing, promotes excellence in nursing practice and shapes health and social care policy.

Key points

- Most children with additional learning needs (ALN) go to mainstream schools in the UK. However, the proportion attending special schools has risen every year since 2013–14, even though the overall number of children assessed as having ALN has fallen since 2003.
- In a recent National Education Union Cymru member survey, 89% of respondents said that they had received either 'no training' or 'some training but not enough' in preparation for the Additional Learning Needs (ALN) reform.
- More opportunities are needed for learning disability nurses to work with children and young people.
- Only a minority of children and young people with a learning disability are likely to encounter a learning disability nurse. For this reason, all nurses need to have an awareness of their needs. The Improvement Cymru Learning Disability Education Framework for healthcare staff could be a model for increasing awareness of all educational staff (including, but not limited to, nurses) in relation to the needs of

children and young people with learning disabilities and, their role in meeting such needs.

- Investing in the education of learning disability nurses, both at pre-registration (undergraduate) and post-registration level, is essential for ensuring people with learning disabilities can be supported at every stage of their lives, including at school.

Access to education

The [Additional Learning Needs and Education Tribunal \(Wales\) Act 2018](#) (ALN Act) introduced a new Additional Learning Needs (ALN) system which began to replace the preceding Special Educational Needs (SEN) system in September 2021. In this document, “ALN” is used to refer to needs of children classified as having additional needs under either system, unless specifically referring to the SEN system itself.

The ALN Act also contains duties for relevant bodies to have due regard to the UN Convention on the Rights of the Child (UN CRC) and the UN Convention on the Rights of Persons with Disabilities (UN CRPD). This does not apply to UN CRPD Articles 24(2) (a) and (b), which guarantee the right to inclusive education, due to the UK Government’s reservation. The UK was one of only two countries to include such a reservation.

Research has shown that disabled children benefit socially and academically from being educated in mainstream schools.¹ Most children with additional learning needs (ALN) do, in fact, go to mainstream schools in the UK. Less than 10% attend special schools and, in Wales in 2020-21, the percentage of children with ALN attending special schools in Wales was only 5.6%.

However, that proportion has risen every year since 2013–14², when only 4.1% of pupils with ALN attended special schools. Moreover, the underlying number of pupils with ALN attending special schools has risen every year since at least 2003³. This trend is surprising, given that the overall numbers of children considered to have ALN relating to severe or profound learning disabilities *fell* somewhat between 2003-4 and 2015-16, whilst those relating to mild or moderate learning disabilities fell significantly.⁴

¹ Wang, H.L. (2009). Should all students with special educational needs (SEN) be included in mainstream education provision? - A critical analysis. *International Educational Studies*, 2(4), 154-161.

² StatsWales. (2023). *Pupils with additional learning or special educational needs by sector and year*. <https://statswales.gov.wales/Catalogue/Education-and-Skills/Schools-and-Teachers/Schools-Census/Pupil-Level-Annual-School-Census/Special-Educational-Needs/pupilssen-by-sector-year>

³ StatsWales. (2023). *Pupils with additional learning or special educational needs by sector and year*. <https://statswales.gov.wales/Catalogue/Education-and-Skills/Schools-and-Teachers/Schools-Census/Pupil-Level-Annual-School-Census/Special-Educational-Needs/pupilssen-by-sector-year>

⁴ StatsWales. (2016). *Pupils with special educational needs by major need and year*. [Pupils with special educational needs by major need and year, to January 2016 \(gov.wales\)](#)

It is important to distinguish between the number of children in mainstream schools who have ALN and those *classified* as having ALN. The reported number of children with ALN in mainstream education in Wales decreased by 20% between 2020/21 and 2021/22. However, the Welsh Government has stated that this reduction is due to previous statistics including some children inappropriately under the SEN system.⁵ The reduction of 18,000 children in mainstream education is accounted for by a changing definition and a consequent reduction of children recorded as having lower or moderate ALN. There may also have been an impact from the pandemic and children consequently not being seen or assessed face to face as they would have been previously. The underlying population of children, however, has not changed. This has significant implications, since it is unlikely their needs have changed, and yet they may not have access to specialist support.

In 2019, the ONS found the percentage difference between disabled and non-disabled people in Wales attaining a degree was 13.7%.⁶

Childcare

Despite schemes in Wales such as Flying Start offering family-focused support, families continue to face barriers in finding the help they need. Mencap reported that families have told them they experience difficulties in:

- finding out what their child's needs are once they suspect a problem
- finding good quality information about their child's needs and opportunities to develop and access support
- finding good quality support to meet their needs and the needs of their child in the early years
- finding professionals who have the right skills and attitudes to work well together to meet their child's additional needs.⁷

Early years services, in particular health visiting, are imperative to ensuring every child has a successful start to life and their family members feel supported. It is important that every child has access to this key service. Health boards must evaluate what services they provide and ensure they are following a 'no wrong door' approach.⁸

Children and young people with a learning disability, their families and carers, too often, still face complicated and stressful experiences navigating through services. The 'no wrong door' approach prevents individuals being 'bounced' between services who cannot agree who is best placed to provide care for the

⁵ Senedd Research Service. (2022). *Identifying Additional Learning Needs: Has the bar been raised or was it previously too low?* [Identifying Additional Learning Needs: Has the bar been raised or was it previously too low? \(senedd.wales\)](https://www.senedd.wales/identifying-additional-learning-needs-has-the-bar-been-raised-or-was-it-previously-too-low/)

⁶ Office for National Statistics. (2019). *Disability and education, UK: 2019*. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/bulletins/disabilityandeducationuk/2019>

⁷ Mencap. (2016). *Early Years - what we think*. <https://www.mencap.org.uk/about-us/what-we-think/early-years-what-we-think>

⁸ Children's Commissioner for Wales. (2020). *No Wrong Door: bringing services together to meet children's needs*. https://www.childcomwales.org.uk/wp-content/uploads/2020/06/NoWrongDoor_FINAL_EN230620.pdf

individual. The Children's Commissioner describes the 'no wrong door' as a wrap-around approach which see the individual, their families, and carers at the centre of care and expresses that it is not the responsibility of the individuals or their families to navigate complex systems. There is a need for health boards to invest in health services for children with a learning disability.

Barriers for schools in offering accessible provision

The ALN system began to replace the SEN system in September 2021 with the intention of creating a unified system for supporting learners from 0 to 25 with ALN.⁹ In a National Education Union (NEU) Cymru member survey carried out shortly before the introduction of the new system¹⁰, 89% of respondents said that, in preparation for ALN reform, they had received either no training or not enough.

Disabled people have the same right to access public services as their non disabled peers. However, in order to ensure equal access and outcomes (as is required under the Equality Act 2010) there is a need to make reasonable adjustments. It is also important that sufficient learning disability nurses are available to support people with a learning disability, and that *everyone* who works with people with learning disabilities understands the complexities of providing care for someone with a learning disability and their responsibilities in relation to providing such care.

The education and childcare workforces will encounter and be responsible, directly or indirectly, for people who have a learning disability. It is important that, in carrying out their roles, all staff understand how to make reasonable adjustments under the Equality Act 2010 and care for or communicate with someone with a learning disability to ensure that their needs are identified and met in a timely and appropriate manner. This includes teachers and childcare workers, but also school nurses, who have a key role to play here but may not have had specific education in this area.

A pivotal way for ensuring the general workforce are aware of the needs of people with a learning disability is to provide educational opportunities for them to develop their understanding. This is already happening in the health sector with the implementation of the Improvement Cymru Learning Disability Education Framework for health care staff. It is also being explored in the social care sector.

The Framework was developed by the University of South Wales¹¹ following the Paul Ridd Foundation's successful petition for mandatory learning disabilities

⁹ Welsh Government. (2022). *The additional learning needs transformation programme: frequently asked questions*. <https://www.gov.wales/additional-learning-needs-transformation-programme-frequently-asked-questions-html>

¹⁰ National Education Union Cymru. (2021). *Make learning fair and equitable - background briefing*. <https://neu.org.uk/sites/default/files/2023-06/Wales%20manifesto%20Ask%20One.pdf>

¹¹ Improvement Cymru. (2021). *Learning disability educational framework for healthcare staff in Wales*. <https://phw.nhs.wales/services-and-teams/improvement-cymru/newsand-blog/publications/learning-disability-educational-framework/>

training for health care staff.¹² Paul Ridd had severe learning difficulties and died in an NHS Wales hospital in 2009. The care he had received was later found to have contributed to his death.¹³ The Paul Ridd Foundation campaigns to raise awareness of the issues people with a learning disability experience when accessing health care. The Learning Disability Education Framework should reduce the risk of diagnostic overshadowing, which occurs when someone's behaviour, or a change in their health status, is wrongly attributed to a learning disability instead of a health condition. Diagnostic overshadowing can lead to a failure to offer treatment to people with a learning disability in circumstances where a non-disabled person would be treated.

The Framework introduces three tiers of competence. Its lowest ("foundation") tier is applied to all staff in health care settings including receptionists, administrative staff, porters, managers and board members. The foundation level covers many areas, but this means that all staff should, for example, understand that all behaviour has meaning, and that behaviour is a means of communication.

At each level of competence, the Framework provides a comprehensive analysis of the values, knowledge and skills that are required of the general workforce to provide care and support for those with a learning disability.

Similar frameworks, with a foundation tier for all staff and more advanced tiers for those in closer or more regular contact with disabled children and young people, could help to promote the health and wellbeing of disabled people and reduce the discrimination they experience.

Learning disability nurses

There are approximately 16,000 children with a learning disability in Wales.¹⁴ The true number is likely greater. A child with a learning disability is more likely to face challenges with physical and mental health, family poverty and difficulty at school.¹⁵

Multi-agency working is an essential part of a school's day-to-day support for pupils with disabilities. The range of external agencies and specialist services that schools work with varies considerably between schools, depending on the range and complexity of their pupils' needs. It may include specialist nurses, speech and language therapists, occupational therapists, representatives from

¹² Paul Ridd Foundation petition prompts debate over health inequalities. (2019, November 6). *BBC News*. <https://www.bbc.co.uk/news/uk-wales-50304722>

¹³ Paul Ridd Foundation. *About Paul*. <https://paulriddfoundation.org/paulsstory/>

¹⁴ Mencap. *How common is learning disability?* <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability>

¹⁵ Mencap. (2016). *Early Years - what we think*. <https://www.mencap.org.uk/about-us/what-we-think/early-years-what-we-think>

local health boards, child and adolescent mental health services (CAMHS), and many more.¹⁶

A learning disability nurse provides specialist health care and support for people with a learning disability, their families and staff teams. Children with a learning disability are between 2.5 and 4.5 times more likely to have fair or poor general health as reported by their main carer. Even this may underrepresent their poorer health compared with the general population: carers of people with learning disabilities tend to estimate that the person they care for is healthier than medical examinations suggest.¹⁷ By adulthood, health screening reveals high levels of unmet physical and mental health needs,¹⁸ and approximately 98% of all people with a learning disability have been prescribed medication. The average number of medications prescribed is 6.2.¹⁹

However, identifying and treating the health needs of a person with a learning disability can be complicated by communication difficulties, unusual presentations of symptoms, and diagnostic overshadowing. Learning disability nurses have knowledge and skills other professionals may not in relation to identifying and responding to such needs. This highlights why learning disability nurses have such an important role to play in providing long-term care and reducing health inequalities.

Some children's learning disabilities are identified at birth. Children who do not have this experience may face a long wait for their learning disability to be recognised, and they can face challenges accessing the right educational support. Their disability may only be identified when they are older and the impact has become clear.

Learning disabilities can be difficult to identify very early in life,²⁰ but this only illustrates the importance of the knowledge and skills of learning disability nurses who are experts in the early identification of needs. If appropriate services and support are provided early, then the impact of disability may be reduced or eliminated. Learning disability nurses have a key role in identifying needs and in planning, delivering and arranging support to reduce or prevent these adverse impacts and support the child's development, wellbeing and quality of life.

Learning disability nurses are not the only people responsible for caring for an individual with a learning disability, but they do bring specialist knowledge and

¹⁶ Estyn. (2020). *Pupils with special educational needs in mainstream schools: a good practice report*. <https://www.estyn.gov.wales/system/files/2022-01/Pupils%20with%20special%20educational%20needs%20in%20mainstream%20schools.pdf>

¹⁷ Emerson, E. & Baines, S. (2010). *Health Inequalities & People with Learning Disabilities in the UK: 2010*. https://strathprints.strath.ac.uk/34862/1/vid_7479_IHaL2010_3HealthInequality2010.pdf

¹⁸ Emerson, E. & Baines, S. (2010). *Health Inequalities & People with Learning Disabilities in the UK: 2010*. https://strathprints.strath.ac.uk/34862/1/vid_7479_IHaL2010_3HealthInequality2010.pdf

¹⁹ Learning Disability Mortality Review (LeDeR) programme. (2020). *Annual Report 2020*. <https://www.england.nhs.uk/wp-content/uploads/2021/06/LeDeR-bristol-annual-report-2020.pdf>

²⁰ Oxfordshire County Council. *Learning disabilities: coping with a diagnosis*. <https://fisd.oxfordshire.gov.uk/kb5/oxfordshire/directory/advice.page?id=Dp9uBGpwbPg>

expertise that is invaluable when providing care and support for an individual with a learning disability. They also facilitate the coordination of care and support services.

In its 2018 Improving Lives Programme²¹, the Welsh Government recognised that there is a lack of learning disability nurses in special schools, and a lack of access to them in mainstream schools. This situation persists in 2023. School nursing is an advanced nursing qualification, and a school nurse may have originally qualified in any of the four fields of nursing (adult nursing, children's nursing, mental health nursing or learning disability nursing). To better support children with a learning disability and their families, more school nursing posts should be filled by learning disability nurses, while school nurses from other nursing backgrounds need access to education relating to the needs of children with a learning disability. The Welsh Government should increase the currently small numbers of new learning disability nurses educated each year.

It is also important that learning disability nurses are able to work alongside many other staff, including health visitors, midwives, community nursing teams, paediatric wards, child and adolescent learning disability services, child and adolescent mental health services, and palliative care. There are already examples of some specialist child and adolescent learning disability services working alongside CAMHS, for example in Aneurin Bevan University Health Board. This should be the norm.

It is essential that there is a workforce able to provide the right services and deliver the right level of support at the right time for people with a learning disability.

In Wales, nursing student numbers are decided by the Welsh Government. The numbers have increased overall, but the places commissioned for learning disability nursing remain at 87, having risen in 2022 after spending four years static at 77.²² Despite these low numbers, Welsh education providers have been unable to recruit even this many students for at least four years.^{23,24}

²¹ Welsh Government. (2018). *Learning disability improving lives programme*.

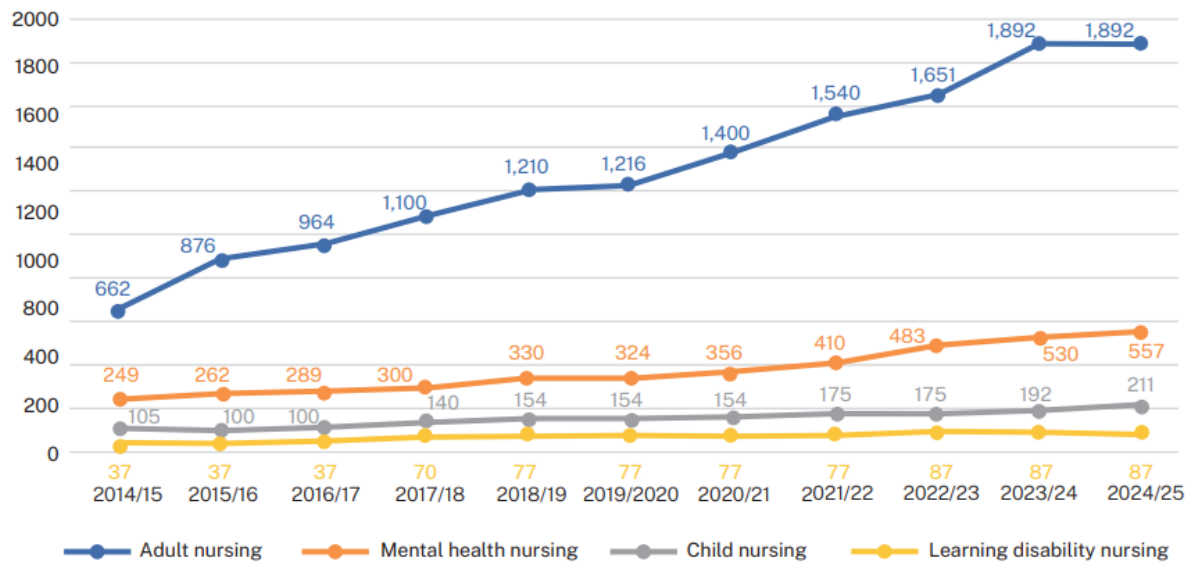
<https://www.gov.wales/sites/default/files/publications/2019-03/learning-disability-improving-lives-programme-june-2018.pdf>

²² Royal College of Nursing Wales. (2023). *Nursing in Numbers 2023*. <https://www.rcn.org.uk/Professional-Development/publications/rcn-nursing-in-numbers-english-uk-pub-011-188>

²³ Health Education and Improvement Wales. (2021). *NHS Wales Education and Training Plan for 2022/23*. <https://heiw.nhs.wales/files/education-and-training-plan-2022-23/>

²⁴ Health Education and Improvement Wales. (2022). *NHS Wales Education and Training Plan for 2023/24*. <https://heiw.nhs.wales/files/heiw-etp-2023-24/>

Graph: Student places commissioned by Welsh Government on pre-registration nursing degrees, 2014-15 to 2024-25. Source: UCAS.



It is also important to note that even the numbers of student places commissioned by the Welsh Government underrepresent the actual need for learning disability nurses. This is partly because Health Education and Improvement Wales (HEIW) routinely recommends figures well below those requested by health boards, but it is also because even those requests may exclude demand in the independent sector.

Tackling this must include an overall investment in learning disability nursing from every health board. Health boards should give specific and conscious attention to ensuring the wider health needs of children and young people with learning disabilities are appropriately prioritised and addressed. This should include learning disability nurses working with children and families from birth (or when learning disability is identified) if they have needs that require the specialist knowledge and skills of a learning disability nurse. There must be more emphasis on making the role of a learning disability nurse visible and seen as an attractive career for younger people.

The skills, knowledge and expertise of learning disability nurses must be maximised to ensure high-quality services and interventions for children with learning disabilities and their families. A ‘no wrong door’ approach would ensure services are wrapped around the individual and their family rather than asking them to navigate a very complex system.