Social research number: 109/2025

Publication date: 26/11/2025

Evaluation of the Code of Practice on the Delivery of Autism Services: Summary of Phase Two

Executive summary

The Code of Practice On The Delivery Of Autism Services (hereafter referred to as the 'the Code') 'sets out what autistic people, their parents and carers can expect from public services in Wales' and aims to ensure that Local Authorities (LAs) and Local Health Boards (LHBs) 'understand their existing responsibilities with regard to providing needs based autism services' (pp.1, 2).

Main findings from the evaluation of the Code

In relation to duties covering diagnostic assessment

There has been substantial national investment since the mid-2010s in establishing and developing children's neurodevelopmental (ND) services and the Integrated Autism Service (IAS). In effect, the Code sets out existing practice in children's ND services and the IAS, meaning areas were largely compliant with the Code and where the Code has led to little change in practice. The main exception to this has been the waiting time target for diagnostic assessment for children and young people, which despite additional investment, and progress in reducing waiting times, remains an important challenge.

In contrast, there has been less focus on, and investment in, autism diagnostic assessments in learning disability (LD) and adult mental health services (AMHS), particularly since the IAS was established in 2016. The Code has encouraged inquiry about these important services that have generally been neglected or overlooked by regional strategic autism groups. However, this process of inquiry has not yet provided sufficient information to judge compliance with the Code. Therefore, it has neither provided assurance that these services (and therefore, LAs and LHBs) are compliant with their duties in the Code, nor has it identified the actions required to address any examples of non-compliance.

In relation to duties covering access to information, advice, assessment and support

Practitioners report that information about autism services is available in each region, and this has improved in several areas since the baseline assessment. However, the range of services that autistic individuals and their families may need information about, signposting, or referrals to, poses challenges for both IAA services and for individual people trying to navigate this often complex landscape themselves. As a result, almost 70 per cent of respondents to surveys of autistic adults and the parents and carers of autistic children, reported that it was either quite or very difficult to get information about the autism services in their area.

Information on how to access social care assessments, usually via information, advice and assistance (IAA) services, is generally publicised on LA websites, although it can be difficult to find and people are not consistently informed of their rights to a needs assessment.

Practitioners report that access to services for children with complex needs has improved, particularly where progress has been made rolling out the NYTH/NEST framework. However, progress in improving access for adults with complex needs has been more uneven, with concerns raised about adult mental health services in some regions. People's lived experiences also appear negative: over 80 per cent of respondents to surveys of autistic adults and the parents and carers of autistic children, who needed to access services like mental health or learning disability services, reported that it was either 'very' or 'quite' difficult to do so.

In relation to duties covering awareness raising and training

Good progress has been made in offering general autism awareness training to health and social care workforces; offering higher level training to those undertaking social care assessments; and ensuring that staff in Children's ND services and the IAS undertaking diagnostic assessments have the skills and competence required.

Progress in undertaking audits of staff training needs across the whole health and social care workforces, and developing and delivering training to address gaps, has been slower. This may help explain why people's lived experiences were often negative: just over 70 per cent of respondents to surveys of autistic adults and the parents and carers of autistic children were 'not at all confident' that health care staff, such as GPs and nurses, understood the impact of autism upon their lives. While just over half were 'not at all confident' that social care staff understood the impact of autism upon their lives.

In relation to duties covering planning and commissioning services

The introduction of the Code has helped increase the profile of some strategic autism groups and encouraged greater engagement by senior local health board (LHB) and/or LA representatives. By highlighting legal duties, it has empowered some staff, such as autism leads, to develop their work and in some areas, led to a strengthening of the autism lead role and the roles regional co-ordinators have taken.

Regional autism groups have generally struggled to take a strategic approach to developing autism services and have tended to be reactive and, in the past, too narrowly focused upon the IAS and children's ND services. Moreover, just over two thirds of the parents and carers of autistic children or young people who responded to the question: 'do you think that parents or carers of autistic children have a say in the development of autism services in your area?', said 'no'.

The recommendations in this evaluation focus upon:

- developing a strategic and system wide approach to improving autism services at a national and regional level

- specific actions needed to address non-compliance in relation to individual duties
- increasing engagement with autistic individuals and their parents or carers through co-productive approaches. These should aim to help rebuild trust and confidence (where this has broken down), improve people's experiences when accessing services and support and inform the evaluation and development of autism services

1. Introduction

1.1 The refreshed Autism Disorder Spectrum Strategic Action Plan aims to ensure that ‘children, young people and adults with autism and their family and carers have their needs understood and are supported to achieve their own wellbeing outcomes and to lead fulfilling lives’ (emphasis omitted, p. 5).

1.2 In support of this, the Code of Practice On The Delivery Of Autism Services (hereafter referred to as the ‘the Code’) ‘sets out what autistic people, their parents and carers can expect from public services in Wales’ and aims to ensure to that Local Authorities (LAs) and Local Health Boards (LHBs)[1] ‘understand their existing responsibilities with regard to providing needs based autism services. These include support for carers and raising awareness amongst autistic people about the support which is available to them’ (The Code of Practice On The Delivery Of Autism Services, pp.1, 2). The Code highlights and reinforces existing duties under the Social Services and Wellbeing (Wales) Act (SSWBW Act) 2014 and the NHS (Wales) Act 2006 and was introduced as an alternative to a separate autism bill.

1.3 The evaluation of the Code was structured in two phases. The first phase focused upon a practitioner view of compliance (The evaluation of the Welsh Government's Code of Practice on the Delivery of Autism Services: Phase one). The second phase also considered the experience of autistic individuals, their parents and carers. The aim was to review the extent to which the duties in the Code were being met by autism services (including action taken to address the findings and recommendations of phase one); to review the experience of service users, such as autistic adults and the parents of carers of autistic children and young people; and to develop recommendations for improvements in meeting the duties.

1.4 Compared to phase one, in phase two, greater emphasis was placed upon encouraging and supporting each region to self-assess their progress and to identify actions that might be required where they were not compliant. This was intended to build upon the work undertaken in the first phase maximising ownership and understanding of the Code amongst those services responsible for compliance. In order to enable the data provided by self-evaluation to be triangulated and explored from different perspectives, data was also collected through:

- discussions with the National Neurodivergence Team (NNT)
- a survey of LA and LHB workforce development leads[2]
- a survey of autistic adults and parents and carers of autistic individuals[3]
- a desk-based review of LA and LHB websites; RPB documents, such as the Population Needs Assessment (PNAs), and other research and evaluations, such as the Health Inspectorate Wales

---

[1] The Code also covers the three NHS trusts: Public Health Wales; the Welsh Ambulances Services NHS Trust; and the Velindre University NHS Trust. However, these were not considered as part of the evaluation.

[2] 21 responses were received, including responses from workforce development leads in: 17 LAs and four LHBs.

[3] There was a total of 442 completed responses from autistic adult and/or the parents and carers of autistic children and young people.

(HIW), Estyn and Care Inspectorate Wales (CIW) review of support for young people's mental health (2024)

Using lived experiences to assess compliance with the Code

Although an important source of data, the evaluation does not treat the lived experience reported by autistic adults and/or the parents and carers of autistic children or young people, as directly comparable to practitioners' assessments of compliance, because:

- we cannot confidently assess how representative their experiences are of all autistic adults and/or the parents and carers of autistic children or young people in a particular region
- the questions asked of autistic adults and/or the parents and carers of autistic children or young people were not always directly comparable with those asked of practitioners
- it is likely that their experiences would often reflect the outcome of a range of factors, including the effectiveness of several different policies, rather than the degree of compliance with a single duty

1.5 A full report presenting the findings and recommendations from the second phase of the evaluation in more detail, has also been published.

2. Compliance with the Code of Practice on the Delivery of Autism Services

Section 1 of the Code: Duties relating to diagnostic assessment

2.1 Section 1 of the Code of practice on the delivery of autism services) (pp. 12-13) includes duties covering diagnostic assessments, including ensuring that:

- there are pathways to diagnostic services (including for those in the secure estate) and post diagnostic support and further assessments where there is a need
- diagnostic assessments take account of NICE best practice guidance for multidisciplinary involvement
- there is compliance with the national waiting time target for children[4]

2.2 For most of these duties, regions are compliant[5]. This reflects the investments in children's neurodevelopmental (ND) services and the Integrated Autism Service (IAS) since 2015, the establishment of national pathways and, in the case of the IAS, a national model. This meant that in effect, the Code simply set out existing practice and has, therefore, led to little change in practice.

2.3 However:

- all regions have struggled to meet the waiting time target for children, given the mismatch between demand and capacity (see e.g. the Review of Neurodevelopmental Services), although progress is now being made
- the mismatch between demand and capacity and, in some regions, difficulties recruiting and retaining staff may threaten the sustainability of services and continued compliance with the Code
- demand pressures have constrained the capacity of services, and in particular children's ND services, to provide pre and post diagnostic assessment support (including referrals for further assessment and support for those who do not meet diagnostic thresholds)

2.4 In relation to other services that undertake diagnostic assessments, such as Adult Mental Health Services (AMHS) and Learning Disability (LD) services, there is much less confidence that regions are compliant with the Code. The Code is increasing regional scrutiny of practice in AMHS and LD services. However, there is little evidence that, at this stage, the Code has led to changes in practice in LD and AMH services. There also remains a lack of scrutiny by regional strategic groups of access to diagnostic assessment for those in the secure estate.

---

[4] There is a 26 week waiting time target from referral to first appointment for children's diagnostic assessments.

[5] The main exception to this is the duty to 'Designate an individual with lead responsibility for maintaining, reviewing and promoting diagnostic pathways for children, young people and adults.' (Code of practice on the delivery of autism services, p. 13,). Individual clinicians were often identified as having responsibility for reviewing pathways for their service. However, it was not possible to identify a named individual for all services, nor always identify when and how pathways had been reviewed, or promoted, and there were no examples given of a single individual with responsibility for overseeing all pathways.

Feedback from autistic adults and parents and carers

2.5 Although autistic adults and parents and carers were not asked any specific question on access to diagnostic assessments or pre- or post-diagnostic support[6], many of the written comments expressed concerns about this, particularly in relation to children. The comments also suggest that many parents, and carers in particular, still anticipate that a diagnosis will unlock access to services and support, they are left bitterly disappointed when they finally get a diagnosis and this does not happen.

Sections 1 and 2 of the Code: Duties relating to information, advice and support and access to social care assessments

2.6 Sections 1 and 2 of the Code of practice on the delivery of autism services (pp 12-13, 22-23) include duties covering information, advice and support and access to social care assessments, including ensuring:

- ‘that as part of their Information, Assistance and Advice [IAA] Service information is available on local autism services’
- there is ‘information and signposting to access assessment services’
- ‘autistic people are aware of the right to access a needs assessment and a carer’s assessment for a carer’
- ‘that awaiting a diagnosis is not a reason to be refused support and other services’
- ‘that IQ is not considered as part of the eligibility criteria for a needs assessment under the SSWBW Act’ (pp. 12-33, 22-22)

Information about autism services

2.7 Access to information about Autism services has been improving since the first Autistic Spectrum Disorder Strategic Action Plan was published in 2008. This has been driven, for example, by the establishment:

- of local infrastructure, centred upon local autism leads and local stakeholder groups, which can provide important forums for sharing information about autism services
- of the IAS in 2017, which (as well as diagnostic assessments for adults) offers support and advice for autistic adults, parents and carers and professionals

2.8 However, there is a tendency for stakeholders to regard the IAS as the ‘autism service’ in each region. The IAS is an important autism service that provides adult autism diagnostic assessment, support and advice for autistic adults, parents or carers, and professionals. However, it is only one of a number of services that offer diagnostic assessments for adults, and it is only one of many services

---

[6] This was because it was judged that unlike practitioners, autistics adults and/or parents and carers were unlikely to have sufficient information to know, whether for example, LAs and LHBs had designated ‘an individual with lead responsibility for maintaining, reviewing and promoting diagnostic pathways for children, young people and adults’.

that will support autistic individuals and their families and carers. It was reported by stakeholders that this somewhat complex policy landscape can be challenging for people to navigate.

Feedback from autistic adults and parents and carers

2.9 The complexity of the landscape may help explain why despite the improvements outlined above, almost 70 per cent of respondents to the surveys (n=274 out of n=402 responses) said that it was either 'quite' or 'very difficult' 'to get information about the autism services' in their area. For example, as one respondent commented: 'there are so many different groups and agencies each purporting to offer something different. It's confusing'.

2.10 Nevertheless, many respondents making written comments made a broader point: they reported that there was little or no support from LA or LHB services, and this left them struggling and feeling alone or isolated. For example, as one person put it:

> 'It's a very lonely place to be. In crisis, struggling, not knowing where to turn and even when you do get there with a diagnosis. you don't actually know what support you can get or have access to. You have to go looking and when our lives are filled with all the little things we do day to day to leave the house, to try and stop a meltdown, you haven't got the time to play researcher too.

Information and signposting to access assessment services[7]

2.11 In relation to diagnostic assessment services, there has been little change since 2023 and across the seven regions awareness of diagnostic assessment and referral pathways differs for different services:

- a national pathway for the IAS was established in 2017 and pathways to individual IASs are generally clear and well publicised on LHB websites
- a national pathway for children's ND services was established in 2015. However, in a number of regions it is reported that pathways to access children's ND services can feel somewhat inaccessible[8] and as outlined above, parents and carers often, raised concerns about difficulties accessing ND services
- pathways into other diagnostic services, such as AMH and LD services are not publicised and are internal pathways within services, as they would generally only be followed by adults already accessing these secondary services. Understanding of how these pathways operate is generally limited amongst the practitioners involved in assessing compliance

2.12 There is signposting to social care assessment via IAA services and, information on how to access social care assessments via IAA services is generally well publicised on LA websites. The introduction of single 'front doors' to children and adult services has simplified pathways and it was widely

---

[7] The term 'assessment' is used in the Code to describe both diagnostic and social care assessments, and this has caused some confusion.

[8] For example: there can be different pathways for preschool and school age children; in order to help strengthen screening, the information required from referrers can be extensive, and may be required from several different referrers; and a number of regions have recently reviewed or are in the process of reviewing and revising pathways and paperwork.

reported that practitioners in, for example, the children's ND service and IAS, play an important role in providing information and signposting people to assessment services, where appropriate.

2.13 Nevertheless, no region consistently ensures that all autistic people are aware of the right to access a needs assessment and that all carers are aware of their right to a carer's assessment. This information is rarely publicised on LA websites and stakeholders report concerns that publicising the right would increase pressure upon social services but was unlikely to mean that more people would be identified as having 'eligible needs'[9].

Feedback from autistic adults and parents and carers

2.14 Feedback from autistic adults and the parents or carers of autistic children and young people indicated that even where people were aware of their rights, there was little confidence that they could either access an assessment or that an assessment would help; this may reflect:

- public perceptions of what constitutes an 'assessment' (as they may be 'assessed', in terms of the SSWBW Act but not feel it was a 'full' assessment')
- the feeling that the only outcome of an assessment that is of value is having eligible needs identified. Whereas the SSWBW Act envisages that needs can be met in different ways, including, for example, signposting to other services

2.15 Therefore, even if LAs are compliant with the Code, this is not necessarily what people want.

Sections 1 and 2 of the Code: Duties relating to access to services for individuals with co-occurring conditions

2.16 Sections 1 and 2 of the Code of practice on the delivery of autism services (pp 12-13, 22-23) include duties intended to ensure that, for example:

- 'where autistic people have co-existing conditions, including mental health and/or learning disabilities, pathways should be in place to enable access to support services which can meet their additional support needs in relation to autism'
- 'that people with an Autistic Spectrum Condition with co-occurring conditions are not excluded from Children or Adults Mental Health Services (CAMHS).'

2.17 Stakeholders consistently reported that LAs and, to a lesser degree LHBs, have moved or are moving towards needs-led, rather than diagnostic or IQ- based services; however:

- as in 2023, neurodivergent children and young people are still reported to be struggling to access CAMHS (see for example, Children's Commissioner for Wales, 2023; HIW, Estyn and CIW, 2024 (2024) How are healthcare, education, and children's services supporting the mental health needs of children and young people in Wales?)

- as in 2023, there appears to still be some confusion amongst stakeholders about the use of IQ as an eligibility criterion for services (which is not compliant with the Code) and using it to

---

[9] An 'individual has an eligible need for care and support if an assessment establishes that they can only overcome barriers and achieve their personal outcomes if the local authority prepares a care and support plan, or support plan for carers, and ensures that it is delivered' (Social Care Wales (2017) Assessing and Meeting the Needs of Individuals, p.1).

determine what the appropriate service to meet care and support needs would be (which is compliant with the Code)

- it was reported that some LA services, such as children's disability services, still require a diagnosis (for example, a diagnosis of autism) to access them[10]
- although IASs increasingly offer autism advice that is open to everyone (and which is seen as good practice), aspects of its support, such as post-diagnostic courses, are limited to those with a diagnosis in line with the national IAS model.[11] Moreover, the national IAS eligibility criteria are defined by ineligibility for secondary services (that is AMH and LD services) (Integrated Autism Service Supporting Guidance). Therefore, in effect, access to diagnostic and support services for adults is still defined by conditions (that is to say, whether someone has a diagnosis of autism or has an LD or mental health (MH) condition that meets the threshold for secondary care). The latter is a concern, where it is felt that the information, help and support offered by AMH and LD services is not as good as that offered by the IAS

Feedback from autistic adults and parents and carers

2.18 Parents and carers of autistic children and autistic adults who responded to the survey and who reported that they needed to access services like MH or LD services, were very negative: over 80 per cent reported that it was either 'very' or 'quite' difficult to do so (n=80 autistic adults, out of n=96 who adults who reported needing to access MH or LD services and (n=218 parents and carers of autistic children and young people, out of n=255 who adults who reported needing to access MH or LD services). A large number of written comments described concerns about access to MH services and a feeling that services were only accessible when an individual's mental health difficulties had escalated to a 'crisis' point. Several people described mental health services as 'broken'. In contrast, far fewer comments were made about LD services and the main written comment (complaint) about LD services was that they could only be accessed by those with a low IQ.

Sections 1, 2 and 3 of the Code: Duties relating to awareness raising and training

2.19 Sections 1, 2 and 3 of the Code (pp 12-13; 22-23 and 30-31) include 22 duties intended to ensure that:

- a range of autism awareness information, resources and training is made publicly available
- health and social care practitioners understand and can signpost people to information, advice and support (including autism services)
- health and social care practitioners have the skills, knowledge and confidence to adapt their practice to better meet the needs of autistic people; and, where required as part of their role, advise and train others and/or undertake diagnostic or needs assessments

---

[10] As noted, a diagnosis may be used to identify the most appropriate service. However, requiring a diagnosis to access some services runs counter to the spirit of the Code, if alternative services that do not require a diagnosis do not, or cannot, provide the same (or similar) levels of support to those services that require a diagnosis.

[11] This is a difficult area; there is broad support for access to support while awaiting a diagnosis, but there are concerns about how robust self-diagnosis is and the negative impacts it may have (see for example, David and Deely, 2024).

Information about and awareness of autism and signposting to services

2.20 As outlined above, compliance with the Code's duties in relation to signposting to information, advice and support has been uneven. Stakeholders in LAs and LHBs reported that few steps have been taken to ensure that health and local authority staff are aware of the IAA service and how to refer autistic people to the service (other than publicising this on LA websites).

Staff skills, knowledge and confidence

2.21 Compliance with the Code's duties in relation to staff training varies, and in general more progress has been made since 2023 by LAs compared to LHBs. In part this may reflect the more limited engagement of LHB, compared to LA, workforce development leads, with the evaluation. This limited the extent to which assessments of LHB's compliance could be made with confidence. As in 2023, the most progress has been made in:

- offering general autism awareness training to health and social care workforces, and in a number of LAs and LHBs, this training is now mandatory[12]
- offering higher level training to those undertaking social care assessments
- ensuring that staff in children's ND services and the IAS undertaking diagnostic assessments have the skills and competence required

2.22 The development of training by the National Neurodivergence Team (NNT) (formerly the National Autism Team (NAT)) has been vital in supporting this. Nevertheless, there have also been important local initiatives, often driven by autism leads, that predate the national training framework (see, for example, Evaluation of the Integrated Autism Service and Autistic Spectrum Disorder Strategic Action Plan and the Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan for details). It is also reported by stakeholders interviewed for this study, that the legal duties articulated in the Code have helped raise the profile and importance of awareness raising and training with workforce development managers.

2.23 In contrast, as in 2023, much less progress has been made in undertaking training needs analyses (TNAs) to assess the autism training needs of all staff working in health and social care and to identify the level of training required according to their job roles and responsibilities. Therefore, while many more health and social care staff will have received training at levels 1 and 2, there is a risk of gaps in relation to training at levels 3 and 4.

2.24 The Code also requires LAs with LHBs to 'ensure that autistic people and their parents and carers are involved in the development and delivery of autism training'. The autism awareness training developed by the NNT has been co-produced, so using this training helps ensure compliance. There are also examples of involving autistic people in developing specific training for an LHB or LA, but this is reported not to be done consistently across LHBs or LAs.

---

[12] For example, in Anglesey, Bridgend and Monmouthshire, autism awareness training is mandatory for social care staff; in Hywel Dda UHB's autism awareness training is mandatory for all staff (and the UHB is now recognised as an 'Autism Understanding' organisation by the NNT); and in Cardiff and Vale UHB, autism awareness training is mandatory for staff within the Mental Health Directorate.

Feedback from autistic adults and parents and carers

2.25 Despite the progress outlined above, in 2024 and 2025, feedback from autistic adults and parents and carers of autistic children and young people suggests that people with lived experience of LA and LHB services still have little confidence in the skills and knowledge of health and social care staff. For example:

- just over 70 per cent of respondents (n=288 out of a total of n=392 respondents) were ‘not at all confident’ that health care staff, such as GPs and nurses, understood the impact of autism upon their lives. Respondents were more confident in relation to social care staff but even so, just under half (n=189 out of a total of n=343 respondents) were ‘not at all confident’ that social care staff understood the impact of autism upon their lives
- when asked, how confident they were that staff would make reasonable adjustments to ensure that they could access autism services, over two thirds of respondents were ‘not at all confident’ that health care staff would do so (n=273 out of total n=402 responses), and half of respondents ‘were not at all confident’ that social care staff would do so (n=199 out of a total n=400 responses)
- the net effect of feeling that staff did not understand autism and were working in a system felt to be ‘broken’, given, for example, as one person put it, ‘limited services, poor funding, little support for child[ren], unacceptable waiting lists’ was that people trying to access services ‘don't feel valued or cared for’

2.26 Although these data are not considered directly comparable with the practitioners’ assessment of compliance, it signals a sharp note of caution on the impact of the progress that LA and LHBs report and the importance of monitoring and evaluating people’s lived experiences of interacting with LA and LHB services.

Sections 3 and 4 of the Code: Duties related to planning and commissioning services

2.27 Sections 3 and 4 of the Code of practice on the delivery of autism services (pp 30-31, 36) include five duties covering a range of areas relating to planning and commissioning services including:

- developing strategic and operational teams which include autistic people to inform service development and appointing a regional ‘autism champion’
- ensuring that the needs of autistic people are considered in the development of Population Needs Assessments (PNAs) and Area Plans
- encouraging innovation and the provision of specialist services
- monitoring and data collection

2.28 The establishment, role and effectiveness of strategic and operational autism groups and the role of the autism champion differs markedly across the seven regions. In all seven regions, there was a ‘strategic’ autism group and in several regions, such as Cardiff and Vale and North Wales, the capacity of the group has increased over the period coved by the evaluation. Their membership has either been widened, and/or engagement from existing members has increased. In addition, the has helped focus attention upon better understanding practice in a wider range of autism services, than groups have traditionally focused upon. However:

- strategic group's scrutiny of, and a role in developing autism services such as IAA, AMH and LD services, were generally limited
- while links are being developed with LA and LHB workforce development leads, it is too early to assess what impact these relationships will have upon workforce development, and the role of autism champion is not yet well established
- while autism is considered in PNAs in each region, with a few exceptions (such as Cardiff and Vale), the extent to which PNAs include a robust assessment of autism needs and services is limited

3. Assessing the likely impact of the Code

3.1 The Code directly addresses the priorities outlined in the 2016 Autism Spectrum Disorder Strategic Action Plan, and as outlined above, compliance with the Code has increased since 2023. However, the extent to which LAs and LHBs are compliant with the Code varies, and the Code is only one of many forces driving changes (making it difficult to isolate the Code's impact). Subject to these two important caveats, the evaluation suggests that, at this stage, in most regions the Code itself has had:

- little impact on access to diagnostic assessments or social care assessments (as in 2023)
- some impact on access to information and advice (unlike 2023, where we identified little impact), although more work is still needed
- an important impact upon awareness-raising work and training (as in 2023), although more work is still needed
- some impact upon planning and commissioning of services (unlike 2023, where we identified little impact)

3.2 The limitations of the Code, which only covers social and health services and not, for example, education, employment or housing services, is also likely to limit its impact upon people's lives.

3.3 Equally, the evaluation has drawn upon an often impressive amount of work undertaken by regional strategic autism groups and RPB staff in assessing compliance and developing plans to address gaps and weaknesses in Autism services. This should, in principle, lead to improvements in services in the future.

4. Conclusions and recommendations

Compliance with the Code

4.1 Although the Code is a restatement of existing duties within the SSWBW Act and NHS Wales Act (rather than the creation of new duties) the evaluation identifies that LAs and LHBs are still embarking on the journey toward full compliance, for example:

- in relation to parts of the Code, regions were already generally compliant with the Code's duties (and therefore, the Code has had little impact). The clearest example of this was in relation to duties addressing access to diagnostic assessment services via children's ND services and the IAS, where, except for the waiting time target, regions were generally compliant
- the regional assessment of compliance has encouraged inquiry about areas that have been neglected or overlooked by regional strategic autism groups, such as diagnostic assessment in LD and AMH services, and access to social care in the secure estate. However, this has not yet provided assurance that LAs and LHBs are compliant with the duties in the Code, nor identified further actions that may be required to ensure compliance in these areas
- the regional assessment of compliance (which this evaluation has supported) has also highlighted several specific duties that LA and LHBs are currently unable to meet. These include:
    - the waiting time for children's diagnostic assessment, which despite additional investments[13] and reductions in waiting times, remains challenging for ND services to achieve
    - duties which are (appropriately) challenging (or stretching) for LAs and LHBs, as they potentially require change across health and social care systems, most notably duties such as the duty to 'ensure that reasonable adjustments are in place for autistic people to ensure they are able to access services in the same way as everyone'
    - duties that practitioners feel run counter to what they consider good practice, such as exercising discretion about whether to tell someone they have the right to a needs assessment if they may have care and support needs
    - duties that conflict with national models and approaches, notably the establishment of the IAS as a service that provides support to people with a diagnosis of autism, as this runs counter to the duty on LAs and LHBs to 'ensure that awaiting a diagnosis is not a reason to be refused support and other services'. Although, as outlined above, steps taken to open up IAS's support offer to those awaiting a diagnosis are welcome, they do not yet provide parity of support for those awaiting diagnosis. In addition, it was also observed that the duty does not require the IAS to offer pre-diagnostic support; instead, the duty requires LA and LHBs to do so, through for example, IAA and access to primary health services

---

[13] Further details are available in the Written Statement: Improving Neurodivergence Services.

4.2 Several regional strategic groups now include LHB and LA representatives with sufficient seniority to inform service development. Nevertheless, the breadth of policy areas where change will be required, means that engagement with other LA and LHB leaders and strategic groups to ‘mainstream’ autism into wider policy, will be required to transform mental health, wellbeing and support services for children, young people, parents, carers and their wider families across Wales, through equality and diversity policies, to workforce development.

4.3 Finally, it is striking that in almost all the areas examined, the feedback from autistic adults and parents and carers is much more negative than practitioners’ assessments of compliance. Whilst autistic adults and parents and carers shared their lived experiences of services and provided valuable insights, a direct comparison should not be made with practitioners’ assessments of compliance. This is because, for example, it is not clear how representative these experiences are of all autistic adults and/or all parents and carers of autistic children or young people. Nevertheless, it signals a sharp note of caution on the impact of the progress that LA and LHBs report and the importance of monitoring and evaluating people’s lived experiences of interacting with LA and LHB services. Equally, it is important to note that the feedback from autistic adults and parents and carers included examples of people with positive experiences. Approaches such as appreciative inquiry, where the focus is on identifying and building on what is working well (rather than what is not working well), are also appropriate to identify how services and support can be strengthened.

4.4 Greater engagement with autistic individuals and their parents or carers through co-productive approaches is also likely to be important. This may be challenging and require additional resources (for example, to ensure that staff have sufficient time to engage with people). Nevertheless, it may be vital to help bridge some of the gaps that there appear to be between services and service users where, for example, sometimes:

- trust appears to have broken down, where people have negative experiences (including historical experiences) and/or have heard about the difficulties other service users have experienced (which is shaping their perceptions of services)
- service users feel misunderstood, abandoned and/or in a battle to access services and support
- service users’ expectations of what services can and should do is misaligned with what services (as they are currently configured) can offer

Enablers and barriers to compliance

4.5 The impact of the Code is influenced by a set of enablers and barriers that have supported or impeded compliance. As in 2023, the main factors that have supported compliance (enablers) include:

- the profile and legal force of the Code (although even here, it is reported that the Code is sometimes seen more as guidance rather than a statutory requirement) and the ways in which it has empowered individuals who previously had the passion to change things, but who had to rely upon persuasion to drive change
- a wider suite of policies and legislation that are not specific to autism but which support and/or require compliance with the Code’s duties, such as the NEST/NYTH framework (in relation to support for children while awaiting a diagnosis); the SSWBW Act (for example, in relation to

access to IAA services and social care assessments) and the Equality Act (in relation to reasonable adjustments)
- Welsh Government funding to develop national autism services such as children's ND services and the IAS and, more recently, additional funding to support the ND Improvement Programme (NDIP)
- the support from the NNT, particularly around training and resources

4.6 As in 2023, the main factors that have hampered compliance (barriers) include:

- the breadth, complexity and structure of the Code which has sometimes been compounded by weakness in regional leadership and co-ordination. For example, in some areas, there have been delays, or senior individuals or groups have not taken responsibility for assessing compliance and identifying the actions required. It has also been difficult to engage all the principal stakeholders, or even, in some cases, to identify in LAs or LHBs who has responsibility for specific duties
- the financial pressures health and social services face as result of high levels of demand and constraints upon their capacity, which can encourage services to turn inward and focus upon what they see as their 'core' role
- the short term nature of some funding, such as some NDIP monies, and the delays in confirmation of funding. These were reported to be limiting RPB's scope to use the money as effectively as they would like

Recommendations for improvements in meeting the duties of the Code

4.7 A series of recommendations have been made to each LA and LHB to address specific areas where they are either not compliant, or there is insufficient evidence to judge compliance with the Code; these focus upon:

- planning and commissioning: strengthening the role of regional strategic groups, operational groups and autism champions, involving people with lived experience and planning tools, such as PNAs, in order to:
  - identify good practice (in their own and other regions), that can be scaled up and/or shared
  - enhance the scrutiny of practice that has been overlooked or neglected by regional strategic groups (for example, in relation to diagnostic assessments in LD and AMH services) and, where needed, identify actions to address gaps or weaknesses
  - ensure that a systems-wide approach to developing autism services, that is informed by better data on services' practice and autistic people's experiences helps ensure that resources (including additional funding such as the NDIP) support innovation and the development of specialist services (where needed) and helps 'mainstream autism' within wider policy development
- awareness raising and training: ensuring that autism is considered in the training needs analyses of the health and social care workforces, co-producing training plans to address identified gaps and shortfalls in staff skills, knowledge, experience and/or confidence; and monitoring and evaluating the effectiveness of this

- improving awareness of, and access to, services: strengthening the mapping and identification of autism services in each area and, where applicable, pathways to access these services and improving sharing of this information

- improving access to diagnostic services: taking action to address demand-capacity challenges facing ND services, drawing upon the Review of Neurodevelopmental Services, and the emerging learning from the first phase of the NDIP

Recommendations for the Welsh Government

4.8 The findings from this evaluation of the autism Code, are likely to be relevant for the Welsh Government, when considering the forthcoming Code of Practice on Neurodevelopmental Services. For example, in considering:

- how awareness of and the profile of the Code amongst individuals and their families, can be raised (given the relatively modest levels of awareness identified in the surveys of autistic individuals and the parents or carers of autistic children)
- how to encourage a system wide response, through duties that are often narrowly focused upon one small part of the system. For example, the current duties in section 4 of the Code, focused upon ‘Planning and Monitoring Services and Stakeholder Engagement’, which encourage a systems wide perspective, could be enhanced
- how funding streams such as the NDIP and the Regional Integration Fund, and advice, support and challenge from the Welsh Government Neurodivergence Improvement Team and NNT can encourage and support systems wide change, for example, by supporting:
    - networking and the exchange of information, practice and ideas;
    - developing national models and/or tools
    - moving toward longer term funding models, and enhancing the integration of ND funding with regional wider planning process, such as PNAs and Areas Plans
    - clarifying the roles that regional autism champions, regional strategic and operational groups, local stakeholder groups and local ASD leads are expected to have in ensuring compliance with the Code, and how these different groups and roles can best complement each other
    - exploring how autism (and ND) policy and the priorities of neurodivergent individuals and their families can be mainstreamed into the delivery of wider policies, such as the NYTH/NEST framework, the ALN transformation programme; the Mental health and wellbeing strategy 2025 to 2035 and parenting support programmes such as Families First
- how best to strike the balance between using duties to specify what must (or should) be done, where, for example, there is consensus and evidence of what works, and what must (or should) be achieved, where for example clear, measurable and achievable outcomes can be specified
- considering how the new ND Code can be streamlined (given the way in which the number of duties in the autism Code became a barrier to compliance); simplified (given the ambiguity around what some duties required, or in some cases tensions between what is considered good practice and what the Code or other guidance requires) and restructured (given the way in which closely related duties often appear in different sections of the Code, rather than being grouped together)

5. Bibliography

David, A.S. and Deeley, Q. (2024) ‘Dangers of self-diagnosis in neuropsychiatry’, Psychological Medicine, 54(6), pp. 1057–1060

Report Authors: Dr Duncan Holtom with Dr Sarah Lloyd-Jones

Pobl & Gwaith | People & Work

Full Research Report: People and Work (2025) Evaluation of the Code of Practice on the Delivery of Autism Services: Summary of Phase Two. Cardiff: Welsh Government, GSR report number 109/2025.
Available at: https://www.gov.wales/evaluation-code-practice-delivery-autism-services-phase-two

For further information please contact:
Dr Christopher Ben Eaton
Social Research and Information Division
Knowledge and Analytical Services
Welsh Government
Cathays Park
Cardiff
CF10 3NQ
Email: Research.HealthAndSocialServices@gov.wales

Mae’r ddogfen yma hefyd ar gael yn Gymraeg.
This document is also available in Welsh.

Digital ISBN 978-1-80633-660-9