



Evaluation of the Code of Practice on the Delivery of Autism Services: Summary of Phase One (a practitioners' assessment of compliance)

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, [Welsh Government, 2021](#)).

Key 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 set out existing practice in children's ND services and the IAS and, with the exception of the waiting time target for children, areas were largely compliant with the Code and the Code has led to little change in practice.
 - 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, and there is less confidence that these services are compliant with the Code.
- In relation to duties covering **access to information, advice, assessment and support**:
 - Information about autism services is available in each region although there is a tendency for stakeholders to regard the IAS as 'the autism service', with less attention paid to the range of services that support autistic individuals and/or their parents or carers.
 - 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 routinely informed of their rights to a needs assessment.
 - 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.
- 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.
 - However, 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.

- 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.
 - However, 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.
- Overall, the **impact of the Code** has been modest to date. Compliance with the Code duties has generally been driven by a range of factors which support the aims of the Code, but which were not developed because of the Code. These include, for example, Welsh Government investment in and support for new national models such as the IAS, and The NYTH/NEST framework.
- However, the introduction of the Code has shone a spotlight on, and encouraged inquiry about, areas that have been neglected or overlooked by regional strategic groups, such as diagnostic assessment in AMHS and LD services.
- The **recommendations in this evaluation** focus upon both developing an overarching strategic approach to improving autism services at a regional level and specific actions to address non-compliance in relation to individual duties.

1. Introduction

- 1.1 The refreshed Autism [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, Welsh Government, 2016a](#)). 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' (pp.1, 2 [Welsh Government, 2021](#)). The Code highlights and reinforces existing duties under the Social Services and Wellbeing (Wales) Act (SSWBWA) 2014 and the NHS (Wales) Act 2006 and was introduced as an alternative to a separate autism bill (ibid.).
- 1.2 The evaluation of the Code is structured in two phases and this first phase focused upon a practitioner view of compliance. The second phase will broaden the lens, to consider the experience of autistic individuals and parents and carers.
- 1.3 The aim of this phase of the evaluation is to review the extent to which the duties in the Code are being met by autism services and to develop recommendations for improvements in meeting the duties. This phase has drawn upon:
- an initial workshop to explore and understand the intent of the Code with members of the Welsh Government and the Welsh Government neurodivergence improvement programme teams²;
 - reviewing the work each region had undertaken to develop a baseline assessment of their compliance with the Code. This included discussions and/or online workshops with the WLGA ND team and stakeholders in each region and a desk based review of each region's self-evaluation of compliance, typically based upon an audit tool developed by the WLGA ND team;

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 Autism is a neurodevelopmental condition (NDC). Other NDCs include, for example, Attention Deficit Hyperactivity Disorder (ADHD) and Tourette's syndrome, and national policy development and teams have shifted from autism to focus upon wider range of NDCs.

- developing new tools and approaches to help gather data and evaluate compliance against the duties in the Code and to identify good practice;
- desk based reviews to, for example, identify what information is provided about autism services on local authority (LA) and local health board (LHB) websites and the extent to which Population Needs Assessments (PNAs) consider autism;
- interviewing key stakeholders (n=25) drawn primarily from health and social services, but also including for example, autism leads, who might be employed by education; and
- discussing the evaluation team's assessment of each area's compliance with regional strategic groups to refine and confirm the assessment and elicit additional information about practice in each region.

1.4 A full report presenting the findings and recommendations from the first evaluation phase in more detail will be published shortly.

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 \(pp12-13\)](#) includes 12 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; and
- there is compliance with the national waiting time target for children³ ([Welsh Government, 2021](#)).

2.2 Investments in children's ND services and the IAS since 2015, the establishment of national pathways and, in the case of the IAS, a national model, means that for most duties, regions are compliant⁴. In effect, the Code simply set out existing practice and has, therefore, led to little change in practice. However:

- all regions have struggled to meet the waiting time target for children, given the mismatch between demand and capacity (see e.g. [Welsh Government, 2022](#));
- the mismatch between demand and capacity and, in some regions, difficulties recruiting and retaining staff may threaten the sustainability of teams and services and continued compliance with the Code; and
- pressures upon services 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).

2.3 In relation to other services that undertake diagnostic assessments, such as AMHS and LD services, there is much less confidence that regions are compliant with the Code. For example, in relation to AMHS, efforts were made through the All Wales Diagnostic Network to build capacity within AMHS (as well as LD services) (ibid). However, from 2016, following the refreshed autism strategy, attention and funding shifted from the Network to establishing the IAS. Although IASs have

³ There is a 26 week waiting time target from referral to first appointment for children's diagnostic assessments.

⁴ 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.' (p. 13, [Welsh Government, 2021](#)). 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.

supported AMHS (e.g. with advice, training, support and joint assessments (see e.g. [Welsh Government 2019](#))), this has tended to focus upon individual cases and individual clinicians. Moreover, although the Code should be increasing regional scrutiny of practice in AMHS and LD services, regional strategic autism groups have focused primarily upon the IAS and children's ND services.

- 2.4 There is considerable uncertainty about the duties in relation to access to diagnostic assessment in the secure estate and a lack of scrutiny of services for those in the secure estate by regional strategic groups. In relation to children, the re-organisation of the Swansea Bay and Cwm Taf Morgannwg health boards (where the only two children's secure units are) has added to the uncertainty about where responsibility lies. Practice in relation to adults is inconsistent and poorly understood by strategic groups.

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

- 2.5 [Sections 1 and 2 of the Code \(pp 12-13, 22-23\)](#) include 12 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'; and
- 'that IQ is not considered as part of the eligibility criteria for a needs assessment under the SSWBW Act' (pp. 12-33, 22-22, [Welsh Government, 2021](#)).

Information about autism services

- 2.6 Interviews with stakeholders and discussions with regional groups identified a number of developments that predate the Code and which have improved information about autism services. These include in particular the establishment of:
- local autism leads in response to the first autism strategic action plan in 2008. Their roles vary, but can include identifying local services and/or providing direct information, advice and support to individuals;
 - local stakeholder groups, which can provide important forums for sharing information about autism services;
 - the [Dewis Cymru website that brings together information about advice and wellbeing](#), and IAA services in each LA, in response to the SSWBW Act 2014; and
 - the IAS, following the refreshed autism strategic action plan in 2016, which (as well as diagnostic assessments for adults) offers support and advice for autistic adults, parents and carers and professionals, although its offer of support varies from region to region.
- 2.7 However, 'autism services' are not defined by the Code (and the term is open to interpretation) and there is a tendency for stakeholders to regard the IAS as 'the autism service' in each region. While the IAS is an important source of information, advice and support, it is only one of many services that will support autistic individuals and their families and carers, and which should be considered 'autism services'. These would include a range of services that are not always badged as 'autism services'⁵ as they do not only work with autistic individuals and/or their parents and carers, such as:
- ND services, LD services and AMHS;

⁵ I.e. 'autism' does not feature in the name of the service.

- social care assessment services;
- Families First, Family Information Services and children’s disability teams; and
- third sector organisations (which are reported to be a key source of support for parents and carers).

It was reported by stakeholders that this somewhat complex policy landscape can be challenging to navigate and means that it can be difficult to identify ‘autism services’ (other than the IAS) on LA and LHB websites⁶. This is important, because these websites (along with IAA services, discussed below) are a key vehicle for disseminating information about local services.

2.8 It is also important to bear in mind that the duties generally focus upon information about, rather than the provision of, autism services⁷ and that, in some ways, the duty is easier to meet in regions where there are fewer services.

Information and signposting to access assessment services⁸

2.9 In relation to diagnostic assessment services:

- a national pathway for children’s ND services was established in 2015 ([T4CYP, 2015](#)). Although the very high level of referrals to the services indicates that people can access them, interviews and discussions with stakeholders identified that pathways remain somewhat opaque in a number of regions and difficulties accessing ND services were sometimes highlighted;
- a national pathway for the IAS was established in 2017 ([National Autism Team, 2017](#)), and pathways to individual IASs are generally clear and well publicised on LHB websites; and
- pathways in other diagnostic services, such as AMHS and LD services, are not publicised and are internal pathways within services.

2.10 Information on how to access social care assessments, usually via IAA services, is generally well publicised on LA websites, although reviews of LA websites identify that it can be difficult to find. Moreover, the evidence suggests that no regions consistently ensured that all autistic people are aware of the right to access a needs assessment and a carer’s assessment⁹. For example, stakeholders from health services typically reported that they make a referral to social care when they judge it to be ‘appropriate’, which is usually when they feel the individual is likely to have eligible needs. They reported concerns about telling people they had a right to an assessment when it is felt likely that they would not benefit from an assessment.¹⁰

2.11 For children, the development of a single point of access, such as the Single Point of Access for Children’s Emotional Wellbeing (SPACE-WB) panel, is seen as good practice (see e.g. [Children’s Commissioner for Wales 2020](#)), but may mean that referrals are not directly made to social services. This caused some discussion about whether this approach was compliant with the Code. It is clearly consistent with the spirit although, arguably, not the letter (or text) of the Code.¹¹

⁶ For example, an internet search for “autism services” in a particular LA will usually identify the IAS and some third sector organisations but will rarely identify other LA or LHB services that can and do support autistic individuals and their parents or carers.

⁷ The main exception to this is the duty to ‘Provide access to services which can assess for autistic spectrum condition and associated conditions which take account of NICE best practice guidance for multidisciplinary involvement’ (p. 12, [Welsh Government, 2021](#)).

⁸ The term ‘assessment’ is used in the Code to describe both diagnostic and social care assessments, and this has caused some confusion.

⁹ As outlined in the [SSWBA guidance \(Welsh Government, 2019\)](#): ‘Any individual or family with a care and support need has a right to an assessment on the basis of that need’.

¹⁰ It is important to note that even if the assessment does not identify that an individual has eligible needs, it may lead to signposting to preventative and wellbeing services (including third sector services) that meet the individual’s needs.

¹¹ For example, the Code states that ‘Where an assessment of autism is undertaken but a diagnosis is not made, if the assessment indicates it is necessary, with the individual’s consent (or for children their parent or carer) a referral is made to social care services for an assessment of social care needs.’ (p. 12, [Welsh Government, 2021](#)).

2.12 There was generally reported to be better sharing of information between autism diagnostic services and social care services for children compared to adults. This was reported to be because, often, the child and family were known pre-diagnosis to social care services, such as Families First. These services usually continued to support the family after the diagnostic assessment. However, adults accessing the IAS for a diagnostic assessment, were reported to be less likely to be accessing adult social care services and therefore to be already known to these services.

Access to services, diagnosis and the use of IQ as an eligibility criterion

- 2.13 Stakeholders consistently reported that LAs and, to lesser degree, LHBs, have or are moving toward needs based rather than diagnostic or IQ based services. However:
- there was some confusion amongst stakeholders between the use of IQ as an eligibility criterion for services (which is not compliant with the Code) and using it to 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 to access them¹²; and
 - while IASs offer autism advice that is open to everyone (and which is seen as good practice), aspects of their support, such as post-diagnostic courses, are limited to those with a diagnosis, in line with the national IAS model.

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

- 2.14 [Sections 1 and 2 of the Code \(pp 12-13, 22-23\)](#) include four 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'; and
 - 'that people with an Autistic Spectrum Condition with co-occurring conditions are not excluded from Children or Adults Mental Health Services (CAMHS).'
- 2.15 Stakeholders reported that a number of factors, not directly linked to the Code, have improved access to services for children and young people with co-occurring conditions. These include:
- the development and roll out of the [NYTH/NEST framework](#) and the Children's Commissioner's campaign for 'no wrong door' to services ([Children's Commissioner for Wales, 2020](#)) which drew upon existing good practice in regions, such as the SPACE-WB panel in Gwent; and
 - advice and training for CAMHS which has helped increase practitioners' skills and confidence supporting autistic children.
- 2.16 Stakeholders reported that compliance with the Code's duties in relation to access to services for children with co-occurring conditions is strongest where the implementation of the NYTH/NEST is most developed. The ways in which the NYTH/NEST framework is supporting compliance with the Code for children and young people with co-occurring conditions, is an important illustration of how autism policy needs to be part of – or mainstreamed into – wider policy. Nevertheless, given the historic difficulties, further investigation of the experiences of children and young people with complex needs is warranted in the second phase of the evaluation.
- 2.17 Progress in relation to access to services for adults with complex needs has been uneven. Stakeholders reported that where progress has been made it has been supported by:

¹² 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) level of support to those services that require a diagnosis.

- the establishment of the IAS, which can support adults who are not eligible for secondary services such as AMHS or LD services (but who may still have mental health difficulties or mild learning disability). However, it is important to note that, in line with the national model, the IAS does not support autistic adults who are accessing secondary services; and
 - awareness raising work, training and consultations particularly with AMHS (discussed below).
- 2.18 However, in the absence of equivalent panels like SPACE-WB, it is reported that some adults with complex needs can still struggle to access services and support and further investigation of their experiences is warranted in the second phase of the evaluation.

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); and
- 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.

Information about and awareness of autism and signposting to services

- 2.20 Stakeholders reported examples of events to raise public awareness of autism. However, the focus has primarily been upon improving access to information for autistic individuals and their families, rather than the general public.
- 2.21 As outlined above in the discussion of section 2 of the Code, compliance with the Code's duties in relation to signposting to information, advice and support has been uneven. Stakeholders reported few steps 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

- 2.22 Compliance with the Code's duties in relation to staff training varies. Stakeholders reported that good progress has been made in:
- offering general autism awareness training to health and social care workforces and, in several LAs, it is now mandatory;
 - offering higher level training to those undertaking social care assessment; and
 - ensuring that staff in Children's ND services and the IAS undertaking diagnostic assessments have the skills and competence required¹³.
- 2.23 The development of training by the National ND team is seen as helpful by stakeholders and there have also been important local initiatives, often driven by autism leads, that predate the national autism training framework. It is also reported by stakeholders that the legal duties articulated in the Code have helped raise the profile and importance of awareness raising and training with workforce development managers.

¹³ However, there is less confidence about the skills, knowledge and experience of staff in LD services or AMHS in regional strategic groups. It is generally reported that LD clinicians and LD services are thought to have the skills, knowledge and experience required. Whereas in AMHS, it is thought that individual clinicians have the skills, knowledge and experience required but there is a doubt about whether the service as a whole does. There has been no formal audit of skills in either LD services or AMHS and there is less understanding of the training staff in these services have completed or of their experience undertaking autism diagnostic assessments.

- 2.24 The Code also requires that LAs and LHBs assess the autism training needs of **all their staff** who are working in health and social care (emphasis added) and ensure that all staff can access the autism training needed. As outlined above (in paragraph 2.19), there are examples of good practice in relation to specific staff groups. However, only two LAs reported that workforce wide training needs analyses had been completed and the development of training plans to address gaps remains uneven at this stage, although this work was underway in several regions.
- 2.25 In addition, the Code requires LAs with LHBs to involve autistic people and their parents and carers in the development and delivery of autism training. The autism awareness training developed by the national ND team has been co-produced, so using this training helps ensure compliance. There are examples of involving autistic people in developing specific training for a LHB or LA, but this is inconsistent.

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

- 2.26 [Sections 3 and 4 of the Code \(pp 30-31, 36\)](#) 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 PNAs and Area Plans;
 - encouraging innovation and the provision of specialist services; and
 - monitoring and data collection.
- 2.27 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; however:
- they tend to focus upon the children's ND service and IAS and scrutiny of, and a role developing, other autism services was generally limited;
 - they do not always include LHB and/or LA representatives with responsibility for implementing the Code or with sufficient seniority to inform service development;
 - the relationship between the autism strategic group, the Regional Partnership Board (RPB) and other RPB strategic groups was not always clear. In part, in the judgment of the evaluation team, this appears to reflect the sometimes uneasy fit between an autism strategic group focused upon a specific condition for all ages and other regional strategic groups with a much wider cross cutting remit for a particular age group, such as children and young people, adults or older people; and
 - the direct involvement of people with lived experience was often limited and links between the strategic group, local autism leads and local stakeholder groups were not always clear.
- 2.28 Interviews and discussions with stakeholders identified that the introduction of the Code has helped develop the profile of some strategic groups and encouraged greater engagement by senior LHB and/or LA representatives. It has empowered some staff, such as autism leads, who can point to the legal duties placed upon LAs and LHBs. In some areas it has also strengthened their role. It has also helped give some autism strategic groups a clearer purpose (focused upon assessing compliance). However, the breadth, length and complexity of the Code has made it difficult for regional autism strategic groups to prioritise actions because:
- an assessment of compliance highlighted so many areas where action was needed;
 - a focus upon compliance with the Code can overshadow areas not covered by the Code but which are important and risks encouraging what was described by stakeholders as a 'tick box' approach to compliance; and

- it can be difficult to see the links between parts of the Code and the bigger picture (or wider system) if the focus narrows to each of the 51 individual duties; as one stakeholder put it, it is 'difficult to see the wood for the trees'.
- 2.29 Several regions reported that they had struggled to identify someone willing to take on the role of autism champion and/or have had champions step down from the role. Moreover, where in post, the profile of autism champions generally remains low. For example, many stakeholders were not clear who their regional champion was.
- 2.30 Given the financial pressures and constraints both LHBs and LAs face, the additional funding provided by the Welsh Government to support autism services through the Regional Integration Fund (RIF) and the Neurodivergence Improvement Programme (NDIP) has been important. It has supported actions to help regions move closer toward compliance by, for example, funding ND services to enhance their capacity to undertake diagnostic assessment and pre and post-diagnostic support and, in some areas, supporting the third sector. However, stakeholders reported that strategic autism groups have not always been involved in decisions about how these funds are used and delays in the release of funds have limited how effectively or strategically they can be used¹⁴.
- 2.31 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. This, in turn, means there is little evidence that the PNA is informing the development of autism services, including specialist services and innovation.
- 2.32 All regions are complying with the duties around data collection¹⁵, although discussions with stakeholders and a review of plans suggests that the use of the data by regional strategic autism groups to inform decisions about service development is not consistent, and groups' knowledge of autistic individuals' lived experience (e.g. of accessing services and support) is often fragmented and anecdotal. Moreover, the data collection duties in the Code are narrow and weakness in the range of data contribute to the weakness in PNAs.

3. Assessing the likely impact of the Code

- 3.1 The Code directly addresses the priorities outlined in the 2016 autism [Strategic Action Plan](#). However, as outlined in section two:
- the extent to which LAs and LHBs are compliant with the Code varies, and
 - the extent to which changes in practice can be attributed to the Code also varies considerably, as the introduction of the Code was usually only one of a range of factors that contributed to the changes observed and/ or the changes predate the introduction of the Code.
- 3.2 Given 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; information and advice; and planning and commissioning of services. However, it has had an important impact upon awareness raising and training, although more work is still needed.
- 3.3 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.
- 3.4 Equally, the evaluation also highlights important improvements in each of these priority areas, albeit improvements which the evaluation suggests the Code has had little or only marginal impact on at this stage. For example:

¹⁴ For example, it was reported that funding decisions came too late in the financial year and, because funding was time limited, it could not be used to recruit additional permanent staff to increase capacity. Given the financial pressures and monitoring of a number of LHBs, there was an unwillingness to take risks and approve funding decisions which relied upon the Welsh Government providing funding in the future.

¹⁵ The requirements of the duty include RPB reporting on the use of RIF and NDIP funds; the Children's ND service providing waiting time data to the Welsh Government; and the IAS providing quarterly data to the National ND team (via Data Cymru).

- while the demand-capacity gap continues to challenge and stretch ND services and waiting lists remain too long, RIF funding (which includes funding for the IAS) and NDIP funding, has helped increase diagnostic assessment capacity somewhat¹⁶. The NHS Delivery Unit's review of Children's ND services should also support action here;
- NDIP funding has also supported improvements in access to support for those awaiting a diagnosis, as have moves toward implementing the NYTH/NEST framework for children, young people and families;
- IAAs, Families First, Family Information Services and, where funded, services targeted at autistic children, adults and/or families¹⁷, including those provided by the third sector, have improved access to information, advice and support for children and families;
- The IAS continues to play a central role in providing access to information and support for autistic adults who are not eligible for support from secondary services; parents and carers (although it is reported by stakeholders that some IASs have reduced the support they offer to parents and carers); and, increasingly, those individuals awaiting assessment or who have not been diagnosed following assessment; and
- the Code has further raised the profile of autism and the importance attached to it by LAs and LHBs at regional and service levels¹⁸. The assessment of compliance with the Code has also shone a spotlight on, and encouraged inquiry and reflection upon areas that have too often been neglected or overlooked by regional strategic autism groups, such as:
 - practice in services such as AMHS and LD services that undertake autism diagnostic assessment;
 - access to information about autism services (other than the IAS);
 - access to services and support for children and adults in the secure estate; and
 - the role that people with lived experience can and should play in shaping training and service design and delivery.

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 a journey toward full compliance¹⁹. For example:
- in relation to parts of the Code, such as diagnostic assessments by the IAS, regions were already generally compliant with the Code's duties;
 - the regional assessment of compliance, has shone a spotlight on, and encouraged inquiry about areas that have been neglected or overlooked by regional strategic autism groups; and
 - the regional assessment of compliance has also highlighted a number of specific duties that LA and LHBs:
 - cannot meet at the moment, most notably the waiting time for children's diagnostic assessment;

¹⁶ As noted, stakeholders reported that while the funding has been very welcome, delays in the release of funding and difficulties recruiting staff have limited its impact.

¹⁷ These include services that, for example, support neurodiverse or disabled children or adults (and not just autistic children and adults).

¹⁸ For example, stakeholders reported that the legal status of the Code helps ensure that colleagues in LHBs and LAs paid attention.

¹⁹ This is consistent with the recent evaluation of the SSWBW Act ([Welsh Government, 2023](#)).

- find challenging to evaluate and, therefore, to assess compliance against, such as the duty to ensure that reasonable adjustments are in place for autistic people to access services in the same way as everyone else²⁰;
- disagree with, as what they consider to be good practice, such as exercising discretion about whether to tell someone they have the right to a needs assessment, is not consistent with the Code duties; or
- find it difficult to comply with because they run counter to a national model and approach²¹.

4.2 The next phase of the evaluation will further explore compliance and the impact of the Code by considering the experiences of autistic individuals and parents and carers.

Enablers and barriers to compliance

4.3 As outlined in section three, the impact of the Code has often been modest. This reflects a set of wider enablers and barriers that have supported or impeded compliance. Key factors that have supported compliance (i.e. enablers) include:

- the profile and legal force of the Code (although even here, it is reported by stakeholders that the Code is sometimes seen more as guidance than a statutory requirement) and the way in which it has empowered individuals who previously had the passion to change things but had 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;
- 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 NDIP; and
- the support from the national ND Team, particularly around training, including the development of national training framework and e-learning modules, and information and resources for parents and carers, children, young people and adults, employers and health, social care and community services (see e.g. [NAT, 2023](#)).

4.4 Key factors that have hampered compliance (i.e. barriers) include:

- the breadth, complexity and structure of the Code which can focus attention upon individual duties in isolation from each other, encouraging a 'tick box' approach to compliance and which also makes assessing compliance and prioritisation of action challenging²²;
- the continued distance between health and social services which means, despite a number of joint duties, there is a tendency to focus upon 'LA' or 'LHB' duties and roles, rather than a genuinely collaborative focus upon how the duties in the Code can best be complied with;
- the financial pressures health and social services face as a result of high levels of demand and constraints upon their capacity, including problems recruiting and retaining staff; and
- weakness in regional leadership and co-ordination where, for example, no individual or group has taken responsibility for assessing compliance and identifying the actions required.

²⁰ The focus upon evaluating process is constrained by the patchy evidence of the implementation of policies. For example, LAs and LHBs have policies on making reasonable adjustments and support this through staff awareness raising and training. However, there has been little evaluation of staff practice across LAs and LHBs (i.e. do they consistently make reasonable adjustments?) which would be a substantial exercise in its own right, and ideally compliance with this duty should also be evaluated by examining the experiences of autistic individuals.

²¹ Most notably, the establishment of the IAS as a service set up to provide post-diagnostic support. 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 a diagnosis.

²² For example, stakeholders expressed concerns that changes in services processes to ensure compliance on paper, might not make any difference to autistic individuals' or their parents' and carers' lives.

Recommendations for improvements in meeting the duties of the Code

4.5 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 at this stage. The recommendations focus upon the four sections of the Code and given the limited impact of the Code to date, focus upon how the impact of the Code could be increased.

- **Section 4 of the Code: Planning and commissioning:** strengthening the role of regional strategic groups, operational groups, autism champions, 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 (e.g. in relation to diagnostic assessments in AMHS and LD services) and, where needed, identify actions to address gaps or weaknesses; and
 - ensure that a systems wide strategic approach to developing autism services is taken. This should in turn:
 - be informed by better data on services' practice and autistic people's experiences (which the second phase of the evaluation should support);
 - help ensure that resources (including additional funding such as the NDIP) support the development of services; and
 - help 'mainstream autism' within wider policy development.
- Given the breadth of the Code, RPBs and strategic autism groups should identify:
 - those areas where the autism strategic group should take a lead or more direct role in developing, shaping and overseeing autism policy and practice; and
 - those areas, such as early help and support for children, young people and families; workforce development and training; and information about and access to social care assessment, best addressed by other regional strategic groups. The role of the autism strategic group here should be ensuring that autism is considered and mainstreamed into policy in these areas.
- **Section 3 of the Code: Awareness raising and training:** ensuring that LAs and LHBs consider autism in 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.
- **Sections 1, 2 and 3 of the Code: 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. As outlined above, this should be mainstreamed into wider LA and LHB strategies to, for example ensure that (as the SSWBW Act requires):
 - staff are aware of the IAA service and how to refer people to the service; and
 - people who may have care and support needs are aware of their right to a needs assessment.
- LAs and LHBs should adopt a range of methods and partners to reach out to practitioners, autistic individuals and their parents or carers, such as websites, social media campaigns, Community Connectors, Navigators, Families First and Family Information Services, children's and adult disability services, third sector organisations, stakeholder groups and networks and autism officers.
- **Section 1 of the Code: Improving access to diagnostic services:** LHBs take action to address demand-capacity challenges facing ND services, drawing upon the [Review of Neurodevelopmental Services](#) and the recent review of children's ND services undertaken by the NHS Delivery Unit; and review, and where needed, strengthen pathways, processes and/or practice in AMHS and LD services (and other services that undertake diagnostic assessments).

Recommendations for the Welsh Government to support regional action

- Continue to publicise and raise the profile and understanding of the Code (and its legal duties) amongst RPBs, LHBs, LAs and the general public.
- Review the Code and/or supporting guidance to provide greater clarity on duties (including what compliance looks like) with regards:
 - the secure estate;
 - which duties apply to diagnostic assessments, which apply to social care assessments, and which apply to both; and
 - informing people who may have care and support needs of their right to a needs assessment.
- Work with the National ND team and networks, such as the autism leads network, to share good practice.
- Encourage greater scrutiny of the extent to which autism is adequately addressed in RPB PNAs, area plans and annual reports.
- Ensure (through evaluation of proposals and reports) that RIF and NDIP funds are used to support compliance with the Code duties.
- Consider the development of autism/ND operational guidance and framework for clinicians in AMHS.

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Views expressed in this report are those of the researchers and not necessarily those of the Welsh Government

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