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

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

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Glossary

Acronym	**Definition**
ADHD	Attention Deficit Hyperactivity Disorder
AMH	Adult mental health
ASC	Autism Spectrum Condition
ASD	Autism Spectrum Disorder
CAMHS	Child and Adolescent Mental Health Service
CBC	County Borough Council
CTM	Cwm Taf Morgannwg
HMP	Her Majesty's Prison
IAA	Information, Assistance and Advice
IAS	Integrated Autism Service
IQ	Intelligence Quotient
LA	Local Authority
LHB	Local Health Board
LD	Learning disability
NAS	National Autistic Society
NAT	National Autism Team
ND	Neuro development or neurodiversity
NDIP	Neurodivergence Improvement Programme
NEST/NYTH	Nurturing, Empowering, Safe, Trusted
NHS	National Health Service
NICE	National Institute for Care Excellence
NNT	National Neurodiversity Team (previously known as NAT)
ONS	Office for National Statistics
PNA	Population Needs assessment
RCT	Rhondda Cynon Taf
RIF	Regional Integration Fund
RPB	Regional Partnership Board

SBAR	Situation, background, assessment, recommendation
SPACE-ND	Single Point of Access for Children's Neurodevelopment
SPACE-WB	Single Point of Access for Children's Emotional Wellbeing
SSWBW Act 2014	Social Services and Well-Being Wales Act 2014
UHB	University Health Board
YOI	Young Offender Institution
WLGA	Welsh Local Government Association

1. Introduction/Background

1.1. Autism is a lifelong developmental condition that affects: ‘how a person communicates with and relates to other people, and how they experience the world around them’ (NAS, 2023).

1.2. The experiences and outcomes for autistic people can often fall short of their neurotypical peers. For example, as Chart 1.1. illustrates, overall disabled autistic people in the UK report much lower levels of wellbeing and higher levels of anxiety than non-disabled people.[1] There is no single reason for this. It can, for example, be linked to difficulties accessing public services and education, training and employment, which can in turn contribute to social and economic exclusion from neurotypical society. As Chart 1.1. illustrates the pandemic also had a large impact upon the wellbeing of people, and overall, it affected some groups, such as disabled people, more than non-disabled people.[2]

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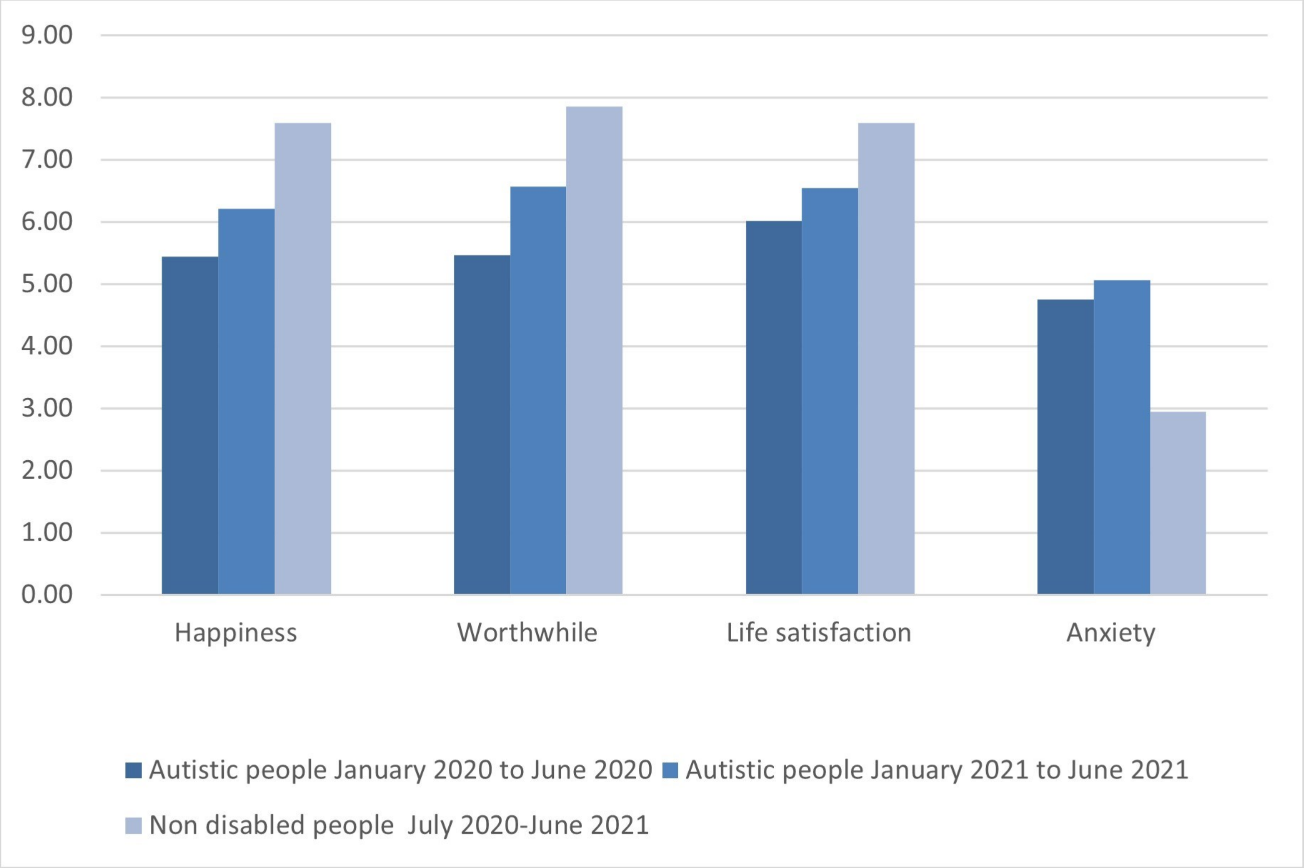
[1] Not all autistic people will consider themselves to be disabled. The diagnostic criteria for autism, which include ‘persistent difficulties with social communication and social interaction’ which ‘limit and impair everyday functioning’ (NAS, 2020), mean that most autistic people would be considered ‘disabled’, by the definition used for this data set. In this data set, a person’s disability status is self-reported and based upon the Government Statistical Service definition, which ‘identifies "disabled" as a person who has a physical or mental health condition or illness that has lasted or is expected to last 12 months or more, that reduces their ability to carry out day-to-day activities.’ (ONS, 2022a). However, because this data is based upon self-reported data, some autistic people might not consider themselves to be disabled, if, for example, it did not reduce their ability to carry out day-to-day activities. Moreover, a social model of disability in which people are ‘disabled’ by barriers in society, not by their impairment or difference, also means that the extent to which autistic people see themselves as disabled, depends upon societal attitudes and practices, rather than just the underlying impairment.

[2] This is reflected in the lower levels of wellbeing recorded for disabled people in January to June 2020, compared to January 2021 to June 2021. Unfortunately, data for non-disabled people is not available for the same time periods.

Chart 1.1. Reponses to the Office for National Statistics wellbeing questions [3] by disabled autistic adults (aged 16-64) January 2020-June 2020; January 2021-June 2021 and non-disabled adults (aged 16-64), July – June 2021 in the UK



Source: Office for National Statistics, Disability and well-being (using Annual Population Survey data).

1.3. In response to the longstanding challenges autistic people and their families have faced, 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). The Strategic

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[3] The four questions are: Overall, how happy did you feel yesterday? Where 0 is 'not at all happy' and 10 is 'completely happy'. Overall, to what extent do you feel the things you do in your life are worthwhile? Where 0 is 'not at all worthwhile' and 10 is 'completely worthwhile'. Question: Overall, how satisfied are you with your life nowadays? Where 0 is 'not at all satisfied' and 10 is 'completely satisfied'. Question: Overall, how anxious did you feel yesterday? Where 0 is 'not at all anxious' and 10 is 'completely anxious'. (ONS, 2022b).

Action Plan was evaluated in 2019. This evaluation identified that progress had been made in delivering the priorities for action including:

- improving the capacity and quality of autism assessment and diagnosis, through the establishment of new children's neurodevelopment (ND) services and the Integrated Autism Service (IAS), although demand for both services was much greater than their capacity;
- improving educational outcomes and experiences for autistic children and their parents and carers' experiences, through the Additional Learning Needs (ALN) transformation programme, although the evaluation noted that parents and carers' relationships with schools and Local Authorities (LAs), were still often adversarial;
- improving employment outcomes for autistic young people through, for example, the Engage to Change programme[4]; and
- increasing societal awareness and understanding of autism through, for example, training and resources developed by the National Autism Team (now the National Neurodivergence Team), although the evaluation identified that take up of some resources was modest.

1.4. Given the challenges, and in support of the Strategic Action Plan, 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' (p.1 Welsh Government, 2021a). The Code highlights and reinforces existing duties under the Social Services and Wellbeing (Wales) Act (SSWBW Act) 2014 and the National Health Service (NHS) (Wales) Act 2006 and was introduced as an alternative to a separate autism bill (ibid.).

Evaluation aims and objectives

1.5. The aim of this evaluation is to review the extent to which the duties in the Code are being met and to develop recommendations for improvements in meeting the duties of the Code.

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[4] The Engage to Change project supported young people aged 16-25 with a learning difficulty, learning disability and/or autism and aimed to help them achieve their full potential.

1.6. The evaluation is structured in two phases and this first phase focused upon a practitioner view of compliance. The main objectives of this first phase were to (in 2023):

- assess the extent to which the duties of the Code are being met and identify gaps in meeting the duties specified in the Code;
- assess the impact the four key areas of the Code have had on service providers, including how it has changed the design and delivery of services;
- identify any challenges service providers have had in implementing the duties of the Code;
- identify existing good practice and consider how it could be integrated across service providers; and
- develop recommendations for improvements in meeting the duties of the Code.

1.7. The second phase will broaden the lens, to consider the experience of autistic individuals and parents and carers drawing together their views and also that of practitioners on the extent to which LAs and Local Health Boards (LHBs), are compliant with the Code (in 2024) and what impact they feel this has had upon their lives. It will also examine whether the recommendations in meeting the duties of the Code identified in stage one have been addressed and identify any challenges service providers have had in implementing the recommendations.

Structure of the report

1.8. Following this introductory section:

- Section two outlines the evaluation approach and methodology;
- Sections 3- 7 outlines the findings in relation to the duties related to
  - diagnostic assessments (section 3);
  - information about and access to autism services (section 4)
  - access to social care assessment (section 4)
  - access to services for autistic individuals with complex needs (section 5)
  - health and social care staff skills and knowledge (section 6); and
  - planning and commission services (section 7)
- section 8 considers the likely impact of the Code;

- Section 9 outlines the conclusions; and
- Section 10 outlines the recommendations.

2. Approach and methodology

Introduction

2.1. A theory based approach to evaluation was taken.[5] This focused upon:

- exploring the requirements of the Code;
- identifying the extent to which practice was compliant with the Code;
- identifying how and why practice had changed, including the extent to which changes in practice could be attributed to the Code and barriers and enablers to change; and
- assessing the likely impact of changes in practice upon autistic adults, autistic children, and their parents or carers.

2.2. This approach, in turn, informed the development of recommendations for improvements in meeting the duties of the Code.

Exploring the requirements of the Code

2.3. The Code is a lengthy document, with overlapping sections and requirements. The language used can also sometimes be somewhat ambiguous. For example, the term 'assessment' is used in the Code to describe both diagnostic and social care assessments, and this has caused some confusion. In order to explore and identify the Code's requirements, the evaluation team undertook multiple close readings of the Code's text and supporting documents, such as the supporting guidance (WG, 2021b) and the evaluation of the SSWBW Act (Welsh Government, 2023a), and discussed stakeholders' interpretation of the text with:

- the Welsh Government neurodivergence improvement programme team[6];
- the Welsh Local Government Association (WLGA) national neurodivergence team (NNT); and

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[5] See for example HM Treasury, 2020 for a discussion of theory based approaches to evaluation.

[6] 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.

- regional strategic autism groups.

2.4. This process started in late January 2023 and continued throughout the evaluation, until the benchmarks for each duty of the Code were finalised in September 2023. Over this period, interpretations of some of the Code's more subjective requirements evolved, through successive discussions with the Welsh Government, the neurodivergence improvement programme team, the NNT and regional strategic autism groups.

2.5. The discussions, and repeated readings of the Code and supporting documents were used to explore both the intention behind the Code (i.e. the desired change or outcomes) and the meaning of the Code's text. This approach was analogous to 'textualism'[7], in which the requirements of the Code were interpreted on the basis of how a 'reasonable' reader would understand the text in context (rather than a strictly literal interpretation)[8]. A series of benchmarks (outlined in the appendix – Annex A) were created to ensure that judgements of compliance against each of the duties, outlined in sections three to seven, were both transparent and consistent across the seven regions. Nevertheless, inevitably there is still a degree of subjective judgement and some examples fall on, or close to, the boundary between different categories.

2.6. The benchmarks took time to develop and as noted, were not finalised until September 2023. Ideally they would have been developed and shared with regions earlier, because, as the report outlines, differing interpretations of the Code and uncertainty about the Code requirements are a key barrier to compliance. However, it took time to identify what constituted compliance, and as the report outlines, there were difficulties where, for example, the plain text of the Code (and what a reasonable reader would understand) appeared to run counter to national models or guidelines.

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[7] See, for example, Molot, 2006, for a discussion of textualism.

[8] For example, the meaning of 'the duty 'Ensure there is information and signposting to access assessment services' was interpreted in context. The reference to 'assessment service' was judged to be a reference to a diagnostic assessment service for autism (rather than, for example, a social care assessment), as the duty was in the chapter covering 'Arrangements for Autism Assessment and Diagnosis'. While the requirements relating to 'information and signposting to access' the service (p. 12 Welsh Government, 2021a), were interpreted given an understanding of how children or adults would normally access an autism diagnostic assessment service.

Identifying the extent to which practice was compliant with the Code and identifying how and why practice had changed

2.7. The evaluation initially reviewed the work each region had undertaken to develop a baseline assessment of their compliance with the Code, in order to identify good practice and also key gaps, where compliance was not clear. Further research was undertaken over nine months (March to October 2023) where gaps were identified. In support of this, the review:

- developed new tools and approaches to help gather primarily qualitative data to inform the evaluation of compliance (see examples in the annexes B, C and D);
- interviewed key stakeholders, primarily staff from Regional Partnership Boards (RPBs), LHBs and LAs including those co-ordinating regional strategies; local authority autism leads; and those with responsibilities for key autism services, such as Children's ND services and the IAS (n=25);
- undertook desk based reviews (e.g. of LA and LHB websites and equalities policies); and
- discussed the evaluation team's assessment of each area's compliance with regional autism strategic groups.

2.8. The evaluation also explored, through interviews and discussions, how and why practice had changed, including the key barriers and enablers.

Assessing the likely impact of changes in practice

2.9. The evaluation took a theory based approach to assessing the likely impact of change in practice, considering factors such as:

- the type, nature and scale of the change in practice;
- the aspirations, experiences and needs of different groups (e.g. autistic adults, autistic children and their parents or carers); and
- the likely impact of changes in practice upon the aspirations, experiences and needs of different groups.

2.10. The approach drew on interviews with stakeholders and a desk based review of prior research, such as previous evaluations of the autism strategy on Wales (Welsh

Government 2019, 2016b) which explored the aspirations, experiences and needs of autistic people and their families in Wales.

Developing recommendations

2.11. The study used the findings on the requirements of the Code; compliance with the Code; and the reasons why practice had or had not changed, along with examples of good and emerging practice[9] within and across the regions, to develop recommendations to improve compliance with the Code.

Strengths and limitations

2.12. This stage one review is a practitioner's perspective upon compliance. However, it does not uncritically accept stakeholders' views. Their views were tested and challenged through, for example:

- interviews and evidence gathered though desk based research;
- the triangulation of responses from different stakeholders; and
- a rigorous theory based approach to evaluating the likely impact of the Code.

2.13. Nevertheless, the review's validity depends to a large degree upon the accuracy and comprehensiveness of stakeholders' assessments of their compliance with the Code. Similarly, assessments of good and emerging practice were very much based upon practitioners' views, albeit views that were tested and challenged by the evaluation team drawing on other data (such as responses from different stakeholders and the wider research literature).

2.14. Moreover, as outlined throughout the report, there are gaps in a number of areas where there was insufficient information to make a firm judgment on compliance. As noted, the length and complexity of the Code proved to be a barrier to assessing compliance as stakeholders' interpretation of the Code sometimes differed and the time needed to work through and assess compliance against each of the duties was considerable.

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[9] Good practice describes practice that was judged by the evaluation team to be appropriate and effective. Emerging practice is used to describe practice that appeared to be both appropriate and effective but where there was insufficient data to make a judgment, with a reasonable degree of confidence.

2.15. 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. This may mean that assessments of compliance are revised, as more information about the lived experience of autistic adults, autistic children and their parents or carers is gathered. This may, for example, reveal gaps between policy intent and policy in practice.

2.16. Furthermore, at this stage, the recommendations focus primarily upon ensuring compliance[10] rather than maximizing the impact of changes or identifying changes that might not be required by the Code but which may be necessary to maximize its impact on how autistic individuals and their families' needs are understood and how they can be supported to achieve their own wellbeing outcomes and to lead fulfilling lives. Better understanding the experiences of autistic individuals and parents and carers will be vital in identifying recommendations to achieve this.

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[10] In some cases, it could be relatively easy to change practice to ensure compliance, but the impact upon the lives and wellbeing of autistic individuals and their parents or carers might be modest. For example, where diagnostic pathways are regularly reviewed but no designated individual with responsibility for this was identified, designating an individual with responsibility (as the Code requires), may have little impact, beyond ensuring compliance with the Code on paper.

3. Compliance with the Code of Practice on the Delivery of Autism Services: Section 1, Duties relating to diagnostic assessment

Introduction

3.1. A diagnostic assessment can be important for an autistic person’s sense of self and identity; it can help inform the choice of interventions to support them and improve access to support; and it can help people assert their right to reasonable adjustments (NHS, 2023). As outlined in the introduction, the evaluation of the Autism Spectrum Disorder (ASD) Strategic Action Plan (Welsh Government, 2019) identified improvements in access to diagnostic assessment following the establishment of the children’s ND service and IAS but also highlighted demand-capacity gaps which were putting pressure upon diagnostic assessment services.

3.2. Section 1 of the Code includes eight duties covering diagnostics assessments, including:

- pathways to diagnostic services (including for those in the secure estate) and post diagnostic support and further assessments;
- ensuring diagnostic assessments take account of National Institute for Care Excellence (NICE) best practice guidance for multidisciplinary involvement; and
- compliance with the national waiting time target for children[11] (Welsh Government, 2021a).

Diagnostic assessment services

3.3. A number of different services undertake diagnostic assessments, most commonly:

- children’s ND services which offers diagnostic assessments for children (up to the age of 18);
- the IAS, which offers diagnostic assessments for adults not eligible for an assessment by Learning Disability (LD) or Adult Mental Health (AMH) services; and

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

- LD and Mental Health (MH) services for adults (with a LD or MH condition).

3.4. As table 3.1. illustrates, compliance with the Code differs for these different types of diagnostic assessment services. The benchmarks used to judge compliance against are included in the appendix - Annex A.

Key to tables 3.1. (and also tables 4.1, 4.2, 5.1 6.1 and 7.1)

🟩 Full compliance + (including going above and beyond the Code requirements)	🟩 Good progress (but not full compliance with the Code)	🟧 Mixed or limited compliance to date	▨ No / insufficient evidence to evaluate compliance	🟥 Clear evidence of non-compliance	Not applicable

Table 3.1. Section 1 of the Code: Access to diagnostic assessment services and post diagnostic support

Duty	Notes	Cardiff & Vale	Cwm Taf Morgannwg (CTM)	Gwent	N Wales	Powys	West Glam	West Wales
LHBs must: 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.	ND	🟩	🟩	🟩	🟩	🟩	🟩	🟩
	IAS	🟩	🟧	🟩	🟩	🟩	🟩	🟩
	AMH	🟩	⬜	⬜	⬜	⬜	⬜	🟩
	LD	⬜	⬜	⬜	⬜	⬜	⬜	⬜
LHBs must ensure that autism assessment and diagnostic services are accessible by individuals detained in the secure estate.	Children	⬜	🟧	⬜	N/A	N/A	⬜	N/A
	Adults	⬜	🟧	🟩	⬜	N/A	⬜	N/A
LHBs must: Ensure that primary and secondary care practitioners are notified of assessment referral pathways for children, young people and adults.	ND	🟩	⬜	🟩	🟩	🟧	⬜	🟧
	IAS	🟩	🟩	🟩	🟧	🟧	🟩	🟧
	AMH/LD	🟧	🟧	⬜	⬜	⬜	⬜	🟧

Duty	Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
LA with LHBs must: Designate an individual with lead responsibility for maintaining, reviewing and promoting diagnostic pathways for children, young people and adults.	ND	🟧	⬜	🟩	🟩	🟩	⬜	🟩
	IAS	🟩	🟥	🟩	🟩	🟩	🟧	🟩
	AMH	🟩	⬜	⬜	⬜	⬜	⬜	🟩
	LD	⬜	⬜	⬜	⬜	⬜	⬜	⬜
LHBs must: Comply with current national waiting time standards for assessment and diagnosis.	ND	🟥	🟥	🟥	🟥	🟥	🟥	🟥
LHBs must: Ensure the collection of information on waiting times for assessment for children, young people and adults complies with current national waiting time standards for autism assessment and diagnosis.	ND	🟩	🟩	🟩	🟩	🟩	🟩	🟩
	IAS	🟩	🟩	🟩	🟩	🟩	🟩	🟩

Duty	Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
LHBs must: Where a diagnosis of autism is made, with the individual's consent (or for most children their parent or carer) a referral is made promptly to post diagnostic support assessments, to be undertaken, if appropriate OR Where an assessment of autism is undertaken but a diagnosis is not made, if the assessment indicates it to be necessary, with the individual's consent (or for children that of their parent or carer) a referral is made for further investigation	ND	🟩	⬜	🟩	🟧	🟩	⬜	🟧
	IAS	🟩	🟩	🟩	🟧	🟩	🟩	🟩
	AMH/LD	⬜	⬜	⬜	⬜	⬜	⬜	🟧

Referral pathways

3.5. As table 3.1. illustrates, across the seven regions awareness of diagnostic assessment and referral pathways differs for different services:

- a national pathway for children's ND services was established in 2015. The very high level of referrals to the service indicates that people are accessing them. However, the specific pathway for each children's ND service (in the sense of the description of the sequence or process through which a referral is made, considered, accepted or rejected, a diagnostic assessment and decision is undertaken and feedback provided), is rarely published. Moreover, stakeholders sometimes raised concerns about difficulties accessing ND services, although this could be an inherent feature of the pathway[12], rather than due to a lack of awareness of the pathway;
- a national pathway for the IAS was established in 2017 and pathways to individual IASs are generally clear and well publicised on LHB websites; and
- 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.

Children's ND services and the IAS

3.6. As table 3.1. illustrates, in relation to children's ND services and the IAS, for most duties regions are compliant. This reflects the investment in these services since 2015, the establishment of national pathways and, in the case of the IAS, a national model means that, in effect, the Code simply sets out existing practice and has, therefore, led to little change. 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, mean services are under considerable pressure

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[12] For example, where access was limited by the information required (by the pathway) to evidence signs and symptoms, pervasiveness, impact on functioning and/or by who and how referral needs to be made.

(ibid.) which may threaten the sustainability of teams and services and continued compliance with the Code; and

- pressures upon services have constrained services', and in particular children's ND services', capacity to provide pre and post assessment support.

Examples of good and emerging practice

The national models for the Children's ND Service and the IAS are both based upon NICE Guidelines which includes guidance for multidisciplinary involvement. However, difficulties some services face recruiting and/or retaining staff and high levels of demand can make it difficult to sustain the levels of multidisciplinary involvement in diagnostic assessments that NICE recommends. There are generally no easy answers to these challenges, but the findings and recommendations of the Review of Neurodevelopmental Services (WG, 2022) and the recent review of ND services undertaken by the NHS Delivery Unit are both important here.

LD and AMH Services

3.7. In relation to other services that undertake diagnostic assessments, such as LD and AMH services, there is much less confidence that regions are compliant with the Code. Unlike the IAS and (to a lesser degree) children's ND services, these services have not benefited from the same level of national attention; the development of national pathways and models; and dedicated investment. Historically, there has been greater expertise and experience of diagnostic assessment for autism in LD services, compared to AMHS (Welsh Government, 2016). However, there is little evidence that practice in these services has been scrutinised by regional strategic autism groups, which have instead focused upon the IAS and children's ND services. The picture in relation to AMHS is more complex. 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. Indeed, there is some suggestion of a weakening of AMHS in one region, as attention and clinicians moved to the IAS. The Code should be increasing regional scrutiny of practice in these services but there is little evidence that this is happening. Instead, regional strategic autism groups have focused primarily upon the IAS. Therefore, there is little evidence that, at this stage, the Code had led to changes in practice in LD and AMH services.

Examples of good and emerging practice

In West Wales, diagnostic assessments for adults experiencing moderate to severe mental health difficulties are provided by the Autism Spectrum Disorder (ASD) service (in AMHS). There is a single point of access for both the IAS and ASD service, with the same referral form for both services and cases are allocated to either the IAS or ASD service at the point of referral. The ASD service offers a multi-disciplinary assessment with involvement from clinical psychology, psychiatry, speech and language therapy, occupational therapy and a specialist nurse. The IAS's offer of post-diagnostic support is available to those assessed either by the IAS or the ASD service.

Access to a diagnostic assessment in the secure estate

3.8. There is considerable uncertainty about the duties in the Code 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[13]. For both children and adults, the responsibility for providing access to diagnostic assessments rests with the LHB where the secure estate is located[14]. In Wales there are:

- one young offender institution (YOI), Her Majesty's Prison (HMP) Parc, in Bridgend which has a unit for 15-17 year olds and Hillside Secure Children's Home in Neath, so responsibility lies with Swansea Bay and Cwm Taf Morgannwg LHBs; and

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[13] This uncertainty about responsibilities does not appear to be specific to autism services in the secure estate (see e.g. Senedd, 2021).

[14] In April 2006, LHBs became responsible for commissioning healthcare for public sector prisons in their area.

- five prisons housing adults in Wales: Her Majesty's Prison (HMP) Cardiff, HMP Parc, HMP Swansea, HMPs Usk and Prescoed and HMP Berwyn, so responsibilities for adults rest with Cardiff and Vale, Swansea Bay, Aneurin Bevan and Betsi Cadwaladr LHBs.

3.9. However, in relation to children, the re-organisation of the Swansea Bay and Cwm Taf Morgannwg LHBs has added to the uncertainty about where responsibility lies[15].

3.10. Practice in relation to adults is inconsistent and poorly understood by strategic groups. For example, in one region it was reported that there was a part time post in the prison with links to the IAS, with support from the forensic team. However the arrangements are fragile and can be dependent upon an individual with an interest in autism and availability. In another region it was reported that there were no pathways for diagnostic assessments for adults in the prison in their region. It was also reported in one region, that a prison is a challenging environment within which to do a diagnostic assessment.

Data collection and the oversight of services

3.11. Data collection requirements differ for each service. The IAS is subject to the most comprehensive data collection, with data collected by Data Cymru and reported to the National Neurodivergence Team. The children's ND service is required to collect data on the national waiting time target for children but there is no other national data collection. In the absence of a more comprehensive national data set, the NHS Delivery Unit has been working with children's ND services to improve data collection on demand and capacity. There are no specific duties (in the Code) covering data collection by LD and AMH services. The lack of data on these services is a key constraint on understanding their performance.

3.12. Although there are examples like West Wales (Hywel Dda LHB) where the Children's ND service and the IAS sit within the same directorate, in most cases they are separate and oversight of the services is also separate. Therefore, while individual clinicians were often identified as having responsibility for reviewing pathways for their service, it was not possible to identify a named individual for all services nor

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[15] Responsibility for secondary and tertiary health care services in Parc prison passed to Cwm Taf Morgannwg UHB following a boundary change on 1 April 2019.

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 (including Children’s ND, IAS, MH and LD service pathways).

3.13. Moreover, regional autism strategic groups have tended to focus upon the children’s ND service and IAS, meaning practice within LD and AMH services have not been subject to the same degree of scrutiny and oversight. One of the effects of the Code has been to cast a spotlight upon pathways to, and practice in, these services.

4. Compliance with the Code of Practice: Sections 1 and 2, duties relating to information, advice and support and access to social care assessments

Introduction

4.1. Autistic individuals and their parents and carers may have health and/or care and support needs and it is, therefore, important that they can access information, advice and support including social care assessments. As outlined in the introduction, the evaluation of the ASD Strategic Action Plan (WG, 2019), identified problems with access to social care and sections 1 and 2 of the Code include six duties covering information, advice and support and access to social care assessments, including that local authorities and/or health boards ensure that:

- 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'; and
- 'that as part of their Information, Assistance and Advice [IAA] Service information is available on local autism services' (pp. 12-33, 22-22, Welsh Government, 2021a).

Access to a social care assessment[16]

4.2. As table 4.1. illustrates, although there is generally signposting to social care assessment services, regions have consistently failed to demonstrate that they ensure that autistic people are aware of the right to access a needs assessment and a carer's assessment for a carer; or that people in the secure estate can access a social care assessment.[17]

4.3. As table 4.2. illustrates, information on how to access social care assessments, usually via IAA services, is generally well publicised on LA websites, although it can

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

[17] A LA is responsible for the care and support needs of a Welsh child who was resident in the LA before entering the secure estate. Whereas, the LA where the secure estate is located, is responsible for the care and support needs of an adult in the secure estate (Social Care Wales, 2017).

be difficult to find. Moreover, in the judgment of the evaluation team, no region consistently ensures that all autistic people are aware of the right to access a needs assessment and a carer's assessment for a carer[18]. Stakeholders from health services typically report 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[19] as it is felt likely that they would not have 'eligible needs' for care and support.[20] In such cases stakeholders questioned how telling everyone who may have a care and support need that they have a right to an assessment would help them and were concerned that this would increase pressure upon social services.

Examples of good and emerging practice

Autistic individuals and/or their parents or carers, who have care and support needs, may not realise they can access help and support. Strategies to increase awareness, and the take up, of support include:

- providing information automatically rather than relying upon professionals' discretion or judgment about whether and when to share information, for example, in Cardiff and Vale, information about an individual's right to a social care assessment is included in the IAS's post-diagnostic feedback forms (which everyone receives);
- pro-actively reaching out to autistic individuals and/or their parents or carers, using online and face to face methods, for example:
  - in Cardiff, when people sign up to The Index, a voluntary register for children and young people with disabilities or additional needs, the welcome

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[18] As outlined in the SSWBW Act 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'.

[19] 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.

[20] 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.' (p.1. Social Care Wales, 2017).

email includes information about parent/carer assessments and how to access them; and

- in Torfaen, the Autism Support Officer who works with parents and carers of autistic children shares information about accessing social care assessments, when she talks to families and can act as a liaison between families and services; and

- helping autistic individuals and/or parents or carers understand or identify that they might be eligible for help and support from social services and making it as easy as possible to access assessments, for example, the Rhondda Cynon Taf County Borough Council (RCT CBC) website provides examples of the sorts of reasons why someone might need help and support from social services.

4.4. Practitioners also play a key role in providing information and signposting people to assessment services. However, as noted above, it was reported that they exercise judgment about whether to refer people. Moreover, for children, the development of a single point of access, such as the SPACE-WB panel, which is seen as good practice (see e.g. Children's Commissioner for Wales 2020), may mean that referrals are not directly made to social services, as the Code suggests they should be, but instead go via panels, who may make a further referral to social services. This is consistent with the spirit, although arguably not the letter (or text), of the Code[21]. The Welsh Government has confirmed that despite the wording of the Code, it would be considered compliant with the Code.

4.5. The 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) are generally not reported. Linking this into wider LA and LHB awareness raising work and training for staff in how to refer people to IAA services is likely to be important.

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[21] 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).

4.6. The skills staff require to undertake a social care assessment are considered in section six.

Information sharing between diagnostic and social care services

4.7. There was generally reported to be better information sharing between autism diagnostic services and social care services for children compared to adults. This was reported to be because often when a child is referred for a diagnostic assessment, the child and family are already known to social care services such as Families First. These services usually continue 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 not already known to these services).

Table 4.1. Section 1. Access to a social care assessment

Duty	Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
LAs must: Ensure there is information and signposting to access assessment services.		🟩	🟩	🟧	🟧	🟩	🟩	🟧
LAs must: Ensure that autistic people are aware of the right to access a needs assessment and a carer's assessment for a carer. The process of obtaining these should align with the diagnosis.	Children	🟧	⬜	🟥	🟧	🟧	🟧	🟥
	IAS	🟩	🟥	🟥	🟧	🟧	🟧	🟥
	AMH/LD	🟧	⬜	🟥	⬜	⬜	⬜	🟥

Duty	Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
LA and LHBs must: Ensure that where an assessment of autism is undertaken and a diagnosis is / 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: LA and LHBs must: Ensure prompt sharing of information between autism diagnostic services and social care services about the needs of children and adults diagnosed with autism where it is indicated that additional support may be required. LA and LHBs must: Ensure prompt sharing of information between autism diagnostic services and social care services about children and adults not diagnosed but where it is indicated necessary that a referral for further assessment is required	Children	🟧	⬜	🟧	🟧	🟩	⬜	🟩
	IAS	🟩	🟩	🟧	🟧	🟩	🟩	🟧
	AMH/LD	🟩	⬜	🟧	⬜	⬜	⬜	⬜

Duty	Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
Local Authorities with Local Health Boards and NHS Trusts must: Ensure there are pathways for further assessment after referral within the secure estate to ensure young people and adults who are detained can access assessment services and social care support	Children	▨	▨	▨	▨	▨	▨	▨
	Adults	▨	▨	🟩	▨	N/A	▨	N/A

Information about autism services

4.8. The duties in relation to autism services, other than diagnostic assessment services[22] discussed in section 3, generally focus upon information about, rather than the provision of, autism services. This means (somewhat perversely) that having fewer services is likely to make compliance easier.

4.9. Evaluating compliance is difficult because ‘autism services’ are not defined by the Code and the term is open to interpretation. 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[23] as they do not only work with autistic individuals and/or their parents and carers, such as:

- ND, AMH and LD services (discussed in section 3);
- 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, and also autistic adults.

4.10. 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 websites. This is important, because these websites (along with IAA services discussed below) are a key vehicle for disseminating information about local services and, unless someone knows what to search for, it can be difficult to identify LA and LHB ‘autism services’[24].

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[22] 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).

[23] I.e. ‘autism’ does not feature in the name of the service.

[24] 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 help and support autistic individuals and their parents or carers.

Examples of good and emerging practice

Given the breadth and diversity of 'autism services' there is a wide range of people, including local autism leads, services such as the IAS (as in Cardiff and Vale and Gwent), the third sector and LA and LHB staff such as Community Connectors (as in Pembrokeshire), or disability navigators (as in Denbighshire) who all have an active role in identifying local autism services and ensuring that IAA services understand the range of services in their area.

Creating directories of services and/or dedicated websites can be helpful, although they need to be updated regularly. For example:

- Dewis Cymru is widely used;
- RCT CBC have published a directory of autism services;
- Bridgend has a regularly updated directory of autism services and all staff have an icon on their computer to access it; and
- Flintshire, Conwy, Denbighshire and Neath Port Talbot all have (or are developing) dedicated webpages to bring together information about local autism services.

It is also important to ensure that information about autism services is embedded in other websites that people will go to for information and to access support. for example:

- partners, led by parent/carer groups, are developing an autism hub across the four sub-regions of Neath Port Talbot. This draws upon the example of Swansea Info-Nation which provides information and advice on mental health and wellbeing to young people.

Developing autism expertise within IAA services can also be important: for example:

- Bridgend CBC is also working on embedding autism IAA into all general IAA the LA offers; and

- in Cardiff and Vale, an autism IAA service is provided by the IAS.

Table 4.2. Section 2. Access to information about autism services

Duty	Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
LHBs Must: Ensure that primary and secondary healthcare practitioners are aware of the autism services available in their local areas and have clear pathways for referral. AND Make arrangements to ensure that health services are aware of the autism services available in their local areas and have clear pathways for referral	Children	🟨	🟨	🟩	🟨	🟨	⬜	🟨
	Adults	🟨	🟨	🟨	🟨	🟨	🟨	🟨
LAs with LHBs should: Ensure that health and local authority staff are aware of the Information, Advice and Assistance service and how to refer autistic people to the service		🟨	🟨	🟨	▨	🟨	🟨	🟨

Duty	Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
LAs must: Ensure that as part of their Information, Assistance and Advice Service information is available on local autism services AND As part of their duties under the SSWBW Act, ensure the Information, Assistance and Advice Service provides information on local autism services.		🟩	🟢	🟢	🟢	🟢	🟢	🟢
LAs with LHBs should: make arrangements to ensure a range of autism awareness information, resources and training is made publicly available.	Children	🟨	🟢	🟢	🟢	🟨	🟨	🟨
	Adults	🟨	🟢	🟨	🟢	🟨	🟨	🟨
LA and LHBs must: Ensure that reasonable adjustments are in place for autistic people to ensure they are able to access services in the same way as everyone else.		🟨	🟨	🟨	🟨	🟨	🟨	🟨

Key factors shaping information about autism services

4.11. A number of developments that predate the Code have improved information about autism services. These developments (outlined below) have not simplified the policy landscape but they have improved information about it. In particular:

- local autism leads, established in response of the first autism strategic action plan in 2008, whose 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 establishment of Dewis Cymru and, in each LA, IAA services, in response to the SSWBW Act 2014; and
- the establishment of the IAS, following the refreshed autism strategic action plan in 2016, which offers support and advice for autistic adults, parents and carers and professionals, although its offer of support varies from region to region.

5. Sections 1 and 2 of the Code: Duties relating to access to needs based services (e.g. for those with co-occurring conditions)

5.1. Many autistic individuals have co-occurring conditions[25] and are sometimes described as having 'complex' needs, in part because they do not easily 'fit' into existing service structures. Historically, those who have a learning disability and autism have generally been able to access LD services (Welsh Government, 2016b). However, there have been longstanding concerns about autistic children and autistic adults' access to Child and Adolescent Mental Health Services (CAMHS) and AMHS and to other services such as eating disorder services (see e.g. Senedd, 2018; Children's Commissioner for Wales, 2020, 2023). This reflects a number of interlinked factors that can limit an autistic individual's access to these services including:

- gaps in staff knowledge, skills and confidence which can mean they are reluctant to support autistic individuals;
- the way in which an individual's problems, such as their mental health difficulties, can be attributed to their autism, rather than causes such as traumatic experiences which services are more confident addressing; and
- the pressures upon services, which has led to thresholds for access being raised.

5.2. In response, sections 1 and 2 of the Code include five 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:'
- that 'awaiting a diagnosis is not a reason to be refused support and other services'; and

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[25] For example, as the English national autism framework identifies, "None of the individual autism diagnostic criteria are exclusive to autism' and ' autism also co-occurs with other conditions more often than it occurs as a sole diagnosis" (NHS, 2023).

- ‘that [intelligence quotient] IQ is not considered as part of the eligibility criteria for a needs assessment under the SSWBW Act’

Access to services, diagnosis and IQ

5.3. As table 5.1. illustrates, stakeholders consistently reported that LAs and, to lesser degree, LHBs have, or are moving toward, need rather than diagnostic or IQ based services. However:

- there was some confusion amongst stakeholders about the use of IQ as an eligibility criteria 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 them[26]; and
- while 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. Moreover, because the (national) IAS eligibility criteria are defined by ineligibility for secondary services (i.e. AMH and LD services) (WLGA, 2020), in effect, access to diagnostic services for adults is still defined by conditions (i.e. whether someone had a LD or MH difficulty that meets the threshold for secondary care).

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[26] 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.

Table 5.1 Access to needs based services

Duty	Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
LAs and LHBs must: Ensure that awaiting a diagnosis is not a reason to be refused support and other services.	Children	🟩	🟥	🟢	🟧	🟢	🟧	🟩
	Adults	🟢	🟥	🟧	🟧	🟧	🟧	🟩
LAs and LHBs must [ensure that]: 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	Children	🟢	🟧	🟢	🟧	⬜	⬜	🟢
	Adults	🟢	🟧	🟧	🟧	⬜	🟢	🟢
LHBs must: Ensure that people with an Autistic Spectrum Condition with co-occurring conditions are not excluded from Children or Adults Mental Health Services (CAMHS). Consideration of core ASC indicators and their influences on individuals must inform the care and support offered and its outcomes	Children	🟢	🟧	🟧	🟧	⬜	⬜	🟢
	Adults	🟢	🟧	🟧	🟧	⬜	🟧	🟢

Duty	Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
LAs must: Ensure that IQ is not considered as part of the eligibility criteria for a needs assessment under the SSWBW Act.	LA	🟧	▨	🟩	🟩	🟩	▨	▨
LHBs must: ensure IQ is not considered as part of the eligibility criteria	LHB	🟥 *	▨	▨	🟧	🟩	▨	▨

*Although progress is being made on what is seen as a historical issue, that is now being addressed.

Key Factors shaping access to services for autistic children (0-17) with co-occurring conditions

5.3. Stakeholders report that a number of factors have improved access to services for children and young people with co-occurring conditions. These include:

- the development and roll out of the NEST framework[27] 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[28] panel in Gwent; and
- advice and training for CAMHS which has helped increase practitioners' skills and confidence supporting autistic children.

5.4. The ways in which the 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 [29]– into wider policy (see boxed text).

Mainstreaming autism in policy

In many regions, compliance with the Code will require, or will be more effectively achieved, if autism is mainstreamed into wider policy. For example:

- access to services for autistic children with complex needs should be improved by regional work to take forward the NEST framework and 'no wrong door' recommendations;
- autism training for the social care workforce should be supported by the Social Care Workforce Development Programme;
- actions to ensure that there is information and signposting to access assessment services and that autistic people who may have care and support

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[27] NEST is based upon the principles: ' Nurturing - taken care of and cherished'; 'Empowering - feeling strong and listened to'; ''Safe - feeling protected and able to be yourself' and 'Trusted - reliable and there for you' and is usually referred to as the "NEST framework'. (Welsh Government, 2023b).

[28] This is the Single Point of Access for Children's Emotional Wellbeing, but is usually referred to as "SPACE-WB".

[29] The 'gender mainstreaming' model may be useful here in ensuring that an autistic – or neurodiverse - perspective is 'incorporated in all policies at all levels and at all stages, by the actors normally involved in policy-making.' (Council of Europe, 2023).

needs are aware of their right to a needs assessment, should be part of wider LA strategies to meet the duties to all people, under the SSWBW Act[30]; and

- actions to ensure reasonable adjustments are made and services are more inclusive for autistic individuals should be an integral part of LA and LHB equality, inclusion and diversity policies.

Regional strategic groups may have a key role in engaging with these programmes and policy areas to ensure that the needs and interests of autistic individuals and their parents and carers are considered when policy is developed, delivered and evaluated.

5.5. Compliance with the Code’s duties in relation to access to services for children with co-occurring conditions is reported (by stakeholders) to be strongest where the implementation of the NEST Framework is most developed. Given historic difficulties, further investigation of the experiences of children and young people with complex needs is warranted in the second phase of the evaluation.

Key factors shaping access to services for adults with co-occurring conditions

5.6. Progress in relation to access to services for adults with complex needs has been uneven. Stakeholders report that where progress has been made it has been supported by:

- the establishment of the IAS which can support adults who are not eligible for secondary services such as AMH or LD services (but who may still have MH difficulties or mild LD). However, it is important to note that, in line with the national model, the IAS does not support autistic adults who are accessing secondary MH or LD services; and
- awareness raising work, training and consultations particularly with AMHS (discussed below).

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[30] For example, this could be integrated into campaigns such as ‘Do you look after someone?’, focused upon raising awareness of carers rights and support services.

5.8. 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.

Examples of good and emerging practice

Two key factors can support access to support to services for people with co-occurring needs:

- a single point of access to services, to reduce the risks that people get ‘bounced’ between services; and
- collaboration between services to help ensure that, for example, professionals have easy access to the expertise they need to support individuals with co-occurring conditions. This in turn can help ensure that they have the confidence to support individuals with co-occurring conditions.

Single points of access to health services, such as Gwent’s SPACE-WB panel, have been strongly advocated by the Children’s Commissioner for Wales, and are much more common for children than they are for adults. Nevertheless, there are examples in adult health services, such as the single point of access to both the ASD and IAS services in West Wales.

The most frequently identified example of collaboration between services to provide easy access to expertise, was collaboration between the IAS and AMHS in areas such as Cardiff and Vale. Other notable examples include:

- the collaboration between the IAS and the adult ASD service in West Wales. The IAS and the adult ASD service were initially merged to create ‘IAS Plus’, providing a single point of access for diagnostic autism assessments for both adults who meet, and those who do not meet, eligibility criteria for statutory MH services. However, steps are now being taken to also increase diagnostic capacity in CAMHS and in AMHS, such as CMHTs (meaning more diagnostic assessments can be done in these services). Some staff in these services have been trained in diagnostic assessment, and arrangements made for them to attend the Children's ND or the joint IAS/ADHD multi-disciplinary team forum to help with case formulation. In addition, shadowing opportunities in the IAS, are provided for clinicians in AMHS to consolidate their practice by observing diagnostic assessments. They can then lead on their own diagnostic assessment under supervision, until they feel confident and competent. In addition, two MH practitioners (nurses from CMHTs) are employed within the IAS using NDIP funding and are reported to be markedly strengthening the IAS's interface with MH services; informing practice around MH issues in the IAS; and enhancing the IAS's pre and post diagnostic support offer.

- Similarly in West Wales there is close collaboration between the IAS and the adult Attention Deficit Hyperactivity Disorder (ADHD) services, given the frequency with which autism and ADHD co-occur. The services are co-located and are seeking to align and offer a single point of contact/access for all referrals. It is reported that the majority of Clinicians within the IAS and Adult ADHD service are now dual diagnosis trained, which means the services will be able to offer diagnostic assessment of both ADHD and ASD in a timelier manner and allows for more joined up working to explore primacy of need at point of referral; and
- in Gwent, there is reported to be a good working relationships between the IAS and LD service, which are effectively co-located on the same floor in the same building.

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

6.1. As the ministerial forward to the Code identifies ‘it is important that the way in which autistic people and those with other neurodiverse conditions communicate and interact with the world is understood’ (Welsh Government, 2021a). This is vital to ensure that services and society are ‘kinder’ and more inclusive (e.g. by ensuring that reasonable adjustments are made). In response, sections 1, 2 and 3 of the Code include 11 duties intended to ensure that, for example:

- ‘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

6.2. Stakeholders reported examples of events to raise public awareness of autism. However, the focus to date has generally been upon improving access to information for autistic individuals and their families and practitioners (such as health and social care staff), rather than the general public.

Staff skills, knowledge and confidence

6.3. As table 6.1. illustrates, compliance with the Code’s duties in relation to staff training varies. It is reported that good progress has been made in:

- offering general autism awareness training to health and social care workforces, and in several LAs this training is now mandatory;

- offering higher level training to those undertaking social care assessment[31]; and
- ensuring that staff in Children's ND services and the IAS undertaking diagnostic assessments have the skills and competence required [32].

6.4. The development of training by the National Neurodivergence Team (formerly the National Autism Team) has supported this but there have also been important local initiatives, often driven by autism leads, that predate the national training framework (see e.g. Welsh Government 2019, 2016). 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.

6.5. However, the Code also requires that LAs with LHBs and NHS trusts 'should as part of workforce planning, assess the autism training needs of **all their staff** who are working in health and social care and identify the level of training required according to their job roles and responsibilities' and 'make arrangements to ensure that **all staff** can access the training identified to meet their autism knowledge and awareness training needs' (emphasis added) (p. 31, Welsh Government 2021a). There are, as outlined above, examples of good practice in relation to specific staff groups but, with the exception of one LA, little evidence reported by interviewees of workforce wide training needs analyses and the development of training plans, to address gaps, at this stage. However, a survey of workforce development managers, suggested that while often still a work in progress, this was being taken forward in most LAs. Linking this work into wider workstreams, such as the Social Care Workforce Development Programme is likely to be important.

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[31] For example, LAs are required to 'Ensure that any person carrying out a needs assessment under the SSWBW Act has the skills, knowledge and competence to carry out the assessment. Where the assessor does not have experience in the autism condition, the local authority must ensure that a person with that expertise is consulted.' (p. 30, Welsh Government, 2021).

[32] For example LHBs are required to 'Ensure that any person carrying out an assessment of autistic spectrum condition with an individual has the knowledge, skills and competence required, to undertake the assessment and provide a diagnosis' (p. 30, Welsh Government, 2021). However, less is known about the skills, knowledge and experience of staff in LD services (although there is generally felt to be the skills, knowledge and experience needed) and AMHS (where skills, knowledge and experience has tended to be rest with individuals, rather than services as such).

Examples of good and emerging practice

Monmouthshire council provides autism training to the whole LA workforce (beyond social care). They use the NAT questionnaire as part of staff induction to assess autism awareness and use the NAT autism training framework with the training team for social care. The NAT online training and communication module is mandatory across the LA and staff are required to have autism awareness certificates; and they have set up a platform which monitors training and ‘pings’ people when they haven’t done some training or need an update.

Moreover, as a result of the Code, the Monmouthshire autism lead started a six monthly ‘let’s talk autism’ session for LA staff. The session focuses upon sharing information, ‘firefighting’ and offering advice. These sessions have also been run with police services.

6.6. In addition, the Code 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 National Neurodivergence Team has been co-produced, so using this training helps ensure compliance. There are also examples of involving autistic people in developing specific training for a LHB or LA, but this is not reported to be done consistently across LHBs or LAs.

Table 6.1. Section 3. Workforce development and training

Duty	Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
LAs and LHBs must: Ensure that autism awareness training is included in general equality and diversity training programmes offered for all staff working in health and social care.	LA	🟩	🟧	🟩	🟧	🟩	🟧	🟩
	LHB	🟧	⬜	🟩	🟥	⬜	⬜	🟩
As part of workforce planning [LA and LHBs should], assess the autism training needs of all their staff who are working in health and social care and identify the level of training required according to their job roles and responsibilities	LA	🟩	🟧	🟧	🟧	🟧	🟧	🟧
	LHB	🟧	🟧	🟧	🟧	🟧	⬜	🟧
LHBs must: Ensure healthcare professionals have the knowledge and training in autism they need to undertake their roles, where relevant engaging with specialist professional registration bodies.		⬜	🟧	🟧	🟧	⬜	⬜	🟧

Duty	Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
LA and LHBs must: Ensure that health and social care support for autistic people detained in the secure estate is provided by appropriately trained practitioners	Children	⬜	⬜	⬜	🟧	⬜	⬜	⬜
	Adults	⬜	⬜	🟩	🟧	N/A	⬜	N/A
LAs must: Ensure that where services are commissioned local authorities must ensure autism services are provided by appropriately trained and skilled staff.		🟩	⬜	⬜	🟧	⬜	⬜	🟧
LAs and LHBs must: Make arrangements to ensure that all staff can access the training identified to meet their autism knowledge and awareness training needs.	LA	🟩	🟥	🟧	🟧	🟧	🟧	🟧
	LHB	🟧	🟥	🟧	🟧	🟧	⬜	🟧
LHBs must: Ensure that staff receive appropriate training in autism and associated behaviour and sensory needs at a level appropriate to their involvement	Children's ND and IAS	🟩	⬜	🟧	🟧	🟧	⬜	🟧
	Other services	🟧	🟥	⬜	⬜	⬜	⬜	🟧

Duty	Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
LAs and LHBs should: Where the need for specialist training is identified, ensure that training provision takes account of National Institute for Health and Care Excellence (NICE) guidelines.		⬜	⬜	🟩	🟩	⬜	⬜	⬜
LHBs must: Ensure that any person carrying out an assessment of autistic spectrum condition with an individual has the knowledge, skills and competence required, to undertake the assessment and provide a diagnosis.	Children's ND service	🟧	⬜	🟩	🟧	⬜	⬜	🟩
	& the IAS	🟩	🟩	🟩	🟧	⬜	🟩	🟩
	LD & MH services	🟧	🟧	⬜	🟧	⬜	🟧	⬜
LAs must: Ensure that practitioners assessing an autistic individual's eligibility for social care services have sufficient knowledge and skills to understand the impact of autism on the individual's ability to achieve the five elements of well-being without care and support.		🟩	🟧	🟩	🟩	⬜	🟩	🟩

Duty	Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
LAs and LHBs should: Ensure that autistic people and their parents and carers are involved in the development and delivery of autism training. This may include consultation *on training materials or involvement in delivery of training.		🟩	🟧	🟩	🟩	⬜	🟩	🟧

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

7.1. RPBs are responsible for ensuring there are services, care and support in place to meet the needs of people in their local area. Strategic planning and commissioning should underpin each of the Code's duties and also a range of other complementary actions not covered (or required) by the Code but which are needed to meet people's needs. Sections 3 and 4 of the Code include five duties covering a range of areas 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 Assessments and Area Plans';
- encouraging 'innovation' and the provision of specialist services; and
- monitoring and data collection.

Strategic and operational teams

7.2. 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[33], however:

- they tend to focus upon the children's ND service and IAS and, as noted, scrutiny of, and a role developing, other autism services was generally limited;
- they did not always include LHB and/or LA representatives with responsibility for implementing the Code and sufficient seniority to inform service development;
- the relationship between the autism strategy group, the RPB and other RPB strategic groups was not always clear. In part 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

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[33] Operational groups were much less visible.

cutting remit but for a particular age group, such as children and young people, adults or older people[34]; and

- the direct involvement of people with lived experience was often limited and links between the strategic group and local autism leads and local stakeholder groups were not always clear.

7.3. The introduction of the Code has helped increase the profile of some strategic groups and encouraged greater engagement by senior LHB and/or LA representatives. It has also empowered some staff, such as autism leads, who can point to the legal duties placed upon LA and LHBs. The introduction of the Code also helped give some groups a clearer purpose (as they focused upon assessing compliance), although the breadth, length and complexity of the Code may have 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 also 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 51 individual duties.

7.4. The Code Guidance suggests that ‘strategic autism steering groups’ should be made up of ‘members …of sufficient seniority to inform service development’ while ‘operational steering groups…[should] include and represent autistic people and can inform service improvement’. However, (somewhat confusingly) the duty says that LAs and LHBs must ‘Develop strategic and operational teams which include autistic people to inform service development.’ [35] (p. 34, 36. Welsh Government 2022a). Moreover, the Supporting Guidance, which includes a diagram on page 70 outlining the relationships between different groups, does not mention ‘operational groups’

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[34] For example, this raises questions about which sub-group(s) of the RPB, regional autism strategic groups should report to and through.

[35] Therefore, there was some confusion over whether autistic individuals should be members of strategic groups or not.

(Welsh Government 2022b). This may help explain why there were generally few examples of, and much less clarity about the role of 'operational groups' and how they related to 'strategic groups' at a regional level, although in many areas local autism stakeholder groups fulfil a role that is analogous to that outlined in the guidance.

7.5. 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.

7.6. 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, it is reported by stakeholders 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 used[36].

Population Needs Assessments and data collection

7.7. While autism is considered in Population Needs assessments (PNAs) in each region, with a few exceptions (such as Cardiff and Vale and North Wales), the extent to which PNAs include a robust assessment of:

- the extent to which autism needs are not being met;
- the range and level of autism services required to meet identified needs;
- the range and level of autism services required to deliver the preventative services required; and

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[36] 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.

- how autism services will be delivered taking into consideration population, culture and language with specific reference to the Welsh language (Welsh Government, 2021a),

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.

Examples of good and emerging practice

North Wales PNA has one of most comprehensive discussion of autism, for example it includes: a discussion of autism services; quantitative data (e.g. numbers of autistic individuals); qualitative data on people‘s experiences and what they would like changed; an analysis of issues such as inequalities; the Welsh language; safeguarding; and the impact of the pandemic. It also identifies priorities for action.

7.8. All regions are complying with the duties around data collection[37], although 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, including the gaps in the data about people's lived experiences, contribute to the weakness in PNAs.

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[37] 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 Neurodivergence team (via Data Cymru).

Table 7.1. Section 4. Planning, commissioning and monitoring autism services and stakeholder engagement

Duty	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
LA and LHBs must jointly: Develop strategic and operational teams which include autistic people to inform service development.	🟩	🟥	🟩	🟧	🟧	🟩	🟧
LHBs and LAs must jointly: Ensure an autism champion role is appointed in each regional partnership board area and is included in the governance structure of the board.	🟩	🟧	🟩	🟩	🟧	🟩	🟧
LHBs with LAs must: jointly comply with relevant duties in the SSWBW Act, Parts 2 and 9 to ensure that needs of autistic people are considered in the development of Population Assessments and Area Plans.	🟩	🟥	🟩	🟩	🟧	🟩	🟧
LA and LHBs must: Ensure that where needs for specialist service provisions are identified, where possible these are made available.	🟧	🟧	🟧	🟧	⬜	⬜	🟧
LA and LHBs must: Encourage innovation in the development of autism services	🟩	🟧	🟧	🟩	🟧	⬜	🟧

Duty	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
LHBs and LAs must: Ensure compliance with Welsh Government data collection and monitoring requirements	🟩	🟩	🟩	🟩	🟩	🟩	🟩

8. Assessing the likely impact of the Code

8.1. The Code directly addresses the three priorities outlined in the 2016 autism Strategic Action Plan:

- 'Assessment and Diagnosis';
- 'Meeting Support Needs'; and
- 'Awareness Raising, Information and Training' (p. 6. Welsh Government, 2016a)

8.2. As the plan explains, these priorities were identified 'in response to what people with autism, their families and carers have said is important to them' and the 'key priority themes and actions that stakeholders felt would 'make a real difference to the lives of children and adults with autism' (ibid.). Although this evaluation has not systematically assessed whether these remain priorities for autistic children, adults and their families and carers[38], previous evaluations and reviews (see e.g. Welsh Government, 2019) and feedback from stakeholders, suggest they do remain priorities. Improvements in these areas can therefore be expected to contribute to ensuring that (as the Strategic Autism Action Plan outlines) children, young people and adults with autism and their family and carers have their needs understood, are supported to achieve their own wellbeing outcomes and to lead fulfilling lives (p 5, Welsh Government, 2016a).

8.3. However, as outlined in sections four to seven:

- 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, or the changes predate the introduction of the Code.

8.4. Given these two important caveats, the evaluation suggests that at this stage, in most regions, the Code itself has had:

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[38] Phase 2 of the evaluation will provide scope to consider this.

- little impact on access to diagnostic assessments or social care assessments;
- little impact on access to information and advice;
- an important impact upon awareness raising work and training, although more work is still needed; and
- little impact upon planning and commissioning of services.

8.5. 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.

8.6. 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. This should, in principle, lead to improvements in services in the future. 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:

- 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 somewhat[39]. 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 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 families[40] and carers, including those provided by the third sector, have improved access to information, advice and support for children and families;

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

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

- 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 (i.e. LD and MH services); parents and carers (although it is reported that some IASs have reduced the support they offer to parents and carers); and, increasingly, those individuals awaiting diagnosis, or who have not been diagnosed; and
- the Code has further raised the profile of autism and the importance attached to it by LAs and LHBs at regional and service levels[41]. 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 LD and AMH 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

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[41] For example, stakeholders reported that the legal status of the Code helped ensure that colleagues in LHBs and LAs paid attention.

9. Conclusions and recommendations

Compliance with the Code

9.1. 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 embarked on journey toward full compliance[42]. For example:

- in relation to parts of the Code, most notably access to diagnostic assessment services via children's ND services and the IAS, with the exception of the waiting time target, regions were already generally compliant with the Code's duties;
- whilst (as noted above) 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, such as diagnostic assessment in LD and AMH services, and access to social care in the secure estate, 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; 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;
  - are (appropriately) challenging (or stretching) for LAs and LHBs but also therefore challenging to evaluate, making it difficult to assess compliance. 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'[43];
  - disagree with, as what they consider good practice, such as establishing panels to provide a single point of access to services, or exercising discretion about whether to tell someone they have the right to a needs assessment if

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

[43] The evaluation has examined the steps taken to try to ensure that ensure that reasonable adjustments are in place, but ideally this should be evaluated by examining the experience of autistic individuals.

they may have care and support needs, are not necessarily consistent with the letter (or text) of the Code; or

- find it difficult to comply with because they run counter to a national model and approach; most 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.

9.2. Moreover, even when regional strategic groups include LHB and LA representatives with sufficient seniority to inform service development, 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. For example, in transforming MH, well-being and support services for children, young people, parents, carers and their wider families across Wales, through equality, inclusion and diversity policies, to workforce development. Moves to a broader focus upon neurodiversity, and including, for example, ADHD, as well as autism, in the remit of regional strategic groups, may help reinforce the need to move beyond a focus upon individual conditions, to an approach more focused upon people's differences and needs.

9.3. The next phase of the evaluation will further explore compliance and the impact of the Code by broadening the lens to consider the experiences of autistic individuals and parents and carers. This may identify areas where regions are compliant on paper, but not in practice, or where compliance with the Code has not been sufficient to improve people's lives and experiences.

Enablers and barriers to compliance

9.4. As outlined in section 8, the impact of the Code itself 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 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 framework (in relation to support while awaiting a diagnosis); the SSWBW Act (e.g. 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 NDIP; and
- the support from the National Neurodivergence Team, particularly around training and resources.

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

- the breadth, complexity and structure of the Code which can, for example, focus attention upon individual duties in isolation from each other, rather than the system as a whole, and may even overshadow or crowd out a focus upon other priorities (such as action in relation to education, which is not covered by the Code). The complexity of the Code also makes assessing compliance challenging, can make prioritisation difficult (e.g. when 'dashboards' are filled with red or amber 'lights', signalling non-compliance[44]), and can encourage what some stakeholders' described as a 'tick box' approach to compliance[45];
- the continued distance between health and social services, which means despite a number of joint duties, there is still 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 result of high levels of demand and constraints upon their capacity, including problems recruiting and retaining staff, which can encourage services to turn inward and focus upon what

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[44] A number of regions have used RAG rating to create spreadsheets highlighting areas of non-compliance.

[45] 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.

they see as their ‘core’ role. This can undermine systems leadership[46] and can make prioritising action to support compliance with the Code challenging (when services face other competing priorities demanding attention and resources); and

- weakness in regional leadership and co-ordination where, for example, there have been delays or no individual or group has taken responsibility for assessing compliance and identifying the actions required.

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[46] This can discourage system leadership, by discouraging leaders from collaborating and reaching across organisational boundaries. It can also encourage blaming poor experiences of autistic individuals upon other parts of the system, such as other services’ failures or weaknesses, rather than encouraging collaborative action to improve autistic people’s experiences.

10. Recommendations for improvements in meeting the duties of the Code

10.1. 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. 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[47];
    - enhance the scrutiny of practice that has been overlooked or neglected by regional strategic groups (e.g. in relation to diagnostic assessments in LD and AMH services) and, where needed, identify actions to address gaps or weaknesses; and
    - ensure that a systems wide approach to developing autism services, that is informed by better data on services' practice and autistic people's experiences (which the second stage of the evaluation should support); 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 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. A range of methods and partners are likely to be needed to reach out to

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[47] For example, some stakeholders highlighted the lack of exemplars of good practice as a constraint, and the potential inefficiencies if each region developed its own approach to, for example, training.

practitioners, autistic individuals and their parents or carers, such as websites, social media campaigns, Community Connectors, Families First and Family Information Services, children’s and adult disability services, education settings (such as schools, colleges and universities), third sector organisations, stakeholder groups and networks and autism officers; and

- **Improving access to diagnostic services**: taking action to address demand-capacity challenges facing ND services, drawing upon the Review of Neurodevelopmental Services (Welsh Government 2022) and the recent review of children’s ND services undertaken by the NHS Delivery Unit.

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Annex A. benchmarks

Table A.1. Benchmarks for compliance: Duties related to access to diagnostic assessment services

<table>
<tr><th>Duties</th><th>Full compliance + (including going above and beyond the Code requirements)</th><th>Good progress (but not full compliance)</th><th>Limited or uneven progress to date</th><th>Not compliant</th></tr>
<tr><td rowspan="2">LHBs Must:
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.</td><td colspan="2">• Detail of multidisciplinary involvement in diagnostic assessments (e.g. multiple disciplines involved in history / observation / clinical interview and/or decision on diagnosis) in the service offering diagnostic assessments for children and adults (e.g. Children’s ND, IAS, AMHS, LD)</td><td rowspan="2">• Detail of multidisciplinary involvement in diagnostic assessments, but significant gaps or weakness in teams (e.g. due to staff vacancies)</td><td rowspan="2">• Clear evidence that NICE best practice guidance for multidisciplinary involvement are not followed.</td></tr>
<tr><td>• Each services’ team has adequate capacity to undertake robust diagnostic assessments (e.g. in terms of numbers of staff and staff skills and competence)</td><td></td></tr>
<tr><td>LHB and NHS trusts must:
• ensure that autism assessment and</td><td>• Details of the pathways for young people and adults in different secure estate settings in the region (e.g. Local</td><td>• Details of how young people and adults in different secure estate settings in the region could access a</td><td>• Discussion of how young people and adults in different secure estate settings in the region could potentially access</td><td>• Clear evidence that autism assessment and diagnostic services are not accessible by</td></tr>
</table>

<table>
<tr><td>diagnostic services are accessible by individuals detained in the secure estate.</td><td>Authority Secure Children’s Homes, Young Offenders institutions, prisons)
• Evidence that autism assessment and diagnostic services are accessible by individuals detained in the secure estate (e.g. examples of this happening)</td><td>diagnostic assessment service.</td><td>a diagnostic assessment service.</td><td>individuals detained in the secure estate.</td></tr>
<tr><td rowspan="2">LHBs Must:
• Ensure that primary and secondary care practitioners are notified of assessment referral pathways for children, young people and adults.</td><td colspan="3">• Details of how primary and secondary care practitioners are notified of assessment referral pathways to the service</td><td rowspan="2">• Evidence that primary and secondary care practitioners have not been notified of assessment referral pathways for</td></tr>
<tr><td>• Evidence that primary and secondary care practitioners understand and use pathways (e.g. analysis of referral rates and rates of inappropriate referrals to different services by different staff groups; surveys of staff awareness).</td><td>• Evaluation team’s judgment (based upon evidence provided) about whether steps taken to notify primary and secondary care practitioners are likely to be sufficient: they are.</td><td>• Evaluation team’s judgment (based upon evidence provided) about whether steps taken to notify primary and secondary care practitioners are likely to be sufficient: they are not .</td></tr>
</table>

LHBs Must: Comply with current national waiting time standards for assessment and diagnosis.	• The Children's ND service waiting time has been under < 26 weeks for the last three years .	• The Children's ND service waiting time has been close to or under the 26 weeks for the last year OR • strong progress has been made in reducing it over the last year and it looks likely that it will be met within the next year.	• The Children's ND service waiting time is above the 26 week waiting time, but good progress is being made in reducing it and there is chance that that it will be met within the next year (although this is unlikely).	The Children's ND service waiting time is considerably greater than > 26 weeks and it is very unlikely that it will be met within the next year.
LHBs Must: Ensure the collection of information on waiting times for assessment for children, young people and adults complies with current national waiting time standards for autism assessment and diagnosis.	• The Children's ND service provides waiting time data to the WG			• Data is not provided.
	• Data from services is analysed to identify trends and inform demand-capacity planning, decisions about funding, service development etc. • Data from services is shared with and scrutinised by the RPB (e.g. autism strategy and operational groups)		• However, concerns are raised about the data that is provided.	

Where a diagnosis of autism is made, with the individual’s consent (or for most children their parent or carer) a referral is made promptly to post diagnostic support assessments, to be undertaken, if appropriate. Where an assessment of autism is undertaken but a diagnosis is not made, if the assessment indicates it to be necessary, with the individual’s consent (or for children that of their parent or carer) a	• Referrals (where indicated/appropriate) to post diagnostic support assessments / or further investigation are part of the pathways for the_service undertaking diagnostic assessments. This includes assessments by the service itself and also referral to third parties.			• There is clear evidence that referrals are not being made by the services, following a diagnostic assessment (irrespective of the outcome), when indicated/appropriate and the parent/child/adult has given consent
	• These referrals are always made following a diagnostic assessment (irrespective of the outcome), when indicated/appropriate and the parent/child/adult has given consent. • Referrals (where appropriate) for post-diagnostic support assessments are routinely accepted by other services (e.g. SLT, OT, social care) • Referrals (where appropriate) for further investigation (e.g. for another ND condition) are routinely accepted by	• These referrals are sometimes made by the services, following a diagnostic assessment (irrespective of the outcome), when indicated/appropriate and the parent/child/adult has given consent or people are encouraged to self-refer. • No information is available on whether these are accepted or there are problems reported (e.g. referrals being rejected by other services)	• These referrals are sometimes made by the services, following a diagnostic assessment (irrespective of the outcome), when indicated/appropriate and the parent/child/adult has given consent or people are encouraged to self-refer, but there is little evidence of this happening and/or there are significant problems reported (e.g. referrals being rejected by other services); AND/OR • The capacity of the service to offer post-diagnostic assessments is very limited	

referral is made for further investigation	other services (e.g. AMHS / ADHD services)			
LAs with LHBs Must: • Designate an individual with lead responsibility for	• Name of designated individual with lead responsibility for maintaining, reviewing and promoting diagnostic pathways for the service is provided.		• There is reported to be an individual with lead responsibility for maintaining, reviewing	• No one is responsible for maintaining, reviewing and promoting diagnostic

maintaining, reviewing and promoting diagnostic pathways for children, young people and adults.	• The designated individual has lead responsibility for maintaining, reviewing and promoting all autism diagnostic pathways (for different services e.g. Children's ND, the IAS, LD and AMHS) • The designated individual has reviewed all autism diagnostic pathways within the last 12 months	• The designated individual has reviewed the service's autism diagnostic pathway within the last 12 months.	and promoting diagnostic pathways for the service (but they are not named) AND/OR • There is no evidence that they have maintained, reviewed and promoted diagnostic pathways.	pathways for the service
LHBs Must: • Ensure the provision, publication and regular review of assessment and diagnostic pathways for children, young people and adults which take into account NICE	• Copy of / link to the diagnostic pathways for the service is provided		• There is reported to be a pathway, but no further details reported; and • concerns are raised about the operation of the design or pathway which may suggest that it is not complaint with NICE guidelines.	• There is reported to be no pathway and/or serious concerns are raised about the design and/or operation of the pathway which mean it is not complaint with NICE guidelines.
	The diagnostic pathway includes: • a single point of referral (including self-referral for adults) to diagnostic services; • acceptance of all 'appropriate referrals (e.g. if there is evidence	• Services provide assurance that the diagnostic pathway takes into account NICE best practice guidance.		

best practice guidance.	of pervasive signs and symptoms that are impacting on functioning); • When referrals are not accepted, the referrer is provided with rationale for this, alongside advice on how to improve the referral or which other service to refer to as appropriate.* • Assessments are planned in a person centred way ensuring sufficient information to create a profile of the individual's need is gathered, whilst ensuring a prudent, flexible approach to the use of resources; • There is a timely discussion involving all those involved in the assessment process			

	which leads to a decision about the outcome of the assessment, a profile of the individual’s strengths and difficulties and recommendations for future support. • A professional who has been involved in the assessment process will communicate the outcome of the assessment with the family (and where appropriate the child). This is followed up in writing, and where consent is given, should be shared with other professionals who support the child. • Information and guidance is provided, alongside advice on			

	where and how to access future support. • Detail provided of a recent review of the pathway (i.e. within last 12m) including results of the review (e.g. audit against the national guidelines for children’s ND services and the IAS; and equivalents for other services e.g. AMHS)			

Table A.2. Benchmarks for compliance: Duties related to access to social care assessments

<table>
<tr><th>Duties</th><th>Full compliance + (including going above and beyond the Code requirements)</th><th>Good progress (but not full compliance)</th><th>Limited progress to date</th><th>No / insufficient evidence to evaluate compliance</th></tr>
<tr><td rowspan="2">LAs must
• Ensure there is information and signposting to access assessment services.</td><td colspan="2">LA websites provide clear and comprehensive information on:
• How to access a social care assessment; and
• how to raise concerns about the wellbeing of a person who appears to have care and support needs</td><td rowspan="2">LA websites provide information on:
• How to access a social care assessment; and
• how to raise concerns about the wellbeing of a person who appears to have care and support needs,
• but the information is unclear, incomplete et.</td><td rowspan="2">• There is no or clearly inadequate information and signposting to access assessment services.</td></tr>
<tr><td>Websites also provide information on:
• How the social care and support systems operates with regards to autism services in the area;
• the types of care and support available to autistic people; and
• how to access the care and support that is available; and</td><td></td></tr>
</table>

	• LAs publicise how to access social care assessment via a range of media (e.g. websites, posters, leaflets in GP surgeries, libraries etc)			
	LA staff (including but not limited to IAA services) can provide advice on: • How to access a social care assessments;	LA IAA services can provide advice on: • How to access a social care assessment; and	LA IAA services can provide: • access to assessment services	

	• the types of care and support available to autistic people ; • how to access the care and support that is available; and • how to raise concerns about the wellbeing of a person who appears to have care and support needs.	• how to raise concerns about the wellbeing of a person who appears to have care and support needs.		
	• The numbers of people seeking a social care assessment is monitored against benchmarks (e.g. expected /projected rates) and when this is lower than expected/projected this is investigated and action is taken to raise rates.			
LAs must: • Ensure that autistic people are aware of the right to access a	• In services that undertake diagnostic assessments, where it appears than an individual may have a need for care and support, <u>all</u> individuals are told that they have the right to an assessment, as part of the post-diagnostic support and feedback		• In services that undertake diagnostic assessments, where it appears than an individual may have a	• Substantial evidence that people are not or are unlikely to be aware of their right to access a needs assessment and a

needs assessment and a carer's assessment for a carer. The process of obtaining these should align with the diagnosis.	• Based upon the judgment of the evaluation team, adequate steps have been taken to actively reach out to autistic individuals and carers, who may have a need for care and support needs, to inform of them their right to an assessment (e.g. by working with the third sector, support groups, social media campaigns etc)		need for care and support, some (but not all) individuals are told that they have the right to an assessment, as part of the post-diagnostic support and feedback	carer's assessment for a carer.
LA and LHBs Must ensure that • Where a diagnosis of autism is made, with the individual's consent (or for most children their parent or carer) a referral is made promptly to post diagnostic support assessments,	• Where appropriate, an individual who may have a need for care and support, is always referred for an assessment. • There is always prompt sharing of information between autism diagnostic services and social care services	• Where appropriate, an individual who may have a need for care and support, is always referred for an assessment OR • advised to self-refer for an assessment AND • There is prompt sharing of information between autism diagnostic	• Where appropriate, an individual who may have a need for care and support, is advised to self-refer for an assessment.	• There is evidence that individuals who may have a need for care and support, are neither referred not advised to self-refer for an assessment.

to be undertaken, if appropriate. • ensure 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.: • Ensure prompt sharing of information between autism diagnostic services and social care services about children and adults who are / not	about children and adults not diagnosed but where it is indicated necessary that a referral for further assessment is required • The outcome of referrals to social care services for an assessment of social care needs is monitored, and if necessary, action taken (e.g. if high numbers of referrals are not accepted).	services and social care services about children and adults not diagnosed but where it is indicated necessary that a referral for further assessment is required •		

<table>
<tr><td>diagnosed but where it is indicated necessary that a referral for further assessment is required</td><td></td><td></td><td></td><td></td></tr>
<tr><td rowspan="2">LA and LHBs Must:
• Ensure there are pathways for further assessment after referral within the secure estate to ensure young people and adults who are detained can access assessment services and social care support.</td><td colspan="2">• There is clarity about responsibilities for further assessment after referral within the secure estate to ensure young people and adults who are detained can access assessment services and social care support.</td><td rowspan="2">• There is a lack of clarity about responsibilities and/or pathways and apparent weakness in pathways and/or access to social care assessments in the secure estate.</td><td rowspan="2">• There is clear evidence that pathways for further assessment after referral within the secure estate are not adequate in design and/or operation.</td></tr>
<tr><td>• There is evidence that pathways for further assessment after referral within the secure estate to ensure young people and adults who are detained can access assessment services and social care support, are working well, and are regularly monitored .</td><td>• There are reported to be pathways for further assessment after referral within the secure estate to ensure young people and adults who are detained can access assessment services and social care support.</td></tr>
</table>

Table A.3. Benchmarks for compliance: Duties related to related to information about and access to autism services

<table>
<tr><th>Duties</th><th>Full compliance + (including going above and beyond the Code requirements)</th><th>Good progress (but not full compliance)</th><th>Limited progress to date</th><th>Not compliant</th></tr>
<tr><td rowspan="3">LHBs Must:
• Ensure that primary and secondary healthcare practitioners are aware of the autism services available in their local areas and have clear pathways for referral.
• Make arrangements to ensure that health services are aware of the autism services available in their local areas and have clear pathways for referral</td><td colspan="2">• In the judgment of the evaluation team, adequate steps have been taken to ensure that Health and LA staff know how to refer autistic people to autism services (e.g. training, awareness raising activity). Note: this could e.g. be via the IAA or a ‘front door’ to services.</td><td rowspan="3">• There is a basic knowledge about how to refer to core autism services (e.g. the IAS)</td><td rowspan="3">• There is evidence that primary and secondary healthcare practitioners are not aware of the autism services available in their local areas and do not have clear pathways for referral.</td></tr>
<tr><td colspan="2">• Local autism services have been mapped; and
• information about autism services is provided on LA and/or LHB websites.</td></tr>
<tr><td>• Clear referral pathways to autism services are published (with copies provided). Note: this could e.g. be via the IAA or a ‘front door’ to services.
• Health and LA staff routinely refer autistic people to autism services.</td><td></td></tr>
</table>

	• The numbers of people referred to autism services is monitored against benchmarks (e.g. expected /projected rates) and when this is lower than expected/projected this is investigated and if appropriate, action is taken to raise rates.			
LAs with LHBs should • ensure that health and local authority staff are aware of the Information, Advice and Assistance service and how to refer autistic people to the service	• The IAA service and how to access it, is clear on LA websites			• In the judgment of the evaluation team, no or clearly inadequate steps have been taken to ensure that health and LA staff are aware of the IAA service and how to refer autistic people to the service
	• In the judgment of the evaluation team, adequate steps have been taken to ensure that Health and LA staff are aware of the IAA service and how to refer autistic people to the service.			
	• Health and LA staff are awareness of the IAA service and how to access it is monitored (including e.g. the appropriateness and numbers of referrals they make to IAA services).			

LAs must: • Ensure that as part of their Information, Assistance and Advice Service information is available on local autism services • As part of their duties under the SSWBW Act, ensure the Information, Assistance and Advice Service provides information on local autism services.	• Local autism services have been mapped; and • IAA services provide information on: - the types of autism services available; and - how to access autism services.		• IAA services provide information on: the types of autism services available, but there are significant weakness. For example, local autism services have not been adequately mapped, AND/OR for example there is too much emphasis upon the IAS as the autism service in the area.	• Information on autism services is not available from IAA services.
	• IAA services have a good knowledge of autism services (including the full range of services that support autistic people) and routinely refer autistic individuals / their parents or carers to autism services. • Ideally, the numbers of people referred to autism services by the IAA is monitored against benchmarks (e.g. expected /projected rates) and when this is lower than expected/projected this is investigated and if appropriate, action is taken to raise rates.			

<table>
<tr>
<td rowspan="3">LAs with LHBs should
• make arrangements to ensure a range of autism awareness information, resources and training is made publicly available.</td>
<td colspan="3">• A range of autism awareness information, resources and training is made publicly available (e.g. on websites)</td>
<td rowspan="3">• No arrangements have been made to ensure a range of autism awareness information, resources and training is made publicly available.</td>
</tr>
<tr>
<td colspan="2">• In the judgment of the evaluation team, the information, resources and training are comprehensive, clear and easy to find and access.</td>
<td rowspan="2"></td>
</tr>
<tr>
<td>• There is a comprehensive description of autism information, resources and training offered to different groups[48], including:
- health care staff
- social care staff
- other LA staff (e. housing, leisure services)
- autistic individuals
- parents and carers
• there is a comprehensive description of material and training designed to</td>
<td></td>
</tr>
</table>

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[48] This should include: general awareness information about the impact of autism; information to autistic people, their families or carers about their rights; information about local opportunities tailored for autistic people; information about local training available which can support autistic people and their family or carers; information to help autistic people and their family or carers to prepare for the future; and the contact details of the Information, Advice and Assistance service

	raise the awareness of autism amongst LA, and LHB staff and the wider public. This includes promoting a social model of disability. [49] - Evidence of steps taken to ensure accessibility for different groups (e.g. link to website where it is publicly available; leaflets and posters in GP surgeries, libraries etc). - The take up, and experiences of those taking up information, resources and training, and its impact (e.g. upon awareness and understanding) is			

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[49] As the supporting guidance outlines: ‘Raising awareness of autism in the community’ and ‘Recognising the Social Model of disability, to create a society inclusive of autistic people, there needs to be an understanding of autism across the community. Local authorities as providers/commissioners of publicly available facilities, along with health and third sector providers, should adapt their services to meet the needs of autistic people, removing barriers to inclusion. This can be achieved by: i. supporting autistic people and their family or carers to have opportunities to be involved in community activities and share experiences ii. providing general awareness information about the impact of autism iii. providing information to autistic people, their families or carers about their rights iv. providing information about local opportunities tailored for autistic people v. providing information about local training available which can support autistic people and their family or carers vi. providing information to help autistic people and their family or carers to prepare for the future vii. providing the contact details of the Information, Advice and Assistance service.’ (pp25-26,Welsh Government 2022b).

	monitored and used to inform development of information, resources and training			
LA and LHBs: • Ensure that reasonable adjustments are in place for autistic people to ensure they are able to access services in the same way as everyone else.	• There are robust LA and the LHB policies on identifying and then making reasonable adjustments			• There is consistent evidence that reasonable adjustments are not being put in place for autistic people to ensure they are able to access services in the same way as everyone else.
	• These policies are underpinned by comprehensive training and awareness raising strategies.			
	• The experiences of autistic individuals accessing services are monitored, and if appropriate, action is taken to improve their experiences (e.g.. by strengthening training and awareness raising work)			

Table A.4. Benchmarks for compliance: Duties related to access to needs based services

Duty	Full compliance + (including going above and beyond the Code requirements)	Good progress (but not full compliance)	Limited progress to date	Not Compliant
LA and LHBs must • Ensure that awaiting a diagnosis is not a reason to be refused support and other services.	• Support is consistently offered to people on the basis of need rather diagnosis. This includes support for those awaiting assessment.		• Support is generally offered to people on the basis of need rather diagnosis, but there are examples where a diagnosis is needed to access specific services and support.	• There is evidence that autistic people awaiting a diagnosis cannot access support and other services because they are awaiting a diagnosis
	• There is reported to be a strong pre-diagnostic support offer by ND services (such as the IAS and Children's ND service) OR other services such as Early Years services			
LA and LHBs Must [ensure that]: • Where autistic people have co-existing conditions, including mental health and or	• Diagnostic pathways should include investigation of potentially co-occurring conditions; • Pathways to enable access to support services which can meet their additional support needs in relation to autism are in place and publicised. This includes. for example, joint work between ND and MH services, and Single Points		• Support is available from a range of sources including other health and social care services (e.g. ADHD, mental health, eating disorder and substance	• There is evidence that autistic people with co-existing conditions, cannot access support

learning disabilities, pathways should be in place to enable access to support services which can meet their additional support needs in relation to autism	of Access (SPoA) to facilitate access to services and support. • A referral for a diagnostic assessment of autism a or a diagnosis of autism does not prevent, delay, or hinder referral to other services (e.g. MH, LD services) or the provision of support. For example, if ADHD is suspected, information on exercise, sleep and planning can be provided or if anxiety is suspected, information on coping strategies is provided, while an individual waits for further assessment. • Staff in support services have the necessary skills and knowledge and understanding of autism required[50] (see table A.5 for detail). • Support services make reasonable adjustments for autistic people (see table A.4. for details).		misuse services) the third sector (including local support groups). • However, it is not clear - if staff in support services have the necessary skills and knowledge and understanding of autism required; - Support services make reasonable adjustments for autistic people; AND/OR - demand-capacity pressures ND services face delay access to support / joint working with other services (e.g. MH services).	services which can meet their additional support needs in relation to autism
	• Referrals for further assessment do not cause delays in providing immediately necessary support. • The experiences of and outcomes for autistic individuals with			

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[50] There is relevant experience and expertise (in relation to autism) within CAMHS/AMHS and/or support from partners such as IAS?

	co-occurring conditions are evaluated and this is used to inform service development.			
LHBs Must: - Ensure that people with an Autistic Spectrum Condition with co-occurring conditions are not excluded from Children or Adults Mental Health Services (CAMHS[/AMHS]). Consideration of core ASC indicators and their influences on individuals must inform the care and support offered and its outcomes	- There are pathways for autistic people who have co-occurring mental health conditions to enable access to assessment services, which can meet their additional support needs in relation to autism. For example: diagnostic assessment pathways include provision for further investigation for co-occurring conditions. - Additional steps been taken to ensure that autistic people with co-occurring MH conditions, can access an assessment by MH services (e.g. reasonable adjustments to services are made; practitioners involved in assessments have the necessary skills and knowledge and understanding of autism (e.g. through training and/or access to expert advice and consultations (e.g. by the IAS)).			- There is evidence that Autistic people with co-occurring conditions are excluded from CAMHS/ AMHS
	- A referral for a diagnostic assessment of autism a or a diagnosis of autism does not prevent, delay, or hinder referral to MH services. - A diagnosis of autism does not prevent, delay, or hinder referral to / support from MH services.		- Although a referral for a diagnostic assessment of autism and/or a diagnosis of autism should not in principle prevent referral to MH services, but in practice, there may be delays or difficulties in	
	- The numbers of autistic people with co-occurring conditions accessing other services (e.g. MH, LD			

	services) is monitored against benchmarks (e.g. expected /projected rates) and when this is lower than expected/projected this is investigated and action is taken to ensure they can access these services. • Their experiences of support and outcomes are also monitored, and if this identifies concerns, action is taken.		the referral being made or being accepted.	
LAs must ensure that • IQ is not considered as part of the eligibility criteria for a needs assessment under the SSWBW Act.	• IQ is not considered as part of the eligibility criteria for a needs assessment under the SSWBW Act (although IQ may be used to determine the appropriateness of provision) and • Services and support focus upon people's needs and 'what matters to them', rather than their diagnosis, IQ or condition		• In principle, IQ should not be considered as part of the eligibility criteria, however it is reported that in practice it can be.	• IQ is considered as part of the eligibility criteria for a needs assessment under the SSWBW Act OR for services.

LHBs Must: • ensure IQ is not considered as part of the eligibility criteria	• There is robust monitoring to ensure that IQ is not considered as part of eligibility criteria.			

Table A.5. Benchmarks for compliance: Duties related to workforce development and training

Duty	**Full compliance + (including going above and beyond the Code requirements)**	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not Compliant**
LAs and LHBs must: • Ensure that autism awareness training is included in general equality and diversity training programmes offered for all staff working in health and social care.	• There are minimum training standards for all health and social care staff. This includes mandatory level 1 training (or equivalent) in understanding autism and effective communication as part of general equality and diversity training programmes for <u>all</u> staff working in health and social care. • There are minimum training standards for staff in other LA	• Level 1 autism awareness training (or equivalent) is included in general equality and diversity training programmes offered for <u>all</u> staff working in health and social care.	• Autism awareness training is being developed and/or currently offered to staff working in health and social care, but is, for example - not yet fully integrated into general equality and diversity training programmes; and/or - not yet offered to all health and social care staff; - the importance of, and ways to access the	• Evidence that autism awareness training is either not included in general equality and diversity training programmes OR in the judgment of the evaluation team is clearly inadequate.

	departments (e.g. housing) • Take up of training is monitored (and action is taken to raise take up if required)		training, have not been publicised; and/or - take up is not monitored.	
As part of workforce planning [LA and LHB should], • assess the autism training needs of all their staff who are working in health and social care and identify the level of training required according to their job roles and responsibilities LHBs Must: • Ensure healthcare professionals have the knowledge and training in autism they need to undertake their roles,	• As part of workforce training needs analysis, an analysis of autism training needs has been carried out for all health and social care staff (including those in the secure estate). • Specialist training needs for staff in all services that undertake diagnostic assessments and/or provide post-diagnostic support have been assessed.	• The National training framework Job profile and tasks or an equivalent is used to identify training needs. • Training for specific roles is mandatory. • Specialist training needs for staff in the children's ND service and IAS have been assessed (e.g. sensory profiles for OTs), but not other services that undertake diagnostic assessment.	• There is an offer of training at different levels (e.g. autism aware – autism enhanced) • But, for example the training is: - not mandatory, - not monitored or has very low take up - is not adequate/sufficient for different roles; and/or - is not regularly updated	• Clear evidence that for example: - The training needs of staff who are working in health and social care have not been assessed; - Staff lack the knowledge and training in autism they need to undertake their roles; and/or

where relevant engaging with specialist professional registration bodies. • Ensure that health and social care support for autistic people detained in the secure estate is provided by appropriately trained practitioners. • Make arrangements to ensure that all staff can access the training identified to meet their autism knowledge and awareness training needs. • Ensure that staff receive appropriate training in autism and associated behaviour and sensory needs at a level appropriate to their involvement. • LAs and LHBs should:	• There are minimum autism training standards for all health and social care staff. These identify the level of training required according to their job roles and responsibilities are at least equivalent to the National training framework [Job profile and tasks](#)) • The training plan identifies (i) the training offer (and requirements) and (ii) how different groups can access training (including for example, reasonable adjustments, and a mix of face to face and online learning options).	• Training is delivered to meet identified needs, and regularly updated.		- health and social care support for autistic people detained in the secure estate is not provided by appropriately trained practitioners.

• Where the need for specialist training is identified, ensure that training provision takes account of National Institute for Health and Care Excellence (NICE) guidelines.	• Training needs are identified at the recruitment stage; inform individual development plans and include mandatory training for different roles. • Take up of training is monitored; (and action is taken to raise take up if required); and data on uptake is provided. • Appropriate training provision is made available on a continuing basis, including new staff and existing staff who change their job roles. • Level 2 training (or equivalent) is updated at least			

	every three years and more specialist training is updated annually. • Specialist training takes account of National Institute for Health and Care Excellence (NICE) guidelines.			
LHBs must: • Ensure that any person carrying out an assessment of autistic spectrum condition with an individual has the knowledge, skills and competence required, to undertake the assessment and provide a diagnosis.	• An autism training needs analysis has been carried out for all health and social care staff undertaking diagnostic assessments (including e.g. those in LD and MH services). • There are minimum training standards for all health and social care staff undertaking diagnostic assessments. These cover both the diagnostic assessment tools (e.g. DISCO, ADOS etc) and the wider understanding of autism required; and • training is regularly updated.		• Staff undertaking diagnostic assessments are offered training, but for example: - it is not mandatory - is not regularly updated; AND/OR - is not adequate /sufficient to equip staff with the skills and knowledge required.	• There is evidence that some staff carrying out an assessment of autistic spectrum condition with an individual do not have the knowledge, skills and competence required.
	• The training standards identify the level of training required according to their job roles and			

	responsibilities and use or mirror the national training framework. - As well as training, consideration is given to the experience needed, and how this can be developed. - Specialist training is updated annually. - Staff knowledge, skills and competence are monitored (e.g. as part of annual reviews)			
LA Must [ensure]: - Where services are commissioned local authorities must ensure autism services are provided by appropriately trained and skilled staff.	- An autism training needs analysis (using The National training framework Job profile and tasks or an equivalent) is part of the commissioning process;	- The skills, knowledge in relation to autism required by staff delivering commissioned services is considered. This uses the National training framework	- The skills, knowledge in relation to autism required by staff delivering commissioned services is considered, but for example; - it is not clear how training	- There are examples of (including evidence) that commissioned services are not provided by appropriately

	• training requirements are specified as part of the process; and • training requirements monitored by the LA or LHB.[51]	Job profile and tasks or an equivalent; and • training requirements are specified as part of the process.	requirements are identified; and/or - there is little/no consistency in the specification of minimum standards across different contracts.	trained and skilled staff
LAs and LHBs should: • Ensure that autistic people and their parents and carers are involved in the development and delivery of autism training. This may include consultation on training materials or involvement in delivery of training.	• NAT Level 1 and 2 training (which has been co-produced) or an equivalent that has been co-produced is used; • Evidence is provided that the design and/or delivery of all other training that is used, is co-produced (with examples given). • Autistic individuals in strategic or operational autistic	• NAT Level 1 and 2 training (which has been co-produced) or an equivalent that has been co-produced is used AND • There are examples of or plans to involve autistic people and their parents and carers in the development and delivery of other autism training.	• NAT Level 1 and 2 training (which has been co-produced) or an equivalent that has been co-produced is used OR • There are plans to involve autistic people and their parents and carers in the development and delivery of autism training.	• In the judgment of the evaluation team it is clear that that autistic people and their parents and carers have not been involved in the development and delivery of autism training and there are no credible plans to do so.

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[51] This should for example cover both the training provided and provision, for example, do they offer an autism friendly environment- evidencing they have the necessary knowledge and skills.

<table>
<tr><td></td><td>groups, have a role in the development and oversight of LA and LHB training</td><td></td><td></td><td></td></tr>
<tr><td rowspan="3">LA must:
• Ensure that practitioners assessing an autistic individual’s eligibility for social care services have sufficient knowledge and skills to understand the impact of autism on the individual’s ability to achieve the five elements of well-being without care and support.</td><td colspan="3">• Social Workers are registered with Social Care Wales (and therefore have approved qualifications).[52]</td><td rowspan="3">• There is evidence that practitioners assessing an autistic individual’s eligibility for social care services do not have sufficient knowledge and skills to understand the impact of autism on the individual’s ability to achieve the five elements of well-being</td></tr>
<tr><td colspan="2">• Where specialist skills are required, staff are either
(i) trained to the appropriate level (e.g. in line with the NAT training framework or equivalent) or
(ii) consult someone who has these skills.</td><td rowspan="2">• Training is provided, but is there is little or no evidence of how the need for more specialist skills is met unclear AND/OR
• Significant concerns are raised about the training</td></tr>
<tr><td>• A training needs analysis to identify the skills, knowledge and competence required to undertake an assessment has been carried out and those undertaking assessments have</td><td></td></tr>
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[52] As the Supporting Guidance outlines, ‘Appropriate levels of qualification for undertaking these activities include: • either a registered social work or social care practitioner holding a professional qualification at level 5 or above • or a person holding a social care qualification at level 4 or above, which includes knowledge and skills undertaking person centred assessment, under the supervision of a registered social work or social care practitioner. Additionally, to meet suitably skilled, practitioners should have appropriate understanding and training in autism and related behaviour support.’ (p. 32, Welsh Government 2022b).

	been trained to ensure they meet this requirement. • As part of each assessment, the LA determines if the assessor requires specialist skills (e.g. trained to the level of Autism Enhanced" in the NAT training framework or equivalent; or to assess people without a learning disability but who have 'spiky profiles') or if a person with this training (or equivalent) needs to be consulted. Examples of how this works in practice are given			without care and support.

	- The LA requires the person undertaking the assessment to have the requisite skills, knowledge and competence or to consult someone who has and monitors how effectively this process is in ensuring that staff have the skill and knowledge required.			

Table A.6. Benchmarks for compliance: Duties related to related to the planning, commissioning, monitoring and evaluation of autism services

Duties	**Full compliance + (including going above and beyond the Code requirements)**	**Good progress (but not full compliance)**	**Limited progress to date**	**Not compliant**
LHBs and LAs must jointly: • Comply with relevant duties in the SSWBW Act, Parts 2 and 9 to ensure that needs of autistic people are considered in the development of Population Assessments and Area Plans.	• Autistic people/parents and groups/organisations ae actively involved and engaged in process of developing the PNA and Area Plans • In the judgment of the evaluation team, the PNA includes a robust assessment of: - the extent to which autism needs are not being met; - the range and level of autism services required to meet identified needs; - the range and level of autism services required to deliver the preventative services required; and - how autism services will be delivered taking into consideration population, culture and language with specific reference to the Welsh language.		• The PNA includes an assessment of: - the extent to which autism needs are not being met - the range and level of autism services required to meet identified needs - the range and level of autism services	• There is evidence that the needs of autistic people have not been considered in the development of Population Assessments and Area Plans.
	• There is evidence that the PNA informs the			

	work of the RPB (including autism strategic and operational groups) and the planning and development of autism services. • In the judgment of the evaluation team, the RPB's annual report has a robust assessment of regional progress (including alignment with the Welsh Government autism strategy)		required to deliver the preventative services required; and • how autism services will be delivered taking into consideration population, culture and language with specific reference to the Welsh language.	
LA and LHBs must: • Ensure that where needs for specialist service provisions are identified, where possible these are made available.	• The need for specialist services can be identified through assessment processes, and where appropriate, specialist services can be commissioned.			• There is evidence that where the need for specialist service provisions are identified, and it is reasonable to expect them to be provided, they have not been provided
	• The need for specialist services is considered as part of the PNA process.			
	• Examples are given of specialist services commissioned in this way are provided.			

	• Information on the type of specialist provision that is commissioned for individuals is collated, to identify unmet needs and inform service development			
LA and LHBs must jointly: • Develop strategic and operational teams which include autistic people to inform service development.	• There is a strategic team/group, whose work is informed by local stakeholder group(s) which include a range of people with an interest in autism (including those with lived experience). • The membership of the strategic group includes: - a senior LHB representative with responsibility for implementing the Autism Code and sufficient seniority to inform service development; - senior LA representative(s) with responsibility for implementing the Autism Code and sufficient seniority to inform service development; - ASD Leads; - IAS and ND service Leads and Specialist practitioners; - third sector representative(s); - the autism champion and		• There is a strategic or operational team/group, although its membership falls short of the Code expectations and/or it does not meet regularly and/or has not been effective.	• There are no strategic or operational teams OR teams are ineffective or largely inactive.

	- autistic people.			
	• The strategic group are supported by an operational team/ group which includes autistic individuals and which can inform service improvement and which meets quarterly. • There is evidence that the strategic and operational groups contribute to the PNA and Area Plan; and • There is evidence that the Strategic and operational groups have a key role in identifying - gaps and weakness in service provision and - potential innovations			

<table>
<tr>
<td rowspan="3">LHBs and LAs must jointly:
• Ensure an autism champion role is appointed in each regional partnership board area and is included in the governance structure of the board.</td>
<td colspan="3">• An autism champion has been identified</td>
<td rowspan="3">• No autism champion has been identified</td>
</tr>
<tr>
<td colspan="2">• The autism champion attends RPB meetings and reports on the development of autism services in the region</td>
<td rowspan="2">• An autism champion has been identified, but no information on the role is available.</td>
</tr>
<tr>
<td>• The autism champion:
- has a role within the governance structure of the regional partnership board to ensure that there is effective scrutiny of autism services;
- ensures that stakeholders can take an active role in service development and delivery ;
- is involved in the annual review of the area plan, and reports to the board at least annually; and</td>
<td>• The autism champion: has not yet ensured that for example:
- there is effective scrutiny of autism services; and/or
- stakeholders can take an active role in service development and delivery (e.g. as they are still new to the role)</td>
</tr>
</table>

	- works alongside local authority and health ASD leads			
LA and LHBs must: • Encourage innovation in the development of autism services	• Individual autism services are supported and encouraged to innovate (e.g. through funding, invitations to submit SBARs[53], developing networks of practice; commissioning reviews etc)			• There is no evidence that innovation in the development of autism services is encouraged
	• Strategic and operational groups' remit includes encouraging innovation in the development of autism services and there are example of this (i.e. innovations in the development of services)			
	• The PNA is used to help identify opportunities for service development and improvement (including innovations) • There is robust monitoring and evaluation of autism services, and where for example weaknesses or opportunities are identified, innovative			

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[53] Situation, background, assessment, recommendation

<table>
<tr><td></td><td>responses are considered.</td><td></td><td></td><td></td></tr>
<tr><td rowspan="2">LHB and LAs must:
• Ensure compliance with Welsh Government data collection and monitoring requirements</td><td colspan="3">• The Children’s ND service provides waiting time data to the WG;
• The IAS provides quarterly data to the national Neurodivergence Team (via Data Cymru)
• The RPB provides reports on Neurodiversity for RIF funding purposes.</td><td rowspan="2">• The RPB, LHB or individual services (e.g. the IAS) are not complying with Welsh Government data collection and monitoring requirements.</td></tr>
<tr><td>• Data on other services that undertake diagnostic assessments (e.g. AMHS, LD services is collected)
• Data from different services is analysed to identify trends and inform demand-capacity planning, decisions about funding, service development etc.
• Data from different services is shared with and scrutinised by the RPB (e.g. autism strategy and operational groups).</td><td></td><td>• However, there are concerns about the data that is collected and shared with the Welsh Government (or National Neurodivergence Team) (e.g. in terms of quality, timeliness etc).</td></tr>
</table>

Annex B. Examples of describing the process [document for Autism Strategic Groups]

Ensuring that staff are aware of something

e.g. Ensure that primary and secondary healthcare practitioners are aware of the autism services available in their local areas and have clear pathways for referral.

Describe the process, i.e. how do you ensure that staff are aware e.g.

1. How do you identify autism services in your area?
2. How do you identify the referral pathways?
3. How do you identify which staff in primary and secondary health care need to know about autism services and referral pathways? (If not all primary and secondary health care staff).
4. How do you ensure that those staff in primary and secondary health care who need to know about autism services and referral pathways, know about them. e.g.
   4a. We provide training to staff who need to know, and/or
   4b . We send information about autism services and referral pathways to staff who need to know; and
   4c. (ideally) we monitor and evaluate the awareness of staff in primary and secondary health care, and where gaps are identified, we take action.

Ensuring that staff/services do something

E.g. As part of their duties under the SSWBW Act, ensure the Information, Assistance and Advice Service provides information on local autism services.

Describe the process, i.e. how do you ensure that staff/services do something. E.g.

1. IAA staff undertake a proportionate assessment (where appropriate)[54];
2. IAA staff search their service directory to identify local [autism] services; and

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[54] The assessment is done through discussion and analysis of the five elements of the National Assessment and Eligibility Tool, albeit in proportion to the original enquiry.

3. IAA staff signpost people to appropriate services.

Remember, as in the example above, this may be the same process for anyone who contacts the IAA, that is to say, it does not involve staff doing anything differently because an autistic adult contacts the service (although they may of course make reasonable adjustments).

Ensuring that staff have the skills and knowledge required

e.g. Ensure that practitioners assessing an autistic individual's eligibility for social care services have sufficient knowledge and skills to understand the impact of autism on the individual's ability to achieve the five elements of well-being[55] *without care and support'*

Describe the process, i.e. how do you ensure that staff have the skills and knowledge required e.g.

1. Undertake a training needs analysis (identify what do different staff in different roles need to know and be able to do, e.g.. by using the NAT training framework); identify what training is required given the current workforce's skills and knowledge)
2. Develop a Training plan / Framework (what training will be offered? by whom? how?);
3. Deliver training; and
4. Monitor and evaluate the impact and effectiveness of training.

OR Describe the result of this process

e.g.

Staff are trained to the level of "Autism Enhanced" in the NAT training framework

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[55] Assessments must consider — (a) the person's circumstances, (b) the person's personal outcomes, (c) the barriers to achieving these outcomes, (d) the risks if these outcomes are not achieved, (e) the person's strengths and capabilities ; and (e) the person's strengths and capabilities

Ensuring that autistic individuals are not prevented from accessing a service

e.g. Ensure that people with an Autistic Spectrum Condition with co-occurring conditions are not excluded from Children or Adults Mental Health Services (CAMHS).

Describe any reasons why they might be prevented (e.g. eligibility criteria, lack of staff confidence). If there are none, you are compliant.

Annex C. Example of a guide to assessing compliance with duties in relation to diagnostic assessments

Duties	**Minimum expected information from LA / LHB**	**Potential measure of impact / proxy measures (to test if this is working and if anyone is better off as a result?)**
Local Health Boards and NHS Trusts Must: • Ensure the provision, publication and regular review of assessment and diagnostic pathways for children, young people and adults which take into account NICE best practice guidance. • Ensure the primary and secondary care practitioners are notified of assessment referral pathways for children, young people and adults. Local Authorities with Local Health Boards and NHS Trusts Must:	• Details of all services that undertake diagnostic assessments (e.g. children ND services + Paediatrics? IAS, AMHS, LD services • Copy of / link to the diagnostic pathways for children and for adults • how are primary and secondary care practitioners notified of assessment referral pathways? • Is there a single point of referral (including self-referral for adults) to diagnostic services? • When were the different diagnostic pathways last reviewed? • Name of designed individual	• # of autistic children and adults accessing diagnostic services + Comparison to expected rate • service user experiences of the pathway • *Note impact depends upon multiple factors (see impact chain*)*

- Designate an individual with lead responsibility for maintaining, reviewing and promoting diagnostic pathways for children, young people and adults.		
Local Health Boards and NHS Trusts Must: - Ensure that autism assessment and diagnostic services are accessible by individuals detained in the secure estate.	- Pathway (if different to that outlined above?)	
Local Health Boards and NHS Trusts Must: - 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[56]	- Detail of multidisciplinary involvement in diagnostic assessment (e.g. multiple discipline involved in history / observation / clinical interview and/or decision on diagnosis) in different	- # of autistic children and adults accessing diagnostic services + Comparison to expected rate

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[56] I don't think the guidance for children requires this https://www.nice.org.uk/guidance/cg128/chapter/Recommendations#autism-diagnostic-assessment-for-children-and-young-people; for adults, the NICE guidance describes a comprehensive assessment as ' team-based and draw on a range of professions and skills' (para 1.2.5.) and that specialist community-based multidisciplinary team for autistic adults (the specialist autism team) should be established. The membership should include: psychologists with training and experience in working with autistic adults; nurses; occupational therapists; psychiatrists; social workers; speech and language therapists; support staff (for

	diagnostic services (e.g. Children's ND, IAS, AMHS, LD)	
Local Health Boards and NHS Trusts Must: - Ensure the collection of information on waiting times for assessment for children, young people and adults complies with current national waiting time standards for autism assessment and diagnosis. - Comply with current national waiting time standards for assessment and diagnosis.	- Current waiting times for children's ND services.	- Waiting times?
Local Health Boards and NHS Trusts Must:	- What post-diagnostic support is offered to children and to adults? (e.g. what	- What post-diagnostic support is offered?

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example, staff supporting access to housing, educational and employment services, financial advice, and personal and community safety skills). (para 1.1.13 https://www.nice.org.uk/guidance/CG142/chapter/Recommendations#identification-and-assessment-2

• Where a diagnosis of autism is made, with the individual's consent (or for most children their parent or carer) a referral is made promptly to post diagnostic support assessments, to be undertaken, if appropriate. • Where an assessment of autism is undertaken but a diagnosis is not made, if the assessment indicates it to be necessary, with the individual's consent (or for children that of their parent or carer) a referral is made for further investigation.	interventions? information and guidance? signposting to…?) • Is this available irrespective of the service that undertakes the diagnostic assessment (e.g. is it offered to those diagnosed by AMHS?) • Details of how differential diagnosis and potential co-existing conditions (such as other NDCs; mental and/or physical disorders)[57]** are considered as part of the diagnostic assessment by services* and where appropriate referrals are made	• # of people taking up post diagnostic support • Feedback from service users

*i.e. all services undertaking diagnostic assessments

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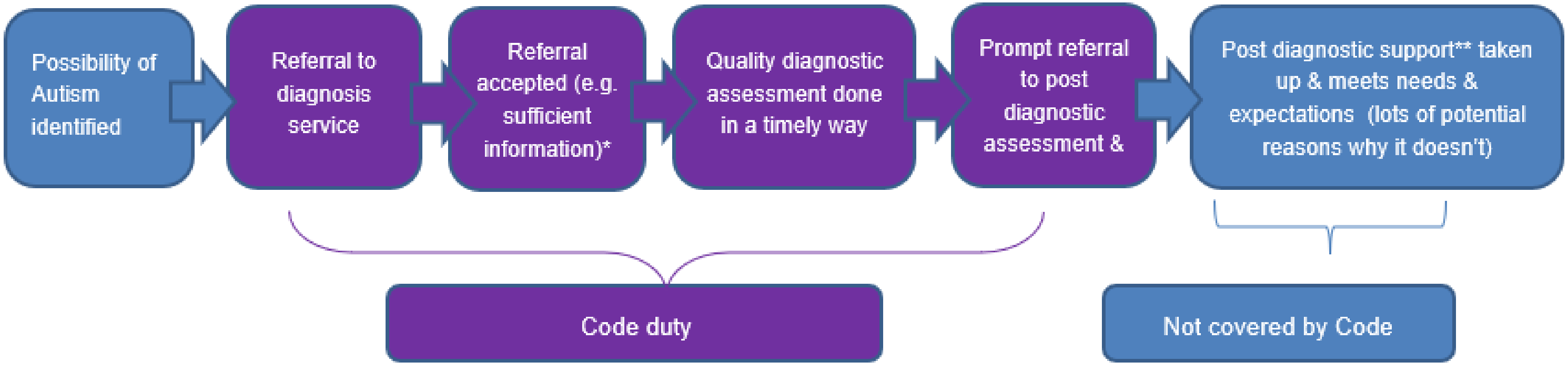
[57] E.g. for adults: 'During a comprehensive assessment, take into account and assess for possible differential diagnoses and coexisting disorders or conditions, such as: other neurodevelopmental conditions (use formal assessment tools for learning disabilities); mental disorders (for example, schizophrenia, depression or other mood disorders, and anxiety disorders, in particular, social anxiety disorder and obsessive–compulsive disorder); neurological disorders (for example, epilepsy); physical disorders; communication difficulties (for example, speech and language problems, and selective mutism); hyper- and/or hypo-sensory sensitivities'

** See NICE guidance, 1.5.15 https://www.nice.org.uk/guidance/cg128/chapter/Recommendations#autism-diagnostic-assessment-for-children-and-young-people

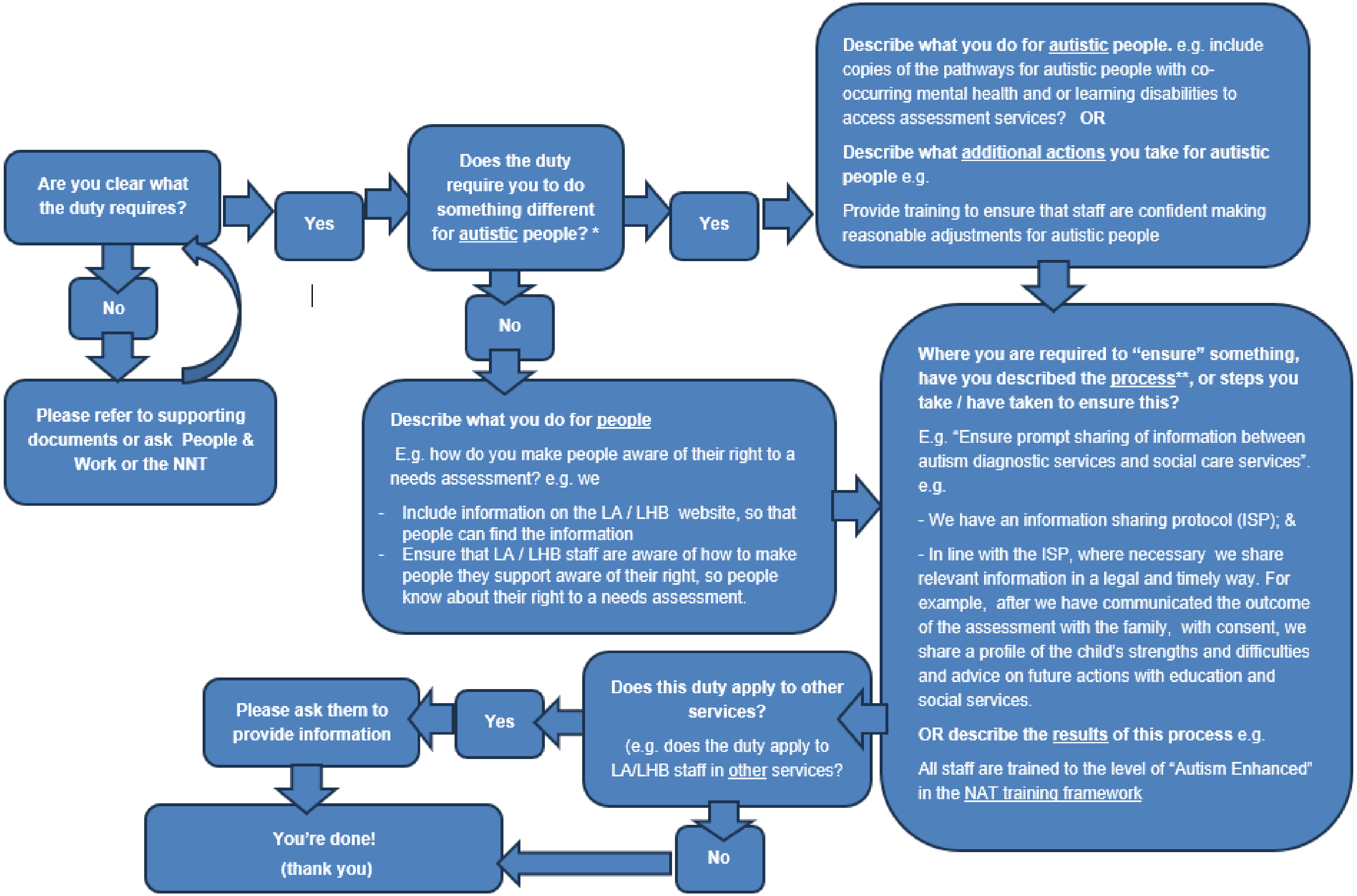
* Diagnosis impact chain. Note the number of potential breaks in the chain may mean no impact even if Code is complied with



*Not covered by Duty as such – but implicit in pathway

** The Code requires a post diagnostic service be offered but no duty exactly on what it looks like.

Annex D. How to judge compliance with the Code [document for Regional strategic Groups]



Are you clear what the duty requires?

No

Please refer to supporting documents or ask People & Work or the NNT

Yes

Does the duty require you to do something different for autistic people? *

No

Describe what you do for people

E.g. how do you make people aware of their right to a needs assessment? e.g. we

- Include information on the LA / LHB website, so that people can find the information
- Ensure that LA / LHB staff are aware of how to make people they support aware of their right, so people know about their right to a needs assessment.

Yes

Describe what you do for autistic people. e.g. include copies of the pathways for autistic people with co-occurring mental health and or learning disabilities to access assessment services? OR

Describe what additional actions you take for autistic people e.g.

Provide training to ensure that staff are confident making reasonable adjustments for autistic people

Where you are required to "ensure" something, have you described the process, or steps you take / have taken to ensure this?**

E.g. "Ensure prompt sharing of information between autism diagnostic services and social care services". e.g.

- We have an information sharing protocol (ISP); &

- In line with the ISP, where necessary we share relevant information in a legal and timely way. For example, after we have communicated the outcome of the assessment with the family, with consent, we share a profile of the child's strengths and difficulties and advice on future actions with education and social services.

OR describe the results of this process e.g.

All staff are trained to the level of "Autism Enhanced" in the NAT training framework

Does this duty apply to other services?

(e.g. does the duty apply to LA/LHB staff in other services?

Yes

Please ask them to provide information

No

You're done!

(thank you)

* For example: the duty to make reasonable adjustments applies to all disabled people, not just autistic people; and if it appears that you may have a need for care and support, you have a right to an assessment (whether you are autistic or not)

** For example to ensure staff have the skills and knowledge required, describe how you determine the skills & knowledge required (e.g. by reference to the NAT Training framework); how you assess if people have these skills (e.g. through a training needs analysis); and how you address any gaps (e.g. through delivery of training)