



Llywodraeth Cymru
Welsh Government

PUBLICATION

Code of Practice on the delivery of autism services: impact assessment

An assessment of impact of the Code of Practice on the delivery of autism services across Wales.

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What action is the Welsh Government considering and why?

The purpose of the Statutory Code of Practice on the Delivery of Autism Services is support continued improvement in the development and delivery of autism services in Wales.

Autism is a lifelong developmental condition that affects how a person communicates with and relates to other people and how they experience the world around them. Around one per cent of children and just over one per cent of adults are estimated to be autistic. A substantial proportion of autistic people, especially those with fluent language and normal-range ability, are not identified in childhood and enter adulthood without a diagnosis.

The Welsh Government first published the first Autism Spectrum Disorder Strategic Action Plan (ASD SAP) for Wales in April 2008. Its purpose was to set a clear direction of travel for the development of services by ensuring that specific and measurable actions were undertaken and on the basis of evidence of prevalence and need, commissioning inter agency services at a local, regional or national levels. It also aimed to broaden understanding of autism and its prevalence in Wales.

The Welsh Government funds the National Autism Team (NAT) to support the delivery of our autism strategy, the NAT hosts the www.autismwales.org

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website, providing expert advice and resources to support service development. The NAT projects have included work to improve employment outcomes and working with BAME communities to develop appropriate needs based provision.

An **independent evaluation of the Strategy** was published in September 2016 and showed the strategy was successful in raising awareness of autism and in providing training and development tools and resources.

To ensure continued good progress, the national autism strategy was renewed in 2016 with a comprehensive delivery plan taking a holistic and needs based approach to the development and provision of autism services. **Annual progress reports** were published in 2018 and 2019, an updated **Delivery Plan** was published in 2018, containing new commitments, one of which was the issuing of a Code of Practice on autism services in the current Assembly term (i.e. by Spring 2021).

The commitment to introduce a Statutory Code of Practice on the Delivery of Autism Services (the Code) was made in response to the members **Autism (Wales) Bill** which entered the Senedd in 2018. During Stage One Scrutiny of the Bill evidence was provided that autism services were not meeting the needs of those seeking assessment or support when a diagnosis was received. The Welsh Government did not support the Bill because its aims could be met through existing legislation in the Social Services and Well-being (Wales) Act 2014 and the NHS (Wales) Act 2006. When the Bill was rejected at the end of Stage One Scrutiny in 2019, the Welsh Government had made a commitment to focus on the needs of autistic people by issuing a statutory Code of Practice under the existing legislation which re-enforced and clarified existing duties placed on local authorities, health boards and NHS Trusts.

In narrative form, please describe the issue and the action proposed by the Welsh Government. How have you applied / will you apply the five ways of working in the Well-being of Future Generations (Wales) Act 2015 to the proposed action, throughout the policy and delivery cycle?

The Code of Practice is designed to underpin the delivery of the Social Services and Well-being (Wales) Act 2014 (SSWBWA) and the NHS (Wales) Act 2006 to

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secure the provision of services which meet the needs of autistic people and their families or carers. It aims to ensure that the improvements achieved through the delivery of the Welsh Government's Autism Strategic Action Plan are sustainable for the long term.

The Code will promote better awareness of autism amongst statutory services and secure the long term provision of autism services which can meet individual needs and provide support for the families or carers of autistic people. It will seek to improve integration and collaboration between services to prevent individuals from falling between service responsibilities and promote the involvement of autistic people in the design and delivery of the services they receive.

The requirements set out in the Code will also seek to ensure that a range of services and support is available for autistic people and are communicated more effectively. It provides direction to local authorities and local health boards and NHS Trusts on adapting their practice to better meet the needs of autistic people. It will also enable the Welsh Government to intervene where there is evidence that statutory organisations have not complied with the code's requirements.

The Code reflects the Welsh Government's values as set out in the Well-being of Future Generations (Wales) Act 2015, which is aimed at improving the economic, environmental and cultural well-being of Wales. The Act required public bodies in Wales, including local health boards and local authorities, to think about the long term impact of their decisions, to work better with people, communities and each other, and to prevent persistent problems such as poverty, health inequalities and climate change.

Long term

The Code of Practice has been developed to support the development of sustainable autism services which are fit for a rapidly changing world. The Code will enhance the delivery of the 10 year autism strategy last renewed in 2016, and will be supported by a delivery plan.

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Prevention

The Code of Practice reinforces duties in the SSWBWA which has an emphasis on preventative services, to provide early intervention and support and to prevent an escalation of needs requiring intensive or crisis support.

Integration

Part four of the Code places duties on Regional Partnerships Boards, created by the SSWBWA, which have the purpose of bringing statutory services together to work in partnership to develop integrated services. This includes developing joint Population Needs Assessment and Area Plans, the planning and delivery of autism services will be a priority in future PNA. Improved integration and collaboration between services will prevent individuals from falling between service responsibilities and promote the involvement of autistic people in the design and delivery of the services they receive.

Collaboration

As stated above duties contained in part four of the code in relation to Regional Partnership Boards will promote integrated and collaborative working. We also continue to listen to the views of autistic people through direct engagement at events and meetings across Wales and through partnership arrangements with representative organisations. In the development of the draft Code of Practice we held technical groups in July and again in November 2020, to ensure autistic people and representative organisations could contribute their views and shape the development of the Code.

Involvement

As stated above the Code has been produced in partnership with key stakeholders, this includes engagement with autistic people, their representatives, health and local authority stakeholders, third sector organisations and Welsh Government departments. This ongoing involvement

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will continue as the code is implemented and also through the formal monitoring and evaluation of the code.

A Welsh Government Autism Advisory Group has been established to advise on the development and delivery of autism policy. Through its membership, the group seek feedback on the delivery of the autism code from autistic people.

Impact

It is intended the code of practice will achieve the following outcomes:

- Improve the well-being outcomes of autistic people who need care and support and their family/carers who need support
- The implementation of Welsh Government autism policy priorities published in the Autism Strategic Action Plan 2016
- Ensure that Local Authorities and NHS health bodies know the services and support that they are expected to provide for autistic people under existing legislation.

Costs and Savings

A cost benefit analysis is being undertaken to inform future impact evaluation of the Code. Over time, it is anticipated that this Code will provide a cost saving as it will ensure that better, more well-informed decisions are made which will impact not only on the quality of provision and people's personal outcomes, but on overall costs as well.

Mechanism

The powers enabling the making of the statutory Code of Practice on the Delivery of Autism Services is contained within Section 145 of the Social Services and Well-Being (Wales) Act 2014 (SSWBW Act) and constitutes guidance under Section 169 of that Act. It also has been prepared under Sections 1 and 2 of the NHS (Wales) Act 2006.

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Section 145 of the 2014 Act permits Welsh Ministers to issue, and from time to time revise, one or more codes of practice on the exercise of social services functions.

Conclusion

7.1 How have people most likely to be affected by the proposal been involved in developing it?

The statutory Code of Practice has been developed to ensure that local health boards, Trusts and local authorities and their partners understand existing duties to provide needs based autism services, including support for carers and to raise awareness with autistic people about the support which should be available.

The Code has been developed over a significant period of time through direct engagement at events and meetings across Wales. To inform the development of the Code, technical groups and stakeholder events were held providing opportunities for a wide range of key stakeholders including autistic people to have their say on the priorities and actions in the Code. This has included young autistic young people and adults and parents and carers.

The first **public consultation for the Code of Practice** ended in March 2019. Overall, the responses from the first consultation were positive and individuals were generally in support of the proposed guidelines. Based on the feedback received, a number of additional public consultation events and targeted engagement workshops with a wide range of stakeholders (including autistic people) took place.

To ensure accessibility and inclusion for all stakeholders at our public engagement events, we provided an accessibility guide outlining all the details of the venue and the event to ensure that autistic people could prepare ahead of time. All documents were produced bilingually and attendees were asked on their language of preference for the events.

A **second public consultation** for the Code ran from September 2020 until

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December 2020. Responses to the second consultation will be published shortly.

7.2 What are the most significant impacts, positive and negative?

The overarching objectives of the Code and are set out in its four sections.

1. Arrangements for Autism Assessment and Diagnosis
2. Arrangements for Accessing Health and Social Care Services
3. Arrangements for Awareness Raising and Training on Autism
4. Arrangements for Planning and Monitoring Services and Stakeholder Engagement

The Code will ensure that autistic people and their family and/or carers receive appropriate care and support by clarifying the requirements of local authorities, local health boards and NHS Trusts.

The positive effects of the code on the Welsh Language includes training, resources and materials being available bilingually. It is likely that there should be no negative impact on the language as the code is designed to create a fairer and more equitable system for all people eligible for care and support.

We have worked with groups representing people with protected characteristics in the development of the Code to ensure that it includes outcomes and policies that enable their needs and requirements to be met. One such action is the requirement of representation on the regional partnership board through the autism champion role.

The Code takes into account the requirement of the Equality Act 2010 regarding reasonable adjustments. The Act places a legal duty on service providers and those providing goods and facilities to make reasonable adjustments for autistic people so they are not at a disadvantage compared to people without autism. Similarly, the Code directs Local health boards and NHS trusts to ensure that health services are accessible to autistic people and they must not be denied services or support because they are autistic.

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The Code also emphasises the need for autistic people to be involved in decision making about them and the services they receive, as co-production and collaboration with autistic people is required.

The Code is not considered to have an adverse impact in relation to children and young people with disabilities in general, and will have a beneficial impact in relation to autistic children and young people. The Code will seek improvements in the delivery of autism services by requiring consistency and clear pathways to access assessment and support, identifying training needs and the provision of suitable training in autism for different professions.

The Code in seeking to improve access to assessment, diagnosis and support services for children and young people requires compliance with national pathway standards as developed by the **Together for Children and Young People Programme** (T4CYP) and national waiting time standards. There have been recognised problems with long waiting times for assessment across health boards in Wales, a waiting time standard of 26 weeks from referral to first diagnosis appointment has been in place since 2018, however **an early review in 2019** found that the data collection approach is not consistent across Wales and more recently the impact of the Covid-19 pandemic has had a negative impact on waiting times. The Code will be a catalyst to improve compliance with standards and data collection and reporting.

As a result of the consultation on the Code of Practice, changes were made to take on board the feedback from our stakeholders. Examples of the changes made to the Code relate to:

- Terminology – The Code was amended to use Autistic Spectrum Condition (ASC) and autistic people
- Clearer reference has been made in the Code on the importance of the Welsh language in assessments.
- Reference and terminology strengthened in the Code regarding choice, participation and the voice of the child.
- Clarity has been provided in the Code on the Single Point of access and whether it covers both children and adult referrals.
- Stronger emphasis has been made in the Code regarding the provision of alternative support.

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- Clearer reference has been made in the Code regarding offering advocacy support including self-advocacy.

7.3 In light of the impacts identified, how will the proposal:

- maximise contribution to our well-being objectives and the seven well-being goals; and/or,
- avoid, reduce or mitigate any negative impacts?

The Code of Practice reflects the Welsh Government's values as set out in the Well-being of Future Generations Act 2015, which is aimed at improving the economic, environmental and cultural well-being of Wales.

The Code of Practice will contribute to the seven well-being goals, in particular:

A prosperous Wales - The effect of providing timely and appropriate services to autistic people could provide increased access to training and employment for autistic adults who are under-represented in the work force, and improved support their parents/carers to continue in the workplace whilst undertaking their caring responsibilities.

A healthier Wales – The Code aims to improve the lives of autistic people by clarifying the health and social care requirements set out in the Social Services and Wellbeing (Wales) Act 2014 and the NHS Wales Act (2006) which will ensure better health outcomes and higher quality of life for autistic people and their families. This includes making sure that IQ isn't a factor in assessing support needs.

A more equal Wales – The Code will ensure increased awareness and understanding of autism across the community, by requiring awareness training and promoting the provision of reasonable adjustments to enable inclusion of all autistic people in their communities and when accessing services. The code will also recognise the additional requirements of carers.

A Wales of cohesive communities – Section 3 of the Code focuses on the arrangement to promote inclusion of autistic people in mainstream services by

ensuring that information is made available to the wider community to promote understanding of autism and how being autistic can have a different impact on each individual.

A Wales of vibrant culture and thriving Welsh language – The Code of Practice reinforces the requirements of the Welsh Language standards in that Local health boards, NHS trusts and local authorities should make sure Welsh language services are built into planning and delivery and that Welsh language services are actively offered to autistic Welsh speakers without them having to request it.

The Welsh Government continues to support the National Autism Team to work with partners and stakeholders across Wales to improve the lives of autistic people so that they have the same life chances as neuro typical people. In this role the team has produced a range of free resources that autistic people, their families and carers, professionals and the wider community can use. The resources, training and guidance aims to increase the wider understanding of autism whilst offering practical tools, training and advice for autistic people and their families and carers.

The National Autism Team has worked collaboratively with the Integrated Autism Service (IAS) to develop a new data framework to capture IAS data. This is the first year of the new system and is seen as a ‘development year’ and therefore the accuracy of all data may not be absolute, however work is ongoing to ensure we can capture good reliable data which will help inform service activity and demand across Wales.

Our priority for neurodevelopmental and autism services is to ensure that services are sustainable for the long-term. The investment we are making to children’s neurodevelopmental services will continue and we are monitoring the outcomes closely. The Integrated Autism Service will continue to be funded until the conclusion of the demand and capacity review being undertaken during 2021.

The Welsh Government recognises that neurodevelopmental conditions are much more diverse than autism and many individuals will have co-occurring conditions. Through the work we are currently undertaking (through a review of

neurodevelopmental services) we will identify remaining gaps in support and work with partners to deliver sustainable neurodevelopmental services equipped to address the future challenges.

7.4 How will the impact of the proposal be monitored and evaluated as it progresses and when it concludes?

What plans are in place for post implementation review and evaluation?

There will be an evaluation of the Code of Practice within 2 years of its issue. This will help inform the Welsh Government on whether or not the policy is a success and identify areas that may need further work.

Work is currently underway on the review of neurodevelopmental services. It will review the demand, capacity and design of neurodevelopmental services for children, young people and adults in Wales in order to develop recommendations and evidence-informed options for improvements to services. This work will also take into consideration Welsh Language provision, adult and children autism services, transition between children and adult services.

The Code will be implemented from September 2021 and a delivery plan will be in place to set out in more detail the specific actions that will be taken and how they will be measured and monitored.

A National Advisory Group has been established, initially to help develop the delivery plan and once in place, the group will monitor delivery and progress. Membership includes people with autism, including children, as well as their family and carers representatives from statutory and third sector organisations.

Declaration

I am satisfied that the impact of the proposed action has been adequately assessed and recorded.

Name of Senior Responsible Officer / Deputy Director: Anthony Jordan

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Department: Health and Social Services Group, Social Services and Integration
Directorate, Inclusion and Corporate Business Division

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