

Cynulliad Cenedlaethol Cymru
Y Pwyllgor Plant, Pobl Ifanc ac Addysg
Gwaith dilynol ar yr adroddiad
Cadernid Meddwl
MOM: 10
Ymateb gan: Cymdeithas Genedlaethol
Awtistiaeth Cymru

National Assembly for Wales
Children, Young People and Education
Committee
Follow-up on the Mind over Matter report
MOM 10
Response from: National Autistic Society Cymru

Neurodevelopmental services across Wales remain a significant concern for the National Autistic Society Cymru's members. We welcome the committee's work to raise its concern about the length of time children and young people wait for an assessment, the availability and quality of support following an assessment, and the monitoring and reporting arrangements for neurodevelopmental services.

We recognise the Welsh Government's commitment to improving autism and neurodevelopmental services in Wales. The recent decision to continue a focus on neurodevelopmental services in the extension of the Together for Children and Young People programme is welcome, as is the ongoing demand and capacity review into wider autism and neurodevelopmental services. The proposed Code of Practice on the delivery of Autism Services, which the Welsh Government now aims to come into force from September 2021, could also provide a further opportunity to improve neurodevelopmental services in Wales.

Our charity continues to work closely with the Welsh Government to ensure that these commitments are realised and help to drive the necessary improvements. It does, however, remain the case that since Mind Over Matter expressed concerns over neurodevelopmental services, progress in addressing the issues has been slow and, on the ground, very little has changed.

Waiting times

Waiting for an autism assessment is a particularly challenging time for children, young people and families. For many, an assessment provides much needed answers and helps to foster a better understanding of someone's needs. In some circumstances, a diagnosis can open the door to additional support and services.

NICE guidelines and standards, supported by a range of Royal Colleges and professional bodies, state that the wait between a referral and an assessment should be no longer than three months¹. The Welsh Government has a current standard of 26 weeks between referral and assessment, with a target of hitting that standard 80% of the time. The persistent problems with assessment waiting times are evidenced, perhaps most clearly, by the lack of progress in addressing recommendation 13 of the Mind Over Matter report. The report noted the unacceptable waiting times faced by over 1000 children and young people in the Betsi Cadwaladr University Health Board (BCUHB) area. A letter sent from BCUHB to the Health, Social Care and Sport committee on 15th January 2020² states, in relation neurodevelopmental services,

'The target is for assessment within 26 weeks of referral and we do not currently meet this target consistently. At the end of November 2019, 27% of patients were seen within the target, with a waiting list of 1770 children.'

This illustrates an ongoing and significant shortfall between the improvement demanded by the committee in the Mind Over Matter and the progress made to date, with just as many, if not more, children and young people now waiting an unacceptable amount of time for an assessment.

¹ Autism Quality Standard [QS51], NICE, <https://www.nice.org.uk/guidance/qs51/chapter/Quality-statement-1-Diagnostic-assessment-by-an-autism-team>

² Letter from BCUHB to the Health, Social Care and Sport Committee, <http://senedd.assembly.wales/documents/s98007/Paper%20%20Letter%20from%20Betsi%20Cadwaladr%20University%20Health%20Board%20with%20additional%20information%20following%20t.pdf>

This issue is evident across Wales. We know that many children and young people still face significant waits for an assessment, although some health boards perform better than others. This means that the timeliness of your assessment will be greatly determined by where you live in Wales. A paper provided to this committee on 19th July 2019 by the Minister for Health and Social Services³ shows that at that point, only 44% of children and young people in Wales with a suspected neurodevelopmental condition were receiving an assessment within the standard time – well short of the 80% target.

Support

The Welsh Government's refreshed Autism Strategy⁴ states:

‘Timely access to assessment services is vital for families so that each child’s needs are understood and appropriate services are put in place to support them to lead fulfilling lives. An early diagnosis will also enable parents to understand their child’s needs and to seek appropriate support in their caring role.’

We are concerned that the necessary support is not currently being provided at a point when it would be of most benefit to autistic children and families. There is often very little support available to those who are on lengthy waiting lists and there is insufficient capacity within the current system to provide quality, post-diagnostic support to those who go on to receive a diagnosis. For those who have endured a significant wait for an assessment who then don’t receive a diagnosis following an assessment, the lack of advice and support, or onward referrals to new waiting lists, can seem devastating.

³ Letter from the Minister for Health and Social Services to the Children, Young People and Education Committee, <http://www.senedd.assembly.wales/documents/s92916/Letter%20from%20Minister%20for%20Health%20and%20Social%20Services%20following%20the%20evidence%20session%20on%2020%20June%202019.pdf>

⁴ Autism spectrum disorder: strategic action plan 2016, Welsh Government, <https://gov.wales/autism-spectrum-disorder-strategic-action-plan-2016>

Monitoring

As yet, the Welsh Government have not published any reliable, public data on neurodevelopmental performance against waiting times standards. Moreover, whilst we welcome the commitment to collect and publish information on the 26-week waiting time standard between referral and assessment, this captures only a tiny proportion of someone's lived experience. We understand and agree with the committee's concern that resources are balanced appropriately between assessment and support, but if targets exist only to capture waiting times and not the level or quality of support, then this will continue to be an issue.

Recommendations:

We recognise longer term ambitions to improve quality and sustainability of autism and neurodevelopmental services across Wales are underway, however, there is much that can be done in the short term to help address immediate issues and concerns.

Clear pathways

The Together for Children and Young People programme developed an assessment pathway⁵ for children and young people that was successful in helping to establish new neurodevelopmental teams across Wales. However, this pathway only began at the point that a referral had been accepted by the team and ended once a decision was made following assessment.

Many families report significant waits and challenges before a referral is made. Often, referrals are sent back due to a lack of information which can lengthen the wait further. A clear and detailed pathway should be

⁵ Together for Children and Young People Programme, Neurodevelopment Diagnostic Assessment Pathway: https://www.asdinfo.wales.co.uk/resource/T4CYP_Neurodevelopment-Diagnostic-Assessment-Pathway.pdf

developed that includes information about who can make referrals, the information required and indicative timeframes. It should contain details of where support is available whilst waiting for an assessment and continue beyond the diagnostic decision to outline what happens next for those who receive a diagnosis and those who do not.

One of the main issues families raise during this stressful process is a lack of communication with the professionals involved, which could similarly be addressed by providing more clarity around the pathway and helping families to understand upfront what they can expect.

Teacher training

Children, young people and families should be supported to get the most out of their education, whether they have a formal diagnosis or not. However, a lack of knowledge and understanding of autism and other neurodevelopmental conditions in school means that autistic children often do not get the support they need.

We know that a plurality of cases referred to the Special Educational Needs Tribunal relate to cases involving autistic children and young people, increasing by 86% between 2012 and 2016 (21 in 2012/13, 28 in 2013/14, 32 in 2014/15 and 39 in 2015/16)⁶. We also see a significant number of autistic students not in school, either through exclusion, off-rolling or whose families feel forced into home education because of a lack of support in school.

We welcome the desire to improve the support available to autistic pupils and other children and young people with additional learning needs through the forthcoming Additional Learning Needs and Education Tribunal Act. However, unless teachers and school staff have sufficient

⁶ Annual reports, SENTW <http://sentw.gov.wales/about/annual-reports-sentw/?lang=en>

knowledge and understanding of autism, we believe that autistic pupils will continue to be let down.

The Health, Social Care and Sport Committee recommended that all school staff receive mandatory training in autism as part of initial training and professional development in its report on the proposed Autism Bill. The Welsh Government accepted this recommendation⁷. Yet, to date, there has been no further progress in ensuring that this training is being delivered.

Short term increase in capacity

There are complex reasons as to why demand for diagnostic assessments continue to rise and there remain challenges in addressing capacity to meet this demand. Geography, rurality, staff sickness, availability of qualified professionals and lots of other reasons mean that, without a comprehensive strategy, simply putting in more financial resources won't address the current imbalance between capacity and demand.

However, in the short term, additional investment can help to alleviate some specific pressures if used efficiently. Additional resources may allow health boards to hire more clinical staff to undertake assessments, where this is possible. It may also allow health boards to work collaboratively where waiting list pressures are greater in some areas than in others. It could also be that additional investment in administrative staff who can act as a point of contact for families, reduces the burden on clinical professionals.

Wider workforce planning and development

Whilst not an immediate solution, it is crucial that workforce planning and development starts now. The success of the initial Welsh Government

⁷Letter from the Minister for Health and Social Services to the Chair of the Health, Social Care and Sport Committee, <http://senedd.assembly.wales/documents/s84843/Response%20by%20the%20Minister%20for%20Health%20and%20Social%20Services%20to%20the%20Health%20Social%20Care%20and%20Sport%20Committ.pdf>

Autism Strategy in 2008 was that it raised awareness of autism across Wales. From this point, it has been recognised that demand for assessment and support has continued to increase.

It's clear that, particularly in some areas of Wales, there is a lack of appropriately qualified staff leading to significant challenges in recruitment and retention. A longer term strategy to address the lack of professionals qualified to work with autistic people and those within other neurodevelopmental services needs to be initiated immediately so that the issues can be resolved as early as possible.

Conclusion

While there are commitments and initiatives underway to address some concerns about the availability of quality and timely assessments and support for children and young people with neurodevelopmental conditions, progress has not been fast enough and children and young people are missing out on the help and support they need. It is important that the longer term work currently underway is allowed to develop, although we believe there should be greater urgency and some immediate measures to improve outcomes in the short term.