Dadansoddi ar gyfer Polisi
YMCHWIL GYMDEITHASOL Y LLYWODRAETH
GSR
GOVERNMENT SOCIAL RESEARCH
Analysis for Policy

Llywodraeth Cymru
Welsh Government

Social research number: 109/2025

Publication date: 26/11/2025

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

Digital ISBN 978-1-80633-662-3

Evaluation of the code of practice on the delivery of autism services: phase two

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Full Research Report: People and Work (2025). Evaluation of the code of practice on the delivery of autism services: phase two. Cardiff: Welsh Government, GSR report number 109/2025.

Available at: https://www.gov.wales/evaluation-code-practice-delivery-autism-services-phase-two

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Acknowledgements

The authors would like to thank all those who gave their time to support the evaluation through workshops, interviews, by responding to requests for information and data and/or by completing questionnaires.

Special thanks are also extended to Aoife Pryor, Sian Lewis, Julie Annetts, Einir Price, Laura Entwistle and Dr Christopher Eaton from the Welsh Government, Kirsty Jones and Wendy Thomas from the National Neurodivergence Team and Ann Churcher, Rhodri Bowen and Emma Preece from People and Work for their insights, help and ideas in support of this evaluation.

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Glossary

A **social care assessment** is a process used by local authorities to determine what care and support an individual needs, based on their individual needs and circumstances.

A **diagnostic assessment** is a comprehensive evaluation, usually conducted by a multi-disciplinary team of specialists to determine if someone has an autism spectrum disorder (ASD).

The National Autistic Society describes **autism** as a lifelong developmental condition that affects ‘how a person communicates with and relates to other people, and how they experience the world around them’.

Neurodiversity: We all have individual differences in the way that our brains work. However, there are also groups of people that process information in a similar way to each other and are referred to as having the same neurotype. This means that there can be big differences between different neurotypes.

Neurotypical: The biggest of these neurotypes is referred to as neurotypical. This is the most common neurotype. As neurotypical people are in the majority they tend to thrive as the environment is often constructed by other neurotypical people which means that their specific needs are met.

Neurodivergent: Minority neurotypes can include conditions such as autism, attention deficit hyperactivity disorder (ADHD), dyscalculia, dyslexia and Developmental Coordination Disorder and can also be described as neurodevelopmental conditions. Collectively people with minority neurotypes are referred to as neurodivergent.

1. Introduction

The experiences and outcomes of autistic individuals are, as with any group in society, diverse. The data on their experiences and outcomes is somewhat limited and fragmented, making it difficult to fully understand or measure. Nevertheless, there is evidence that the experiences and outcomes for autistic individuals can fall short of their neurotypical peers. For example, as Chart 1.1 illustrates, overall, disabled autistic individuals in the UK, report much lower levels of wellbeing and higher levels of anxiety than non-disabled individuals. Not all autistic individuals will identify as or be considered disabled [footnote 1]. Nevertheless, this data still provides a useful comparison and helps us better understand how the experiences and outcomes for autistic individuals may fall short of other groups in society.

There is no single reason for the differences in experiences. 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 disabled people more than non-disabled people [footnote 2].

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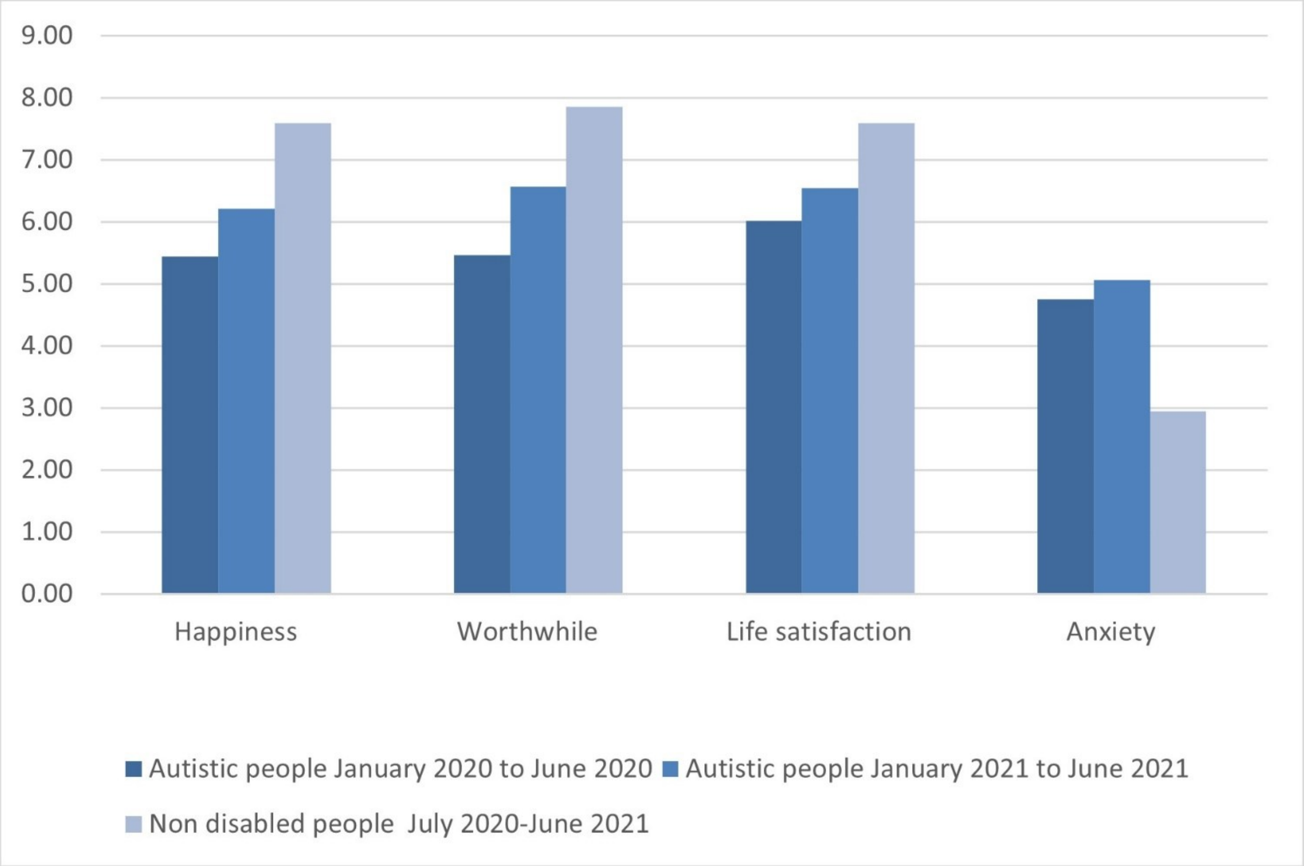
[1] The diagnostic criteria for autism, which include ‘persistent difficulties with social communication and social interaction’ which ‘limit and impair everyday functioning’ (Diagnostic criteria - a guide for all audiences), mean that most autistic individuals would be considered ‘disabled’ by the definition used for the ONS 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’ (Outcomes for disabled people in the UK methodology, 2021 update). However, because the data is based upon self-reported data, some autistic individuals might not consider themselves to be disabled if, for example, their autism does 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 individuals see themselves as disabled depends upon societal attitudes and practices, rather than just the underlying differences.

[2] This is reflected in the lower levels of wellbeing recorded for disabled people in January to June 2020, compared to January 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 [footnote 3] by disabled autistic adults (aged 16 to 64) January to June 2020, January to June 2021 and non-disabled adults (aged 16 to 64) July to June 2021 in the UK



Description of Chart 1.1: A bar chart showing the wellbeing reported by disabled autistic adults and non-disabled adults. It shows that disabled autistic adults reported lower levels of happiness, feelings that life was worthwhile, and satisfaction with life and higher levels of anxiety, than non-disabled adults.

Source: Office for National Statistics, Disability and Well-being (2022b) (using Annual Population Survey data)

In response to the longstanding challenges autistic individuals and their families have faced, the Refreshed Autism Spectrum Disorder: Strategic Action Plan 2016 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, Refreshed Autistic Spectrum Disorder Strategic Action Plan, p.5). The Strategic Action Plan was evaluated in 2019. This evaluation identified that progress had been made in delivering the priorities for action including:

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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'. Question: 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' (Disability and Wellbeing).

- 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 [footnote 4]

- increasing societal awareness and understanding of autism through, for example, training and resources developed by the National Autism Team (NAT) (now the National Neurodivergence Team (NNT)), although the evaluation identified that take-up of some resources was modest

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 Code') 'sets out what autistic individuals, their parents and carers can expect from public services in Wales' (p.1). The Code highlights and reinforces existing duties under the Social Services and Wellbeing (Wales) Act (2014) (SSWBW) and the National Health Service (NHS) (Wales) Act (2006) and was introduced as an alternative to a separate autism bill (the Code of Practice On The Delivery Of Autism Services).

Evaluation aims and objectives

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. The evaluation was structured in two phases. The first phase focused upon a practitioner view of compliance. This second phase broadened the lens to also consider the experience of autistic individuals and the parents and carers of autistic individuals when assessing compliance. The objectives of the second phase were:

- to examine whether the recommendations in meeting the duties of the Code identified in stage 1 have been addressed and identify any challenges service providers have had in implementing the recommendations

- to further assess the extent to which the duties of the Code are being met

- to assess whether service users are aware of the Code and its duties, for example:

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

  - have service users experienced assessments and results of assessments within the timeframe set out in the Code
  - have service users had access to support close to where they live
  - have service users had a say in how services are planned and run
  - have service users been involved in autism training, helping to plan or deliver training
- to assess the extent to which the Code has made a difference to the development and delivery of autism services and develop further recommendations for improvements in meeting the duties of the Code

Structure of the report

Following this introductory section:

- section 2 outlines the evaluation approach and methodology
- sections 3 to 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)
  - planning and commission services (Section 7)
- section 8 considers the experiences of autistic adults and the parents and carers of autistic children and young people
- section 9 considers the likely impact of the Code
- section 10 outlines the conclusions
- section 11 outlines the recommendations

2. Approach and methodology

Introduction

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

- exploring the requirements of the Code
- identifying the extent to which LA and Local Health Boards (LHBs) practice was compliant with the Code. For example, the Code requires that LA and LHBs 'Must' 'Ensure that awaiting a diagnosis is not a reason to be refused support and other services' and the evaluation assessed whether awaiting a diagnosis was a reason why people could be refused support and/or other services
- 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 changessessing the likely impact of changes in practice upon autistic adults, autistic children and their parents or carers

Exploring the requirements of the Code

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 Code of Practice on the Delivery of Autism Services supporting guidance document (Welsh Government, 2021b) and The Evaluation of the SSWBW (2014) Act (Welsh Government, 2023a) and discussed stakeholders' interpretation of the text with:

- the Welsh Government neurodivergence improvement programme team [footnote 6]
- the Welsh Local Government Association (WLGA) NNT/NAT
- regional strategic autism groups

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/NAT and regional strategic autism groups.

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[5] See, for example, HM Treasury Guidance, The Magenta Book: Central Government guidance on evaluation, 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.

The discussions and repeated readings of the Code and supporting documents were used to explore both the intention behind the Code (that is the desired change or outcomes) and the meaning of the Code’s text. This approach was analogous to ‘textualism’ [footnote 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) [footnote 8]. A series of benchmarks (outlined in the appendix – Annex B) were created to ensure that judgments of compliance against each of the duties, outlined in sections 3 to 7, were both transparent and consistent across the seven regions. Nevertheless, inevitably there is still a degree of subjective judgment, and some examples fall on, or close to, the boundary between different categories. Figure 2.1 outlines how the benchmarks were translated into a four-point RAGG (red-amber-green-green) rating scale.

Figure 2.1. RAGG rating of areas compliance

Full compliance + (including going above and beyond the code requirements)	Good progress (but not full compliance with the code)	Mixed or limited compliance / progress to date	No / insufficient evidence to evaluate compliance	Clear evidence of non-compliance	Not applicable
Compliance +	**Good**	**Mixed/ limited**	**Not known**	**Not compliant**	**N/A**

Description of Figure 2.1: Describes the RAGG rating of areas of compliance. Going from a dark green for full compliance to dark red for non-compliance. Overall, the scale has full compliance, good progress, mixed or limited progress, insufficient evidence, non-compliance, and not applicable.

Phase 1 of the evaluation: assessing compliance with the Code

The Evaluation of the Code of Practice on the Delivery of Autism Services: Phase One (a practitioners’ assessment of compliance) was published in 2024. In this first phase, the evaluation reviewed the work each region had undertaken to develop a baseline assessment of their compliance with the Code to identify good practice and also gaps where compliance was not clear. Further research was undertaken where gaps were identified. In support of this, the first phase of the review:

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[7] See, for example, the article, The Rise and Fall of Textualism, for a discussion of textualism.

[8] For example, the meaning of the duty to ‘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 (Code of Practice On The Delivery Of Autism Services, p.12) were interpreted given an understanding of how children or adults would normally access an autism diagnostic assessment service.

- developed new tools and approaches to help gather primarily qualitative data to inform the evaluation of compliance
- interviewed stakeholders (n=25)
- undertook desk-based reviews (for example, of LA and LHB websites and equalities policies)
- discussed the evaluation team's assessment of each area's compliance with regional autism strategic groups

Phase 2 of the evaluation: assessing compliance with the Code

In the second phase, the evaluation sought to take a somewhat different approach. To build on the work undertaken in the first stage and to maximise ownership and understanding of the Code amongst those services with responsibility for complying with the Code, greater emphasis was placed upon encouraging and supporting each region to self-assess their progress and to identify actions that might be required where they were not compliant. To help this, the evaluation team reviewed the lessons from stage 1 and divided the 51 duties in the Code up into four areas, assigning each duty to one of four groups of stakeholders with prime responsibility for specific duties in the Code. These groups consistent of:

- LHB diagnostic assessment services (such as the Children's ND Service, IAS, AMH (Adult Mental Health) and LD (Learning Disability) services) and LHB services for autistic individuals with co-occurring conditions such as CAMHS, AMH and LD services
- LA Information, Advice and Assistance (IAA) and social care assessment teams
- workforce development managers in LAs and LHBs
- the Regional Partnership Board (RPB)

The allocation of duties to each group of stakeholders roughly followed the four sections of the Code, for example:

- LHB diagnostic assessment services were asked to review the duties in section 1 of the Code (Arrangements for Autism Assessment and Diagnosis): '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' (the Code of Practice On The Delivery Of Autism Services, p.12)
- LA IAA services were asked to review the duty in section 2 of the Code (Arrangements for Accessing Health and Social Care Services): 'ensure that as part of their Information, Assistance and Advice Service information is available on local autism services' (Code of Practice On The Delivery Of Autism Services, p. 22)
- LA and LHB workforce development managers were asked to review the duty in section 3 of the Code (Arrangements for Awareness Raising and Training on Autism): 'ensure

that autism awareness training is included in general equality and diversity training programmes offered for all staff working in health and social care' (the Code of Practice On The Delivery Of Autism Services, p. 31)

- RPBs were asked to review the duty in section 4 of the Code (Arrangements for Planning and Monitoring Services and Stakeholder Engagement): 'comply with relevant duties in the SSWBW Act, parts 2 and 9, to ensure that needs of autistic individuals are considered in the development of Population Assessments and Area Plans' (the Code of Practice On The Delivery Of Autism Services, p. 36).

However, the structure of the Code meant that LHB diagnostic assessment services and LA IAA services were also asked to review duties in sections 1, 2 and 3 of the Code; for example, as well as duties in section 1 of the Code (Arrangements for Autism Assessment and Diagnosis), LHB services were asked to review a number of duties in section 2 of the Code (Arrangements for Accessing Health and Social Care Services), such as: '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'. Workforce development managers were also asked to review one duty in section 2 (Arrangements for Awareness Raising and Training on Autism): 'ensure that staff receive appropriate training in autism and associated behaviour and sensory needs at a level appropriate to their involvement' (the Code of Practice On The Delivery Of Autism Services, p. 22).

Moreover, a number of cross-cutting duties in sections 2 (Arrangements for Accessing Health and Social Care Services) and 3 of the Code (Arrangements for Awareness Raising and Training on Autism), such as the duty to 'make arrangements to ensure a range of autism awareness information, resources and training is made publicly available' (ibid., p. 23) and 'ensure that reasonable adjustments are in place for autistic individuals to ensure they are able to access services in the same way as everyone else' (the Code of Practice On The Delivery Of Autism Services, p. 36) were assigned to RPBs to consider, on the basis that no one service had prime responsibility.

Updating the baseline assessment undertaken in phase 1: supporting self-assessment

In order to support the self-assessment of compliance in 2024, roughly one year on from the baseline assessment of compliance in 2023, we provided each group of stakeholders in each region with details of the initial (baseline) assessment of compliance in 2023, and the recommendations made for each duty we asked them to review. Also, where additional information was available, we added this, for example, the stage 1 assessment of compliance (Welsh Government, 2023c) identified very little understanding of compliance in the secure estate. In response, we reviewed His Majesty's Inspectorate of Prison (HMIP) reports for each of the seven secure estate sites in Wales [footnote 9] to identify their findings in

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[9] The Hillside Secure Children's Home in Neath, HMP Parc Young Offenders Institution (YOI) and prison, HMP Cardiff, HMP Parc, HMP Swansea, HMPs Usk and Prescoed and HMP Berwyn.

areas such as access to assessments and staff training and we updated the sections of the initial baseline assessment relating to the secure estate, which we asked LHB and LA services to review [footnote10]. In addition, where there was insufficient information provided in the initial assessment to make a judgment on compliance, we tried to be as clear and explicit as we could be about what additional information would be required to assess compliance.

The evaluation team then reviewed the additional material provided by stakeholders to determine if (a) the additional material was relevant to each of the duties in the Code, and to then consider if (b) we needed to revise our assessment of compliance of each duty, based upon that additional information and the benchmarks developed in phase one. The updated assessments were then shared with regions, to ensure there was an opportunity to correct any mistakes or misunderstandings.

The aim of this approach was twofold:

- to help streamline the process of updating the initial assessment after 12 months and make it more manageable
- to encourage services to focus attention upon those duties they had prime responsibility for, to encourage them to take ownership of these duties and the actions needed to address non-compliance

We aimed to streamline the approach because we observed in the first stage that the length and complexity of the Code caused problems and that there was some uncertainty amongst stakeholders about what information was required to evidence compliance. The feedback we received from stakeholders was that the new approach was effective in streamlining the process of assessing compliance.

However, our assessment was that the revised approach taken in phase two was less successful in encouraging services to take ownership of assessing compliance and identifying actions. We concluded that this was the case, because although there was strong engagement from some services in some regions, there was not in others, with little or no information provided in some cases. Moreover, where information was provided, in some cases the responses raised questions about whether stakeholders:

- were still struggling to understand what the Code requires, including cases where it appeared they lacked confidence in what was required and provided long lists of activity, in the hope that some of it was relevant
- were struggling to devote sufficient time and attention to reviewing compliance

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[10] For example, we updated the assessment of the duties to: ‘ensure that autism assessment and diagnostic services are accessible by individuals detained in the secure estate’ and ‘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’ (Code of Practice On The Delivery Of Autism Services, pp. 12 to 13).

Updating the baseline assessment undertaken in phase one: triangulating data

Compared to phase one, greater emphasis was placed upon self-evaluation in phase two to enable the data provided by self-evaluation to be triangulated and explored from different perspectives. Data was also collected through:

- discussions with the NNT/NAT
- discussions with, and a survey of, ASD leads
- a survey of LA and LHB workforce development leads
- a survey of autistic adults and parents and carers of autistic individuals
- a desk-based review of documents

Collaboration with the NAT/NNT

The NAT was established to help support the roll out of the autism agenda in Wales, including implementation of the Code. Given its role and links to regional strategic groups, LAs and LHBs, and work around awareness raising and training, the evaluation team worked closely with the NAT and the successor organisation, the NNT [footnote 11]. This close collaboration helped ensure that the evaluation could be informed by the work of the NAT/ NNT and, in turn, the evaluation could help inform and support the work of the NAT / NNT.

Survey of Workforce Development Leads

A survey of Workforce Development leads in LA and LHBs was developed and shared in the autumn of 2024 with the help of the NNT. 21 responses were received, including responses from workforce development leads in:

- 17 LAs: one survey response each from Cardiff, Blaenau Gwent, Bridgend, Conwy, Denbighshire, Flintshire, Monmouthshire, Neath Port Talbot, Newport, Pembrokeshire, Powys and the Vale of Glamorgan; two responses each from Carmarthenshire, Ceredigion, Gwynedd and Swansea; and four survey responses from Wrexham
- four LHBs: Aneurin Bevan, Cwm Taf Morgannwg, Hywel Dda and Powys

These responses were used to inform the assessment of each region's compliance to the duties relating to workforce development.

Survey of ASD Leads

A questionnaire for ASD leads was prepared and circulated, to ensure they had an opportunity to provide additional feedback which could be included in the regional assessments of compliance. Four responses were received from ASD leads in Caerphilly,

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[11] In October 2024, the NAT was relaunched as the NNT.

Conwy, Pembrokeshire and Torfaen, and were used as part of the regional assessments of compliance in Gwent, North and West Wales.

Gathering data from autistic adults and parents and carers of autistic individuals on their experience of health and social care services

It was intended that the experiences of autistic adults and the parents and carers of autistic individuals would be explored using surveys and interviews. In order to measure change over time, autistic adults accessing the IAS and parents and carers of autistic children and young people accessing Families First services, would be surveyed at two points in time. However, as outlined below, it was not possible to fully implement the original design.

Surveying parents and carers accessing Families First and adults accessing the IAS

Identifying the experiences of autistic individuals and their parents or carers posed challenges for the evaluation. For example:

- there was no sampling frame from which a representative sample could be drawn (and therefore we cannot report response rates)
- non-probability sampling, such as an open invitation to complete an online questionnaire, created the risks of bias in the sample achieved. This was because there would be little or no control over who responded, making it difficult to judge how representative the responses were

Given these challenges, in order to set a baseline which could be used to measure change over time, it was decided that the evaluation would focus upon the experiences of two defined samples, for which a sampling frame was available: the parents and carers of autistic children accessing Families First services and adults accessing the IAS. Although these two samples would not represent the ‘universe’ of autistic adults and parents and carers of autistic children and young people, it was expected that this approach would provide insights into the experiences of two important groups and would help measure any change in their experiences over time.

A questionnaire for the parents and carers of autistic children accessing Families First services was developed and discussed with the Welsh Government ND Policy, NNT and Families First teams and successfully piloted with the help of Families First services. It was planned that a baseline would be set by running the survey in April 2024 and then running the survey again after around six months in November 2024 to explore if experiences of parents and carers of autistic children accessing Families First services had changed over the intervening period [footnote 12]. The short interval between the base and end line survey was not ideal but was limited by the time available to the evaluation.

However, this was not possible because of delays agreeing and piloting the survey, so there was not sufficient time to run a meaningful follow up survey and instead the evaluation

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[12] The approach is vulnerable to threats to validity such as ‘history’ if, for example, the needs of children accessing Families First services changed over time.

focused upon a wider survey (discussed below) that was not limited to the parents and carers of autistic children accessing Families First services.

A questionnaire for adults accessing the IAS was developed and discussed with the Welsh Government, NNT and Cardiff and Vale IAS. However, attempts to pilot the questions failed because no adults chose to complete the questionnaire and it was agreed with the Welsh Government not to pursue this further.

Surveying autistic adults and parents and carers of autistic children or young people

The Families First questionnaire (outlined above) was used as the basis for a more generic questionnaire that could be completed by both autistic adults and/or parents and carers of autistic individuals (with routing used to ensure the questions were appropriate to each group). This was distributed by intermediary bodies, including the NNT, RPBs, LAs, LHBs and the voluntary sector. In total 442 responses (defined as completed questionnaires) were submitted. This helped offset the problems with other planned strands of the evaluation. The responses are discussed in detail in section 8.

As was the case in relation to the Families First and IAS surveys (discussed above). There was no sampling frame from which a representative sample could be drawn. Therefore, we cannot report response rates, and we cannot be confident that the sample of autistic adults and parents and carers of autistic children or young people is representative. The approach could be described as a type of ‘criterion sampling’, as it was focused upon people defined by either their neurodivergence and/or their particular life experiences as the parent or carer of an autistic individual (see for example, the discussion of Purposive sampling. In The Sage Encyclopaedia of Qualitative Research Methods, pp. 697-8). However, as outlined above, the invitation to take part was distributed by a range of intermediary bodies and there was no sampling frame to draw from and little control over who responded, making it very difficult to judge how representative the people who met the criteria are of the larger group or population of people sharing this characteristic.

In addition, it important to note that the overall results were skewed:

- as Table 2.1 illustrates, women were over-represented in the sample in large part because there were more parents or carers who completed the survey who identified as female than, for example, male autistic adults
- as Table 2.2 shows, roughly half the survey respondents were aged 25 to 44 and roughly 40% were aged 45 to 64, with small numbers aged 16 to 24 and 65 and over
- as Table 2.3 shows, almost 95% identified as ‘White-Welsh, English, Scottish, Northern Irish or British’
- as Figure 2.2 and Table 2.4 illustrate, although there was good spread of representation from across Wales, with responses from every LA in Wales, the population in some LAs were over or under-represented in the sample; for example, there were only two responses from Anglesey and two from Torfaen. In contrast, there were 74 responses from Caerphilly, 47 from Rhondda Cynon Taff and 46 from the Vale of Glamorgan

Table 2.1. The gender of survey respondents

Category (No. of responses)	Female (%)	Male (%)	Other (%)	Prefer not to say (%)
Gender (n=442)	87	10	1	1

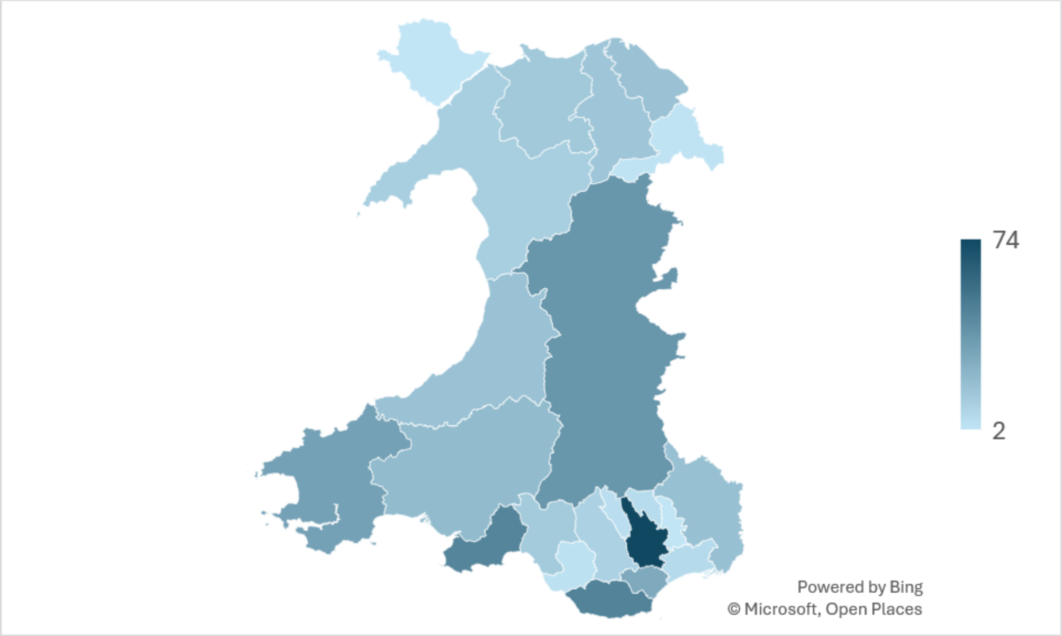
Table 2.2. The age of survey respondents

	16 to 24 (%)	25 to 44 (%)	45 to 64 (%)	65 & over (%)
Age (n=368)	2	54	42	1

Table 2.3. The ethnicity of survey respondents

	White-Welsh, English, Scottish, Northern Irish or British (%)	White Other (%)	All other ethnic groups (%)
Ethnicity (n=431)	94	2	4

Figure 2.2. The Distribution of survey respondents by LA



Description of Figure 2.2: A choropleth map of Wales outlining the distribution of survey respondents by Local Authority.

Table 2.4. The residence of survey respondents

Region	LA	No.	%
Cardiff and Vale	Cardiff	29	7
Cardiff and Vale	Vale of Glamorgan	47	11
Cwm Taf Morganwg	Bridgend	4	1
Cwm Taf Morganwg	Merthyr Tydfil	5	1
Cwm Taf Morganwg	Rhondda Cynon Taff	11	2
Gwent	Torfaen	2	0
Gwent	Blaenau Gwent	6	1
Gwent	Newport	7	2
Gwent	Monmouthshire	19	4
Gwent	Caerphilly	74	17
Swansea Bay	Neath Port Talbot	14	3
Swansea Bay	Swansea	46	10
Powys	Powys	38	9
North Wales	Isle of Anglesey	2	0
North Wales	Wrexham	3	1
North Wales	Gwynedd	12	3
North Wales	Conwy	15	3
North Wales	Denbighshire	16	4
North Wales	Flintshire	18	4
West Wales	Ceredigion	18	4
West Wales	Carmarthenshire	21	5
West Wales	Pembrokeshire	33	7
Total		440	100

As table 2.5. outlines, autistic adults and parents and carers of autistic children and young people completing one of the four survey questionnaires reported accessing wide range of different voluntary sector, LA and LHB services in the last three years. They do not appear to be groups who were not being reached by services.

Table 2.5 The services survey respondents reported the services that they had accessed in the last three years

	Total [1]
A voluntary sector group or organisation	165
NHS Mental Health Services	150
The Children's Neurodevelopmental (ND) Service	139
Local Authority Social Care (this may also be called Social Services, Children's Services or Adult Services)	129
The Integrated Autism Service (IAS)	103
The Local Authority Family Information Service (this may also be called a Family Advice Service)	60
The Local Authority Families First Service	59
NHS Learning Disability Services	31
Other [2]	80

[1] Because respondents could choose more than one service, the total number of services identified is much greater than total number of respondents (N=442)

[2] A range of services were identified, including employment, youth offending and private sector services. However, most written comments in the ‘other’ category recorded the names of voluntary sector groups or organisations.

The lived experience reported by autistic adults and/or the parents/carers of autistic children and young people has been a very important source of data to inform the evaluation. However, the evaluation cannot treat this data as directly comparable to a practitioner’s view of compliance because:

- as outlined above, we cannot confidently assess how representative their experiences are of all by autistic adults and/or the parents and carers of autistic children or young people in a particular region
- the questions asked of autistic adults and/or the parents and carers of autistic children or young people were not always directly comparable with those asked of practitioners. This was because, autistic adults and/or the parents and carers of autistic children or young people and practitioners were likely to have different areas of knowledge. For example, autistic adults and/or the parents and carers of autistic children or young people, would not be expected to know what training had been delivered to health and

social care staff (which practitioners would have), but would be expected to have knowledge of their experiences interacting with health and social care staff

- it is likely that their experiences would often reflect the outcome of a range of factors, including the effectiveness of a number of different policies, rather than the degree of compliance with a single duty. As outlined in section 8 it also appears that experiences of education services in Wales (such as their experiences of school), which is not directly covered by the Code [footnote 13], shaped many people's views and experiences (and their responses to the questions in the surveys)

Therefore, we do not consider the responses from autistic adults and/or the parents and carers of autistic children or young people to be directly comparable, when assessing compliance, and we do not use them as direct evidence of compliance. Nevertheless, there is no suggestion that their responses are not genuine. When discussing findings, stakeholders often confirmed that they were consistent with the anecdotal data and, in some cases, more systematic data (such as the results of surveys or consultations), they had on the experiences of autistic adults and/or the parents and carers of autistic children or young people. In order to provide an indication of how their experiences compare to practitioners' assessments of compliance, we use the RAG rating scale outlined below, in sections 3 to 7.

Figure 2.3. RAG rating of feedback from autistic adults and/or the parents and carers of autistic children or young people.

Good progress: 67 percent or more	Mixed or limited progress: 34 to 66 percent	Not compliant: 33 percent or less
GOOD	**Mixed/ Limited**	**Not Compliant**
…of autistic adults and/or the parents and carers of autistic children and young people give a positive response (for example, 'very easy, quite easy', 'very confident', 'somewhat confident') excluding don't know responses OR give a negative response, such as 'not at all confident'.		

Description of Figure 2.3: Describes the RAG rating of feedback from autistic adults and/or the parents and carers of autistic children or young people. Green indicates good progress (67% or more), amber indicates mixed or limited progress (34 to 66%), and red indicates not compliant (33% or less).

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[13] Education provision for children and young people who have an additional learning need, is covered by The Additional Learning Needs Code for Wales 2021.

Interviews with autistic adults and parents and carers of autistic children and young people

It was intended that the surveys of autistic adults and parents and carers of autistic children and young people would be complemented by interviews with autistic adults and parents and carers. It was planned that they would be contacted with the support of intermediaries, such as third sector organisations like Autism Spectrum Connections Cymru, NAS parents and carers groups, ND services and IAS leads, in order to engage with service users (and those entitled to services who have chosen not to, or who have been unable to, engage with services). Prospective participants were offered a range of ways of taking part, including telephone and video calls using Microsoft Teams or, where participants requested, group discussions and online self-completion questionnaires (discussed above). However, in practice, despite the support of intermediary bodies and potential interest from a handful of people, no autistic adults or parents and carers of autistic children and young people chose to be interviewed. It was agreed with the Welsh Government that the evaluation would respect people’s choices about how they wished to take part in the evaluation, and this strand of the evaluation was halted.

Assessing pre-and post-Code experiences

The Code was published in July 2021 and implemented from 1st September 2021. As the Code is a restatement of existing duties, we judged that it was reasonable to expect and measure compliance from this date (rather than, for example, after a mobilisation or implementation period). Therefore, research with autistic adults and parents and carers of autistic children and young people focused upon their experiences in the last three years. This period was chosen as it covered the period after the Code was published [footnote 14] and to mitigate the risks that interviewees would struggle to accurately recall and describe experiences of more than three years ago.

It was also recognised that people might report a range of experiences, some of which pre-date the Code and some of which came after the Code’s introduction; for example, they might have been diagnosed before 2021 but have sought support from the IAS and/or IAA services more recently.

Exploring the experiences of interacting with IAA services and LA/LHB websites

It was also planned to use engagement with autistic adults and parents and carers of autistic children and young people as way of exploring their experiences of interacting with IAA services and LA/LHB websites. It was planned that autistic adults and the parents and carers of autistic children who took part in the research (as interviewees or group discussants), who had not accessed IAA services and/or websites would be invited to do so and to then provide feedback to the evaluation team on their experiences. This would have been analogous to a ‘mystery shopper’ style approach but would, for example, avoid placing any unnecessary demands upon services (as people would be accessing services they are entitled to) and would aim to make their interaction with services as natural as possible (as it

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[14] The timing of experiences will be considered when assessing impact (for example, if the experiences relate to a period of time before or after practitioners’ report that changes have been made to that service).

would involve autistic adults or the parents and carers accessing those services). Interviewing or seeking feedback from service users about their experiences (as this approach would do) is standard practice and it was judged that the ethical risks associated with this approach were minimised. Unfortunately, as outlined above, no autistic adults and the parents and carers of autistic children chose to be interviewed, it was not possible to implement this strand of the evaluation.

Desk-based review

Wherever possible, data provided through self-evaluation was triangulated with secondary sources, for example:

- LA and LHB websites were reviewed when considering the assessment of practitioners about duties relating to the provision of information about autistic individual's rights or pathways to services [footnote 15]
- RPB documents, such as the Population Needs Assessment (PNA), were reviewed when considering duties relating to PNAs [footnote 16], and LA and LHB documents, such as strategic equality plans, when considering duties in relation to the duty to make reasonable adjustments [footnote 17]
- other research and evaluations, such as the Health Inspectorate Wales (HIW), Estyn and Care Inspectorate Wales (CIW) review of support for young people's mental health (2024), were reviewed when considering access to services for autistic young people with co-occurring conditions and, as noted above, HMIP reports when considering duties relating to the secure estate

Analysing and triangulating data from different sources

Different approaches were taken to analysing data from different sources. For example, data gathered through:

- discussions with the NNT/NAT were used to improve our understanding of the Code requirements, to explore how best to assess compliance and to discuss the evidence collected in compliance. The data gathered in this way was not formally coded, but was synthesised with data collected through, for example, our own reading of the Code

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[15] This included for example, duties in section1 of the Code, such as: 'ensure there is information and signposting to access assessment services' and 'ensure that autistic individuals are aware of the right to access a needs assessment and a carer's assessment for a carer' (Code of Practice On The Delivery Of Autism Services, p. 12) and in section 3 of the Code, such as: 'make arrangements to ensure a range of autism awareness information, resources and training is made publicly available' (Code of Practice On The Delivery Of Autism Services, p. 31).

[16] The duty in section 4, 'comply with relevant duties in the SSWBW Act, Parts 2 and 9 to ensure that needs of autistic individuals are considered in the development of Population Assessments and Area Plans' (Code of Practice On The Delivery Of Autism Services, p. 36).

[17] The duty in section 4: 'ensure that reasonable adjustments are in place for autistic individuals to ensure they are able to access services in the same way as everyone else'.

- surveys of ASD leads, LA and LHB workforce development leads, autistic adults and the parents and carers of autistic individuals, generated quantitative and qualitative data. Quantitative data was analysed by creating descriptive statistics to describe the data and to aid comparison between different groups of respondents and across different surveys. Qualitative data, such as comments made by respondents, were manually coded. The codes were then used to develop and identity themes in the responses, which were interpreted and reported through the use of illustrative quotes

- the desk-based review of documents involved content analysis (to identify the meaning and intent of texts) followed by extraction of data on significant elements of the texts, such as policy objectives

- self-evaluation/assessment data provided by practitioners involved content analysis (to identify the meaning and intent of texts) followed by extraction of data on elements of the texts, such as the different types of evidence provided to demonstrate their assessment of compliance with different duties

Each case where data provided by practitioners was inconsistent with other sources was considered on a case-by-case basis, for example, where practitioners had identified websites as an important source of public information and, in our judgment, the information on the web pages was inadequate in line with the benchmarks developed in stage 1, this directly informed our assessment for compliance.

As sections 3 to 7 outline, the feedback from autistic adults and the parents and carers of autistic children and young people was often not consistent with the assessment of practitioners, because this data might not be:

- directly comparable to the practitioner’s assessments as, for example, it might relate to experiences that predated the Code [footnote 18]

- representative of the experiences of all autistic parents and carers in a particular region

Accordingly, we did not use it to change the assessment of compliance which, as noted, was based primarily upon data provided by practitioners triangulated, where possible, with other sources. However, we noted that the feedback from autistic adults and parents and carers of autistic children and young people was not consistent, and we added a note of caution when we provided each region with the updated assessment of compliance.

Assessing the likely impact of changes in practice

The evaluation took a theory-based approach to assessing the likely impact of change in practice, such as changes in LA and LHB services, considering factors such as:

- the type, nature and scale of the change in practice

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[18] Although steps were taken to mitigate this, and autistic adults and parents and carers of autistic children and young people were asked about their experiences in the last three years (that is to say, in a period after the Code was introduced) it appeared that in some cases, historical experiences of services (which may have predated the Code, or improvements in services) often shaped their views.

- the aspirations, experiences and needs of different groups (for example, autistic adults, autistic children and their parents or carers)
- the likely impact of changes in practice on the aspirations, experiences and needs of different groups

Data to text and explore the theory of change was drawn form a number of sources using different approaches, including:

- interviews with stakeholders
- feedback from autistic adults and the parents and carers of autistic children and young people (discussed further in section 8)
- a desk-based review of prior research, such as previous evaluations of the Autism Strategy in Wales (Evaluation of the Integrated Autism Service and Autistic Spectrum Disorder Strategic Action Plan: final report) which explored the aspirations, experiences and needs of autistic individuals and their families in Wales

Developing recommendations for Phase 2

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 [footnote 19] within and across the regions, to develop recommendations to improve compliance with the Code.

Strengths and limitations of the approach and methodology

The assessment of compliance with the Code is based, to a large degree, on data provided by practitioners. Given their knowledge and involvement in developing and delivering LA and LHB and/or RPB policy and practice, in many ways the practitioners who updated the assessment were the best placed people to judge compliance with the Code. Therefore, this should be considered a strength of the evaluation.

The length and complexity of the Code proved to be a barrier to assessing compliance as stakeholders' interpretations of the Code sometimes differed. The evaluation sought to mitigate these risks by developing a range of tools and support and working closely with the NAT/NNT. As outlined above, the changes made in phase 2 of the evaluation to streamline the process, were welcomed by practitioners. In addition, as outlined throughout sections 3 to 7, although progress has been made since 2023, there are still gaps in some areas, most notably practice in AMH and LD services, where there was insufficient information to make a firm judgment on compliance.

Although the assessment is primarily based upon accepting practitioners' judgments of compliance and (importantly) the data they provided to evidence their judgments, the

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

evaluation did not simply uncritically accept practitioners’ judgments of compliance. Their views were tested and challenged through, for example:

- interviews and evidence gathered though desk-based research
- the triangulation of responses from different stakeholders (including both practitioners and people with lived experience of LA and LHB services) and different sources
- a rigorous theory-based approach to evaluating the likely impact of the Code

It is important to bear in mind that the extent to which the evaluation team could triangulate data from different sources to provide greater confidence in the accuracy of practitioner assessments differed, for example, as noted:

- the evaluation team could easily review publicly available information on, for example, LA and LHB websites, when considering public information on autism services [footnote 20]
- however, they could not easily independently review the training delivered to staff within services [footnote 21]

Exploring the confidence that people with lived experience (that is to say autistic adults and the parents and carers of autistic children or young people) had that health and social care staff, for example, understood autism, provided one way of exploring these questions. However, this was not perfect, for example:

- training is likely to be only one of a number of factors that shapes people’s experiences of services and consequently their confidence that staff understand autism. Therefore, their views cannot be considered a direct measure of the delivery of training
- as outlined above, we cannot be confident that the experiences of the 442 autistic adults and/or parents and carers of autistic children or young people, who took part in the evaluation are wholly representative

The consistency of responses from autistic adults and/or parents and carers of autistic children or young people across Wales suggest they should not be dismissed lightly as atypical experiences. They provide an important note of caution against any complacency on the part of RPB, LA or LHBs. They also highlight the importance of involving people with lived experience in developing and evaluating policy to better understand how policy is experienced in practice and what impact it is making to people’s lives.

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[20] For example, the duty, to ‘make arrangements to ensure a range of autism awareness information, resources and training is made publicly available‘ (Code of Practice on the Delivery of Autism Services, p. 31).

[21] For example, the duty 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….’ (Code of Practice on the Delivery of Autism Services, p. 30).

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

Introduction

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 (Evaluation of the Integrated Autism Service and Autistic Spectrum Disorder Strategic Action Plan: final report) 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.

Section 1 of the Code includes eight duties covering diagnostic 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 NICE best practice guidance for multidisciplinary involvement
- compliance with the national waiting time target for children [footnote 22] (Code of Practice On The Delivery Of Autism Services)

Diagnostic assessment services

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

- children's ND services which offer diagnostic assessments for children (up to the age of 18)
- the IAS, which offers diagnostic assessments for adults not eligible for an assessment by LD or AMH services
- LD and MH services for adults (with an LD or MH condition [footnote 23])

As Table 3.1 illustrates, compliance with the Code differs for these different types of diagnostic assessment services. As section 2 outlines, the assessment of compliance is

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

[23] The National Service model for the IAS identifies that 'the service will provide diagnostic assessment for those aged 18 and over who are not eligible for diagnostic assessment from LD or MH services due to eligibility exclusion' (Integrated Autism Service: Supporting Guidance).

ranked on a four-point RAGG scale [footnote 24], using the colour codes illustrated by Figure 3.1. For each duty, the tables present:

- the baseline assessment in 2023
- the updated assessment of compliance in 2025

Figure 3.1. Key to Table 3.1 to 3.7. RAGG rating of compliance

Full compliance + (including going above and beyond the code requirements)	Good progress (but not full compliance with the code)	Mixed or limited compliance / progress to date	Clear evidence of non-compliance	No / insufficient evidence to evaluate compliance	Not applicable
Compliance +	**Good**	**Mixed/ Limited**	**Not compliant**	**Not known**	**N/A**

Description of Figure 3.1: The key to table 3.1 to 3.5. It describes the RAGG rating of areas of compliance. Overall, the scale has full compliance (compliance +), good progress (good), mixed or limited progress (mixed/ limited), non-compliance (not compliant), insufficient evidence (not known), and not applicable (N/A).

In addition, where applicable, feedback from autistic adult and/or the parents and carers of autistic children and young people is presented, using a three-point RAG scale illustrated by figure 3.2.

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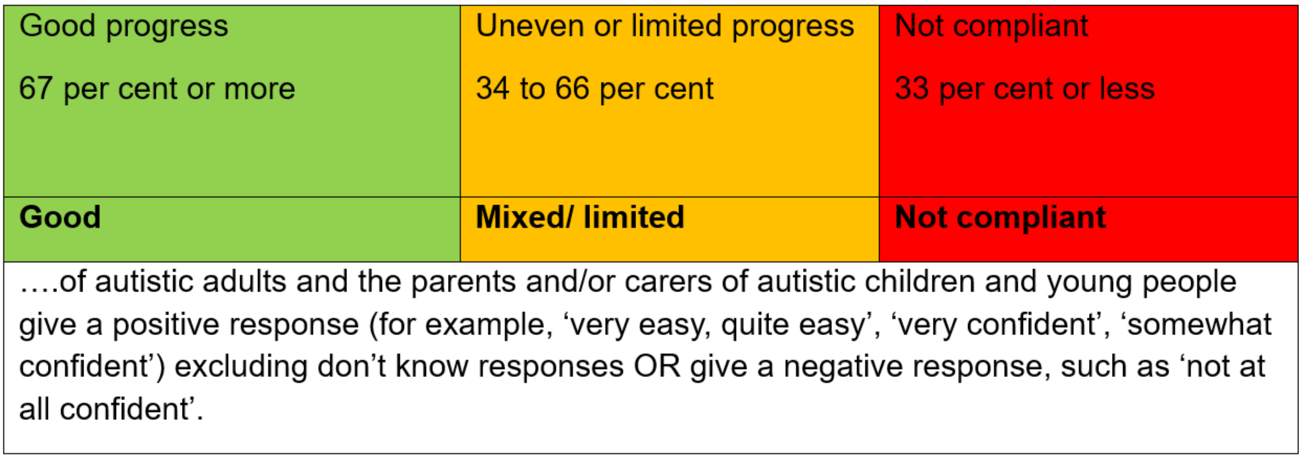
[24] The benchmarks used to judge compliance against are included in Appendix A.

Figure 3.2. Key to RAG rating of feedback from autistic adults and/or the parents and carers of autistic children or young people.



Good progress 67 per cent or more	Uneven or limited progress 34 to 66 per cent	Not compliant 33 per cent or less
Good	**Mixed/ limited**	**Not compliant**
….of autistic adults and the parents and/or carers of autistic children and young people give a positive response (for example, ‘very easy, quite easy’, ‘very confident’, ‘somewhat confident’) excluding don’t know responses OR give a negative response, such as ‘not at all confident’.		

Description of Figure 3.2: Describes the RAG rating of feedback from autistic adults and/or the parents and carers of autistic children or young people. Green describes good progress with 67 percent or more (good), amber is mixed or limited progress with 34 to 66 percent (mixed/ limited), and red is not compliant with 33 percent or less (not compliant).

Table 3.1.1. Section 1 of the Code: Access to diagnostic assessment services (multidisciplinary involvement)

Duty: 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.

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
ND 2023	Good	Good	Good	Good	Good	Good	Good
ND 2025	Good	Good	Good	Good	Good	Good	Good
IAS 2023	Good	Mixed/ limited	Good	Good	Good	Good	Good
IAS 2025	Good	Good	Good	Good	Good	Good	Good
AMH 2023	Good	Not known	Not known	Not known	Not known	Not known	Good
AMH 2025	Mixed/ limited	Not known	Not compliant	Not known	Not known	Not known	Good
LD 2023	Not known	Not known	Not known	Not known	Not known	Not known	Not known
LD 2025	Not known	Not known	Not compliant	Not known	Not known	Not known	Not known

Table 3.1.2. Section 1 of the Code: Access to diagnostic assessment services (in the secure estate)
Duty: LHBs must ensure that autism assessment and diagnostic services are accessible by individuals detained in the secure estate.

Notes	**Cardiff & Vale**	**CTM**	**Gwent**	**N Wales**	**Powys**	**West Glam**	**West Wales**
Children 2023	N/A	Mixed/ limited [Parc YOI]	Not known [Prescoed YOI]	N/A	N/A	Not known [Hillside LASCH]	N/A
Children 2025	N/A	[Parc YOI]	Not known [Prescoed YOI]	N/A	N/A	Not known [Hillside LASCH]	N/A
Adults 2023	Not known [Cardiff]	Mixed/ limited [Parc]	Not known [Usk]	Not known [Berywn]	N/A	Not known [Swansea]	N/A
Adults 2025	Not known [Cardiff]	Mixed/ limited [Parc]	Mixed/ limited [Usk]	Good [Berywn]	N/A	Not known [Swansea]	N/A

Table 3.1.3. Section 1 of the Code: Access to diagnostic assessment services (referral pathways)

Duty: LHBs must: ensure that primary and secondary care practitioners are notified of assessment referral pathways for children, young people and adults.

Notes	**Cardiff & Vale**	**CTM**	**Gwent**	**N Wales**	**Powys**	**West Glam**	**West Wales**
ND 2023	Good	Not known	Good	Good	Mixed / limited	Not known	Mixed / limited
ND 2025	Good	Good	Good	Good	Good	Mixed / limited	Mixed / limited
IAS 2023	Good	Good	Good	Mixed / limited	Mixed / limited	Good	Mixed / limited
IAS 2025	Good	Good	Good	Good	Good	Good	Good
AMH/LD 2023	Good	Mixed / limited	Good	Mixed / limited	Mixed / limited	Not known	Mixed / limited
AMH/LD 2025	Mixed / limited	Mixed / limited	Not known	Not known	Not known	Not known	Mixed / limited
Lived Experience [footnote 25]	Not compliant	Mixed / limited	Mixed / limited	Mixed / limited	Good	Not compliant	Mixed / limited

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[25] Based upon responses from autistic adults and the parents and carers of autistic children and young people to the question: ‘How confident are you that health workers, like GPs and nurses know how to refer people for an assessment?’ answering ‘not at all’.

Table 3.1.4 Section 1 of the Code: Access to diagnostic assessment services (referral pathways)
Duty: LA with LHBs must: designate an individual with lead responsibility for maintaining, reviewing and promoting diagnostic pathways for children, young people and adults.

Notes	**Cardiff & Vale**	**CTM**	**Gwent**	**N Wales**	**Powys**	**West Glam**	**West Wales**
ND 2023	Mixed / limited	Not known	Good	Good	Good	Not known	Good
ND 2025	Good	Good	Good	Good	Good	Not known	Good
IAS 2023	Good	Not compliant	Good	Good	Good	Mixed / limited	Good
IAS 2025	Good	Good	Good	Good	Good	Good	Good
AMH 2023	Good	Not known	Not known	Not known	Not known	Not known	Good
AMH 2025	Not known	Not known	Mixed / limited	Not known	Not known	Not known	Good
LD 2023	Good	Not known	Not known	Not known	Not known	Not known	Not known
LD 2025	Not known	Not known	Not known	Not known	Not known	Not known	Not known

Table 3.1.5. Section 1 of the Code: Access to diagnostic assessment services (waiting times and data collection)
Duty: LHBs must: comply with current national waiting time standards for assessment and diagnosis.

Notes	**Cardiff & Vale**	**CTM**	**Gwent**	**N Wales**	**Powys**	**West Glam**	**West Wales**
ND 2023	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant
ND 2025	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant

Table 3.1.6 Section 1 of the Code: Access to diagnostic assessment services (waiting times and data collection)
Duty: 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.

Notes	**Cardiff & Vale**	**CTM**	**Gwent**	**N Wales**	**Powys**	**West Glam**	**West Wales**
ND 2023	Good	Good	Good	Good	Good	Good	Good
ND 2025	Good	Good	Good	Good	Good	Good	Good
IAS 2023	Good	Good	Good	Good	Good	Good	Good
IAS 2025	Good	Good	Good	Good	Good	Good	Good

Table 3.1.7 Section 1 of the Code: Access to post-diagnostic assessment support
Duty: 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.

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
ND 2023	Good	Not known	Good	Mixed / limited	Good	Not known	Mixed / limited
ND 2025	Good	Good	Good	Mixed / limited	Good	Not known	Good
IAS 2023	Good	Good	Good	Mixed / limited	Good	Not known	Mixed / limited
IAS 2025	Good	Good	Good	Mixed / limited	Good	Good	Good
AMH/LD 2023	Not known	Not known	Not known	Not known	Not known	Not known	Mixed / limited
AMH/LD 2025	Not known	Not known	Not known	Not known	Not known	Not known	Mixed / limited

Access to services: Referral pathways

As Table 3.3 illustrates, there has been little change since 2023 and across the seven regions awareness of diagnostic assessment and referral pathways differs for different services:

- a national pathway for children's ND services was established in 2015. Although the very high level of referrals to the services indicates that people are accessing them, in a number of regions it is reported that pathways to access children's ND services can feel somewhat opaque and/or complex to parents and carers to understand. For example:
    - there can be different pathways for preschool and school age children
    - to help strengthen screening, the information required from referrers can be extensive, and may be required from several different referrers
    - a number of regions have recently reviewed or are in the process of reviewing and revising pathways and paperwork
    - as a result, stakeholders sometimes raised concerns about difficulties accessing ND services
- a national pathway for the IAS was established in 2017 and pathways to individual IASs are generally clear and well publicised on LHB websites
- pathways into other diagnostic services, such as AMH and LD services are not publicised and are internal pathways within services, as they would generally only be followed by adults already accessing these secondary services. Understanding of how these pathways operate is generally limited amongst the practitioners involved in assessing compliance

Although there are examples like Hywel Dda 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, as Table 3.3 illustrates, 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 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 for diagnosing autism (including children's ND, IAS, MH and LD service pathways).

Diagnostic assessment services: Children's ND services and the IAS

As Tables 3.1 to 3.7 illustrate, there has been little change since 2023 in relation to children's ND services and the IAS and, for most duties in the Code, 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 and means that, in effect, the Code simply codified existing practice. However:

- all regions have struggled to meet the waiting time target for children, given the mismatch between demand and capacity (see for example, the Review of Neurodevelopmental Services); the mismatch between demand and capacity and, in some regions, difficulties recruiting and retaining staff, mean services are under considerable pressure (the Review of Neurodevelopmental Services) which may threaten the sustainability of teams and services and continued compliance with the Code
- 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 include guidance for multidisciplinary involvement. However, difficulties some services face in 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 (Welsh Government, 2022), the recent review of ND services undertaken by the NHS Delivery Unit and the Rapid Design of Improvements to NHS Assessment and diagnosis waiting times for Wales, are all important here.

In terms of signposting there are good examples of how information on 'what to expect' can be provided on websites such as CTMUHB IAS webpage. while the PTHB children's ND service webpage has been reviewed and available via the Neurodevelopmental Service internet page for families and professionals (and also the Powys County Council website). The Webpage includes information on the referral and diagnostic assessment process and will be subject to further review and design by the Powys ND Parent or Carer Co-Production forum.

Although demand-capacity pressures continue to challenge services, it is important to note that the quality of data collection is improving and this, coupled with changes in the way children's ND services are operating, means progress has been made in reducing waiting times. Further progress is expected, supported by further investment of £3m, announced in a written statement on reducing long NHS waiting times in November 2024, to reduce the longest waiting times for children's neurodevelopmental assessments across Wales and support the wider work the NHS Executive and LHBs are undertaking to transform services.

LD and AMH Services

As the tables in this section illustrates, 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 AMH services (Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan: Final Report). 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 AMH services is more complex. Efforts were made through the All Wales Diagnostic Network to build capacity within AMH services (as well as LD services) (Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan: Final Report). 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 AMH services in one region, as attention and clinicians moved to the IAS. The Code should be increasing regional scrutiny of practice in these services, and, in some cases, this is happening leading to a downgrading of the assessment of compliance, which is important and provides the foundations for making improvements. However, there is little evidence that, at this stage, the Code has led to changes in practice in LD and AMH services.

Access to a diagnostic assessment in the secure estate

In April 2006, LHBs became responsible for commissioning healthcare for public sector prisons in their area. Therefore, for both children and adults, the responsibility for providing access to diagnostic assessments rests with the LHB where the secure estate is located. In Wales there are:

- two young offender institutions (YOI); HMP Parc [footnote 26] in Bridgend, which has a unit for 15 to 17 year olds and HMP Prescoed, a men's open prison and YOI in Monmouthshire, and Hillside Secure Children's Home in Neath, so responsibility lies with Cwm Taf Morgannwg, Aneurin Bevan and the Swansea Bay University Health Board (UHB)
- five prisons housing adults in Wales: HMP Cardiff, HMP Parc, HMP Swansea, HMPs Usk and Prescoed and HMP Berwyn, so responsibilities for adults rest with Cardiff and Vale UHB, Swansea Bay UHB, Aneurin Bevan UHB and Betsi Cadwaladr UHB

There remains a lack of scrutiny by regional strategic groups of services for access to diagnostic assessment for those in the secure estate and, as noted in section 2, much of the assessment was based upon a desk-based review of HMIP reports rather than information provided by practitioners. This remains a concern as it is widely assumed that the

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[26] 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 and the re-organisation of the Swansea Bay and Cwm Taf Morgannwg LHBs.

prevalence of autism is markedly higher in the criminal justice system than in the general population (Neurodiversity In The Criminal Justice System: A review of evidence).

Data collection

Data collection requirements differ for each service. The IAS is subject to the most comprehensive data collection, with data collected by Data Cymru for the NNT/NAT. 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 [footnote 27]. As Table 3.4 outlines, there were no concerns raised about collection of this data in 2023, and this remains the case in 2025.

In contrast, 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 constraint on understanding their performance. Moreover, as outlined above, regional autism strategic groups have tended to focus upon the children's ND service and IAS, meaning practice within LD and AMH services has not been subject to the same degree of scrutiny and oversight. One of the effects of the Code has been to begin to cast a spotlight upon pathways to, and practice in, these services.

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[27] 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.

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

Autistic individuals and their parents and carers may have health and/or care and support needs and therefore it is 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 (Evaluation of the Integrated Autism Service and Autistic Spectrum Disorder Strategic Action Plan: final report) 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 LAs and/or health boards ensure that:

- there is 'information and signposting to access assessment services'
- 'autistic individuals are aware of the right to access a needs assessment and a carer's assessment for a carer'
- 'that as part of their Information, Assistance and Advice [IAA] Service, information is available on local autism services' (Code of Practice On The Delivery Of Autism Services, pp. 12 to 33, 22 to 23)

As in section 3, the assessment of compliance is ranked on a four point RAGG scale [footnote 28], using the colour codes illustrated by figures 3.1 and 3.2; for each duty, the tables present:

- the baseline assessment in 2023
- the updated assessment of compliance in 2025
- where applicable, feedback from autistic adults and/or the parents and carers of autistic children and young people

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[28] The benchmarks against which compliance is judged are included in appendix A.

Table 4.1.1. Section 1. Access to a social care assessment (information and signposting)
Duty: LAs must: ensure there is information and signposting to access assessment services.

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
2023	Good	Good	Mixed / limited	Mixed / limited	Good	Good	Mixed / limited
2025	Good	Good	Good	Mixed / limited	Good	Good	Mixed / limited

Table 4.1.2. Section 1. Access to a social care assessment (aware of the right to an assessment)

Duty: LAs must: ensure that autistic individuals 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.

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
Children 2023	Mixed / limited	Not known	Not compliant	Mixed / limited	Mixed / limited	Mixed / limited	Not compliant
Children 2025	Compliance +	Not compliant	Mixed / limited	Mixed / limited	Good	Mixed / limited	Mixed / limited
Adults 2023	Good	Not compliant	Not compliant	Mixed / limited	Mixed / limited	Mixed / limited	Not compliant
Adult's 2025	Good	Not compliant	Mixed / limited	Mixed / limited	Good	Mixed / limited	Mixed / limited

Table 4.1.3. Section 1. Access to a social care assessment (aware of the right to an assessment survey responses)

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
Lived Experience: children's rights [footnote 29]	Mixed / limited	Good	Mixed / limited	Mixed / limited	Mixed / limited	Mixed / limited	Mixed / limited
Lived Experience: adults' rights [footnote 30]	Mixed / limited	Not compliant	Mixed / limited	Mixed / limited	Mixed / limited	Good	Not compliant
Lived Experience: carers' rights [footnote 31]	Mixed / limited	Not compliant	Mixed / limited	Mixed / limited	Mixed / limited	Mixed / limited	Mixed / limited

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[29] Based upon the proportion of parents and carers of autistic children and young people who when asked 'do you know that if your child/children may need help or support from social services, you have a right to an assessment of those needs?' responded 'yes'.

[30] Based upon the proportion of autistic adults who when asked 'do you know that if you may need help or support from social services, you have a right to an assessment of those needs?' responded 'yes'.

[31] Based upon the proportion of parents and carers of autistic children and young people who when asked 'do you know that if you may need help or support from social services as a carer you have a right to an assessment of those needs?' responded 'yes'.

Table 4.1.4. Access to a social care assessment (prompt sharing of information)
Duty: 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.

Notes	**Cardiff & Vale**	**CTM**	**Gwent**	**N Wales**	**Powys**	**West Glam**	**West Wales**
Children 2023	Mixed / limited	Not known	Mixed / limited	Mixed / limited	Good	Not known	Good
Children 2025	Mixed / limited	Good	Good	Mixed / limited	Good	Not known	Good
IAS 2023	Good	Good	Mixed / limited	Mixed / limited	Good	Good	Mixed / limited
IAS 2025	Good	Good	Good	Good	Good	Good	Good

Notes	**Cardiff & Vale**	**CTM**	**Gwent**	**N Wales**	**Powys**	**West Glam**	**West Wales**
AMH/LD 2023	Good	Not known	Not compliant	Not known	Not known	Not known	Not known
AMH/LD 2025	Good	Not known	Not compliant	Not known	Not known	Not known	Not known

Table 4.2. Section 1. Access to a social care assessment (secure estate)
Duty: LAs with LHBs 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.

Notes	**Cardiff & Vale**	**CTM**	**Gwent**	**N Wales**	**Powys**	**West Glam**	**West Wales**
Children 2023	Not known	Not known	Not known	Not known	Not known	Not known	Not known
Children 2025	Not known	Good	Not known	Not known	Not known	Not known	Not known
Adults 2023	Not known [Cardiff]	Not known [Parc]	Good [Usk]	Not known [Berywn]	N/A	Not known [Swansea]	N/A
Adults 2025	Good [Cardiff]	Good [Parc]	Good [Usk]	Good [Berywn]	N/A	Not known [Swansea]	N/A

Access to a social care assessment [footnote 32]

Signposting to social care assessment via IAA services and, as Table 4.1 illustrates, information on how to access social care assessments via IAA services is generally well publicised on LA websites. The introduction of a single 'front doors' to children and adult services has simplified pathways and it was widely reported that practitioners in, for example, the children's ND service and IAS, play an important role in providing information and signposting people to assessment services, where appropriate. However, the steps taken to ensure that health and LA staff are aware of the IAA service and how to refer autistic individuals 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.

Moreover, while progress has been made, in some areas, particularly in relation to children, the evaluation team identified concerns that parents and carers of autistic children might be discouraged from seeking an assessment for children, given the association of 'assessments' with 'child protection' on LA webpages. This reflects the stigma and/or fear that can be associated with seeking help from social services; stigma, as parents and carers may feel they have somehow 'failed' and fear about the involvement of social services in their family lives. These concerns, particularly mistrust of social services, or a feeling that they were being blamed, was reflected in a small number of the comments made by the parents and carers of autistic children and young people (discussed in section 8). Nevertheless, it may be possible to overstate the degree of mistrust in social care; for example, in 2023, a Public Perceptions Survey identified that 72% of people said that they had confidence in people working in social care (Social Care Wales, 2023) [footnote 33].

In addition, as Table 4.1 illustrates, in the judgment of the evaluation team, no region consistently ensures that all autistic individuals are aware of the right to access a needs assessment and that all carers are aware of their right to a carer's assessment [footnote 34]. This information is rarely publicised on LA websites and stakeholders report concerns that publicising the right would increase pressure upon social services, but was unlikely to mean that more people would be identified as having 'eligible needs' [footnote 35]; for example, 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. However, 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.

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

[33] This is based upon an unpublished survey of 1000 people discussed in the Valuing Social Care in Wales report.

[34] As outlined in the SSWBA Guidance (Welsh Government, 2019): 'any individual or family with a care and support need has a right to an assessment on the basis of that need'.

[35] 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' (Assessing and Meeting the Needs of Individuals, p.1).

More fundamentally, as the feedback from autistic adults and the parents and carers of autistic children and young people (discussed in section 8) illustrates, even where people were aware of their rights, there was little confidence that they could either access an assessment or that an assessment would help; this may reflect:

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

Therefore, LAs may be compliant with the Code, but this is not necessarily what people want.

Finally, in relation to children, the development of a single point of access for a range of services, such as the SPACE-WB panel, which is seen as good practice (No Wrong Door: bringing services together to meet children’s needs), 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 or to other support that could help meet needs. This is consistent with the spirit, although arguably not the letter (or text), of the Code [footnote 36]. The Welsh Government has confirmed that, despite the wording of the Code, such practice would be considered compliant with the Code.

The skills that staff require to undertake a social care assessment are considered in section 6.

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[36] 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’ (Code of Practice On The Delivery Of Autism Services, p.12).

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 correspondence (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 email includes information about parent or carer assessments and how to access them; and in Torfaen, the Autism Support Officer works with parents and carers of autistic children and shares information about accessing social care assessments when they talk to families and can act as a liaison between families and services
- 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 reasons why someone might need help and support from social services
- 'mainstreaming' autism into local offers; for example, in Carmarthenshire, ALN Parent or Carer drop-in sessions are provided by the Parent Partnership. These provide the opportunity for parents to discuss concerns with Family Liaison Officers. In Carmarthenshire information on the IAS is provided on the CCC FIS website and there is a Disability and Autism webpage which provides useful information in a single place for children and young people with ALN and disabilities and their families. The Connecting Carmarthenshire website has also been established (with an Autism page) which publicises events and opportunities for adults
- ensuring that staff have access to up to date and reliable information, for example, Bridgend has a regularly updated directory of autism services, and all staff have an icon on their computer to access it. Children's, young people's and adults' services can send it out to autistic individuals and to parents and carers and to third sector partners. Bridgend CBC is working on embedding autism IAA into all general IAA, which warrants further investigation as a potential example of good practice

Information sharing between diagnostic and social care services

As Table 4.1 illustrates, there remains in 2025 a patchy picture in relation to information sharing and referrals between autism diagnostic services and social care services. As outlined above, there is a reluctance to make a referral for, or to encourage adults or parents and carers of autistic children and young people to self-refer to, social services, unless diagnostic assessment services believe they are likely to have eligible needs. However, where it is felt that an individual might have eligible needs, it is reported that referrals are made, and information is shared.

It was also reported that 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 to be already known to these services).

Access to a social care assessment in the secure estate

As Table 4.2 illustrates, the picture that emerges in 2025 in relation to access to social care assessments in the secure estate is, on the surface, positive, with progress appearing to be made [footnote 37]. However, as outlined in section 2, much of this is based upon a desk-based review of HMIP reports (undertaken by the evaluation team) and there is a patchy understanding of arrangements in regional strategic groups. Moreover, particularly in relation to children, where the responsibility for the care and support needs of a Welsh child falls on their Welsh home LA, it is very difficult to assess how the duty is fulfilled. This is because social care services in the secure estate appear to be provided by the LA where the secure estate is sited (so for example, Bridgend CBC deliver social care to those who are eligible in Parc YOI).

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[37] An 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).

Table 4.3.1 Section 2. Access to information about autism services (practitioners and services are aware of autism services and have clear referral pathways)

Duty: 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.

Notes	**Cardiff & Vale**	**CTM**	**Gwent**	**N Wales**	**Powys**	**West Glam**	**West Wales**
Children 2023	Mixed/ limited	Mixed/ limited	Good	Mixed/ limited	Mixed/ limited	Not known	Mixed/ limited
Children 2025	Good	Mixed/ limited	Good	Good	Mixed/ limited	Mixed/ limited	Good
Adults 2023	Mixed/ limited	Mixed/ limited	Mixed/ limited	Mixed/ limited	Mixed/ limited	Mixed/ limited	Mixed/ limited
Adults 2025	Good	Mixed/ limited	Good	Good	Mixed/ limited	Mixed/ limited	Good
Lived Experience [footnote 38]	Not Compliant	Not Compliant	Not Compliant	Not Compliant	Not Compliant	Not Compliant	Not Compliant

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[38] Based upon the proportion of autistic adults and parents and carers of autistic children and young people who when asked 'how confident are you that social care staff like social workers, care workers, and family and parenting support services know how to refer people for an assessment?' responded 'not at all'.

Table 4.3.2. Section 2. Access to information about autism services (Health and local authority staff are aware of the Information, Advice and Assistance service)

Duty: 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 individuals to the service.

Notes	**Cardiff & Vale**	**CTM**	**Gwent**	**N Wales**	**Powys**	**West Glam**	**West Wales**
2023	Mixed/ limited	Mixed/ limited	Mixed/ limited		Mixed/ limited	Mixed/ limited	Mixed/ limited
2025	Mixed/ limited	Good	Mixed/ limited	Good	Mixed/ limited	Mixed/ limited	Good
Lived Experience [footnote 39]	Mixed/ limited	Not compliant	Mixed/ limited	Mixed/ limited	Mixed/ limited	Not compliant	Mixed/ limited

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[39] Based upon the proportion of autistic adults and parents and carers of autistic children and young people who when asked ‘in the last three years, if you needed to access autism advice or support services, how easy was it was to get this support?’ responded that it was either ‘quite’ or ‘very difficult’ to do so.

Table 4.3.3. Section 2. Access to information about autism services (Information, Assistance and Advice Service information is available on local autism services)

Duty: 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.

Notes	**Cardiff & Vale**	**CTM**	**Gwent**	**N Wales**	**Powys**	**West Glam**	**West Wales**
2023	Compliance +	Good	Good	Good	Good	Good	Good
2025	Compliance +	Mixed/ limited	Good	Good	Good	Good	Good

Table 4.3.4. Section 2. Access to information about autism services (autism awareness information, resources and training is made publicly available)
Duty: LAs with LHBs should: make arrangements to ensure a range of autism awareness information, resources and training is made publicly available.

Notes	**Cardiff & Vale**	**CTM**	**Gwent**	**N Wales**	**Powys**	**West Glam**	**West Wales**
Children 2023	Mixed/ limited	Good	Good	Good	Mixed/ limited	Mixed/ limited	Mixed/ limited
Children 2025	Mixed/ limited	Mixed/ limited	Good	Good	Mixed/ limited	Mixed/ limited	Good
Adults 2023	Mixed/ limited	Good	Mixed/ limited	Good	Mixed/ limited	Mixed/ limited	Mixed/ limited
Adults 2025	Mixed/ limited	Mixed/ limited	Good	Good	Mixed/ limited	Mixed/ limited	Good

Table 4.4. Reasonable adjustments

Duty: LA and LHBs must: ensure that reasonable adjustments are in place for autistic individuals to ensure they are able to access services in the same way as everyone else.

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
2023	Mixed/ limited	Mixed/ limited	Mixed/ limited	Mixed/ limited	Mixed/ limited	Mixed/ limited	Mixed/ limited
2025	Good	Mixed/ limited	Good	Mixed/ limited	Mixed/ limited	Mixed/ limited	Mixed/ limited
Lived Experience [Footnote 40] LHB	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant
Lived Experience [footnote 41] LA	Mixed/ limited	Not compliant	Mixed/ limited	Mixed/ limited	Mixed/ limited	Not compliant	Mixed/ limited

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[40] Based upon the proportion of autistic adults and the parents and carers of autistic children and young people who when asked 'how confident are you that health workers, like GPs and nurses make reasonable adjustments to ensure that autistic individuals are able to access health services?' responded 'not at all confident'.

[41] Based upon the proportion of autistic adults and the parents and carers of autistic children and young people who when asked 'how confident are you that social care staff like social workers, care workers, and family and parenting support services make reasonable adjustments to ensure that autistic individuals are able to access social services?' responded 'not at all confident'.

Information about autism services

As Table 4.3 illustrates, there remains a mixed picture in relation to the provision of information about autism services, with progress in some areas, but regression in others. However, it is important to bear in mind that:

- much more good practice was identified in 2025 than in 2023 with, for example, the development of new webpages in many areas
- because the progress was not always consistent across the region with, for example, differences in different LAs, the overall assessment of the region's compliance did not necessarily change
- the examples where areas appeared to have regressed were not because the provision of information had deteriorated since 2023 but rather that more information was available in 2025, and it was therefore possible to make a more comprehensive and informed assessment of compliance
- the duties in relation to autism services other than diagnostic assessment services [footnote 42] (discussed in section 3) generally focused upon information about, rather than the provision of, autism services
- this means (somewhat perversely) that having fewer services is likely to make compliance easier (as there are fewer services they need to know about and provide information about)

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[42] 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' (Code of Practice On The Delivery Of Autism Services, p.12).

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 Cardiff and 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. In Cardiff, children and young people community connector posts have been established through the Early Years Pathfinder to work with children and young people and carers while they await an ND assessment. The offer has three strands; knowledge, connection and support and the service will work collaboratively with partner agencies. 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

- in Gwynedd, a directory of autism services has been developed, and the autism team are mapping what is available locally and in Conwy and Denbighshire; a local NAS autism activities directory, produced by autistic individuals for autistic individuals and their families has recently been updated and shared with staff; and online app to bring together local information and resources is also being developed in consultation with autistic individuals and their families

- Bridgend has a regularly updated directory of autism services and all staff have an icon on their computer to access it

- five of North Wales’s LA websites have been developed and provide clear information on local and national services and resources (such as the NNT Website); see for example: Conwy’s ‘autism’ webpage; Denbighshire’s ‘local support for autistic individuals’ webpages; Flintshire’s ‘Autism’ webpage; Gwynedd’s ‘Autism’ webpage, and Wrexham’s ‘Neurodiversity support and resources’ website

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 or carer groups, are developing an autism hub across the four sub-regions of Neath Port Talbot drawing upon the example of Swansea Info-Nation which provides information and advice on mental health and wellbeing to young people

- The Carmarthenshire Local Offer, which provides information in a single place for children and young people with ALN and disabilities and their families, aims to show families what they can expect from a range of local agencies from education to health and social care

IAA teams should be an important resource and also a first point of contact for social services. In North Wales, efforts have been made to raise awareness in IAA teams of autism or neurodiversity webpages and local directories, to complement the use of Dewis. In Gwynedd it is also reported that the NNT has delivered training to IAA teams to raise awareness of their duties under the Code. In addition, it is reported in areas such as Conwy, Flintshire and Gwynedd that:

- the webpages have been shared and promoted with others, such as IAA teams, diagnostic assessment services, local third sector organisations, parent support groups, (in Flintshire) disability wellbeing navigators, and (in Gwynedd) schools, GP surgeries, leisure centres and community groups, and via social media and information days, to help ensure the information is accessible to those who may, for example, be digitally excluded

- initial IAA and signposting for families is offered by family centres (in Gwynedd) where staff have had autism specific training and a Neurodivergent Improvement Programme (NDIP) funded post is being piloted in their service, and in (Wrexham) in wellbeing hubs

Evaluating compliance is also 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. The IAS is an important autism service that provides adult autism diagnostic assessment, support and advice for autistic adults, parents/ carers, and professionals. However, it is only one of a number of services that offer diagnostic assessments for adults and it is only one of many services that will support autistic individuals and their families and carers. Many of these services are not always badged as 'autism' services [footnote 43] 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)
- IAA and social care services
- Families First, Family Information Services and children's disability teams
- third sector organisations (which are reported to be an important source of support for parents and carers and also autistic adults)

However, for the purposes of the Code, they are considered 'autism services' [footnote 44].

As in 2023, 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 an important vehicle for disseminating

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[43] That is to say, 'autism' does not feature in the name of the service.
[44] The term 'Autism services' is widely used, but not explicitly defined by the Code (or the Supporting Guidance Document or the Refreshed Autistic Spectrum Disorder Strategic Action Plan). The Code implies that 'autism services' includes a range of services for autistic individuals and their families, including ND services such as the IAS, but also, for example, IAA services. However, the reference in the Code to 'mainstream services' (Code of Practice on the Delivery of Autism Services, p. 25) suggests these 'mainstream services' are distinct from to 'autism services' and 'autism services' are not simply any service that autistic individuals and/or their families use. Therefore, there is some ambiguity about the scope of the term.

information about local services and, unless someone knows what to search for, it can be difficult to identify LA and LHB autism services [footnote 45].

Self-help and supported self-help services

One of the themes in written comments made by autistic adults and the parents or carers of autistic children or young people (discussed in section 8) was the difficulty many experienced navigating an often complex landscape or patchwork of support services. Some people valued the new information and resources developed by LAs, LHBs and the NNT. However, others struggled, sometimes feeling overwhelmed by the range of information and/or feeling that they did not have the mental bandwidth to undertake ‘research’, given all the other difficulties they might face in their day to day lives. Rather than what might be described as self-help or self-serve models such as websites, they wanted someone to take them by the (metaphorical) hand to guide them and help them understand what options there were and potentially support them to access them (for example, through help filling in referral forms). It also appeared that people often wanted a mix of practical and/or emotional support to help them access information and support services. It is also possible, although not clearly evident in the feedback for this evaluation, that some autistic adults and the parents or carers of autistic children or young people also want more help to make use of, or apply what they have learnt after, for example, attending an online or in person training course. Figure 4.1 seeks to illustrate these two dimensions of agency.

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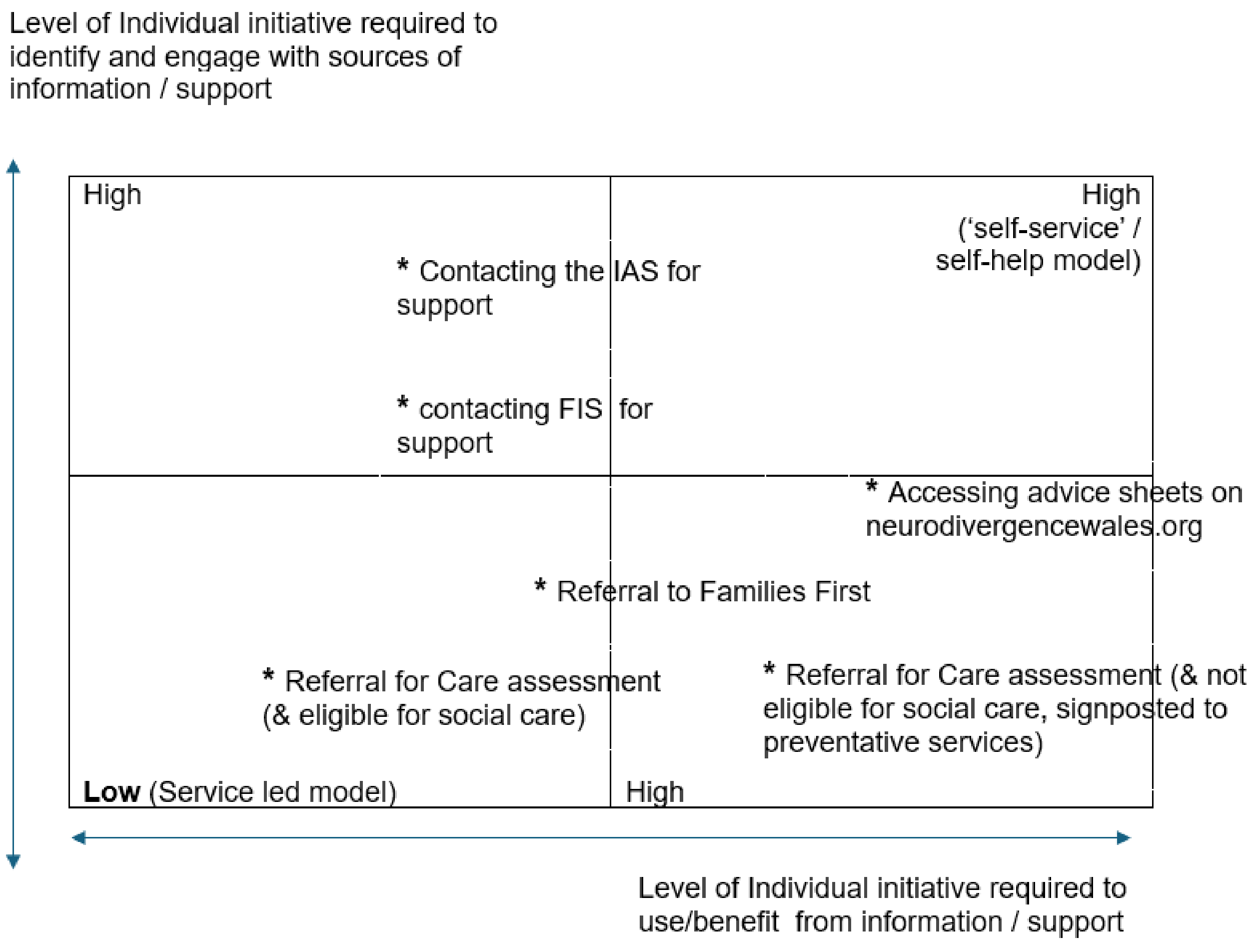
[45] For example, an internet search for ‘autism services’ in a particular LA, will usually identify the IAS and some third sector organisations, but will rarely identify other LA or LHB services that can and do help and support autistic individuals and their parents or carers.

Figure 4.1. Self-service and service led models of information and support



Description of Figure 4.1: A diagram with 4 quadrants mapping self-service and service led models of information and support, against level of individual initiative required to identify and engage with sources of information/ support, by level of individual initiative required to use /benefit from information/ support

Factors shaping information about autism services

A number of developments that predate the Code have improved information about autism services. They have not simplified the policy landscape, but they have improved information about it, in particular:

- local autism leads, established in response to 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, establishment of IAA services in response to the SSWBW Act 2014
- 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

As Table 4.4 illustrates, we assess that some progress has been made in ensuring that reasonable adjustments are in place for autistic individuals to be able to access services in the same way as everyone else. This is principally because of the improvement in workforce development and training (discussed in the next section).

Nevertheless, the feedback from autistic adults and parents and carers of autistic children and young people on this was very negative (Section 8 provides further details). As section 2 outlines, this data is not considered directly comparable with the assessment of compliance based primarily upon data provided by practitioners [footnote 46]. However, as section 2 also outlines, there is no suggestion that their responses are not genuine and the experiences they reported, were often recognised by stakeholders (for example, as consistent with anecdotal data on people's experiences). Therefore, it signals a sharp note of caution on the impact of the progress that LA and LHBs report and the importance of monitoring and evaluating people's lived experiences of interacting with LA and LHB services.

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[46] The responses from autistic adults and parents and carers of autistic children and young people (discussed further in section 8) may relate to historical experiences and it may be too early to judge the impact of improvements in workforce development and training. These responses may also not be entirely representative.

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

Many autistic individuals have co-occurring conditions [47] 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 (Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan: Final Report). However, there have been longstanding concerns about autistic children’s and autistic adults’ access to CAMHS and AMHS and to other services such as eating disorder services (see for example, the Senedd Children, Young People and Education committee report, Mind over matter: A report on the step change needed in emotional and mental health support for children and young people in Wales; reports by the Children’s Commissioner for Wales such as No Wrong Door: bringing services together to meet children’s needs, and A No Wrong Door Approach to Neurodiversity: a book of experiences; and the review by HIW, Estyn and CIW, How are healthcare, education, and children’s services supporting the mental health needs of children and young people in Wales?). 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 in addressing
- the pressures upon services, which has led to thresholds for access being raised

In response, sections 1 and 2 of the Code include five duties intended to ensure that, for example:

- ‘where autistic individuals 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’
- ‘people with an Autistic Spectrum Condition with co-occurring conditions are not excluded from Children or Adults Mental Health Services’
- ‘awaiting a diagnosis is not a reason to be refused support and other services’

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[47] 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’ (A national framework to deliver improved outcomes in all-age autism assessment pathways: guidance for integrated care boards).

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

As in sections 3 and 4, the assessment of compliance is ranked on a four point RAGG scale [footnote 48], using the colour codes illustrated by figures 3.1 and 3.2; for each duty, the tables present:

- the baseline assessment in 2023
- the updated assessment of compliance in 2025
- feedback from autistic adult and/or the parents and carers of autistic children and young people

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[48] The benchmarks against which compliance is judged are included in appendix A.

Table 5.1.1. Access to needs-based services

Duty: LAs and LHBs must: ensure that awaiting a diagnosis is not a reason to be refused support and other services.

Notes	**Cardiff & Vale**	**CTM**	**Gwent**	**N Wales**	**Powys**	West Glam	West Wales
Children 2023	Good	Not compliant	Good	Mixed/ limited	Good	Mixed/ limited	Good
Children 2025	Good	Mixed/ limited	Good	Mixed/ limited	Good	Mixed/ limited	Good
Adults 2023	Good	Not compliant	Mixed/ limited	Mixed/ limited	Mixed/ limited	Mixed/ limited	Good
Adults 2025	Good	Mixed/ limited	Mixed/ limited	Mixed/ limited	Mixed/ limited	Mixed/ limited	Good

Table 5.1.2. Access to needs-based services (support services meeting additional support needs)

Duty: LAs and LHBs must [ensure that]: where autistic individuals 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.

Notes	**Cardiff & Vale**	**CTM**	**Gwent**	**N Wales**	**Powys**	**West Glam**	**West Wales**
Children 2023	Good	Mixed/ limited	Good	Mixed/ limited	Not known	Not known	Good
Children 2025	Good	Good	Good	Mixed/ limited	Not known	Not known	Good
Lived Experience [footnote 49]	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant

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[49] Based upon proportion of parents and carers of autistic children and young people who when responding to the question ‘autistic children sometimes have other needs. In the last three years, if you needed to access support from services like mental health or learning disability services, how easy was it to get this support?’ said that it was either ‘quite’ or ‘very difficult’ to do so.

Notes	**Cardiff & Vale**	**CTM**	**Gwent**	**N Wales**	**Powys**	West Glam	West Wales
Adults 2023	Good	Mixed / limited	Mixed / limited	Mixed / limited	Not known	Good	Good
Adults 2025	Good	Not compliant	Not compliant	Mixed / limited	Mixed / limited	Good	Good
Lived Experience [footnote 50]	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant

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[50] Based upon proportion of autistic adults who when responding to the question ‘autistic adults sometimes have other needs. In the last three years, if you needed to access support from services like mental health or learning disability services, how easy was it to get this support?’ said that it was either ‘quite’ or ‘very difficult’ to do so.

Table 5.1.3. Access to needs-based services (co-occurring conditions are not excluded from Children or Adults Mental Health Services)

Duty: 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.

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
Children 2023	Good	Mixed / limited	Mixed / limited	Mixed / limited	Not known	Not known	Good
Children 2025	Good	Good	Good	Mixed / limited	Not known	Good	Good
Adults 2023	Good	Mixed / limited	Mixed / limited	Mixed / limited	Not known	Mixed / limited	Good
Adults 2025	Good	Mixed / limited	Not compliant	Mixed / limited	Not known	Mixed / limited	Good

Table 5.1.4. Access to needs-based services (IQ is not considered as part of the eligibility criteria for a needs assessment)
Duty: LAs must: ensure that IQ is not considered as part of the eligibility criteria for a needs assessment under the SSWBW Act.

LHBs must: ensure IQ is not considered as part of the eligibility criteria.

Notes	**Cardiff & Vale**	**CTM**	**Gwent**	**N Wales**	**Powys**	**West Glam**	**West Wales**
LA 2023	Mixed / limited	Not known	Good	Good	Good	Not known	Not known
LA 2025	Good	Not known	Good	Good	Good	Mixed / limited	Good
Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
LHB 2023	Not compliant [Note 1]	Not known	Not known	Mixed / limited	Good	Not known	Not known
LHB 2025	Not compliant	Not known	Not known	Mixed / limited	Good	Not compliant	Good

[Note 1] Although it was reported in 2023 that progress was being made on what is seen as a historical issue, that was now being addressed.

Access to needs-based services

As Table 5.1 illustrates, stakeholders consistently reported that LAs and, to a lesser degree LHBs, have moved or are moving towards need rather than diagnostic or IQ- based services, however:

- as in 2023, neurodivergent children and young people are still reported to be struggling to access CAMHS (see for example, the Children's Commissioner for Wales report, A No Wrong Door Approach to Neurodiversity: a book of experiences and the HIW, Estyn and CIW, review, How are healthcare, education, and children's services supporting the mental health needs of children and young people in Wales?)
- as in 2023, there appears to still be some confusion amongst stakeholders about the use of IQ as an eligibility criterion for services (which is not compliant with the Code) and using it to determine what the appropriate service to meet care and support needs would be (which is compliant with the Code)
- it was reported that some LA services, such as children's disability services, still require a diagnosis (for example, a diagnosis of autism) to access them [footnote 51]
- although IASs increasingly offer autism advice that is open to everyone (and which is seen as good practice), aspects of its support, such as post-diagnostic courses, are limited to those with a diagnosis, in line with the national IAS model
- the national IAS eligibility criteria are defined by ineligibility for secondary services (that is AMH and LD services) (Integrated Autism Service Supporting Guidance), therefore, in effect, access to diagnostic and support services for adults is still defined by conditions (that is to say whether someone has a diagnosis of autism or has an LD or mental health (MH) condition that meets the threshold for secondary care). The latter is a concern, where it is felt that the information, help and support offered by AMH and LD services is not as good as that offered by the IAS

Moreover, as outlined above, because there is generally much less oversight and understanding of practice in MH and LD services in regional autism strategic groups and there has been less autism related investment in these services compared to children's ND services and the IAS, there is much less confidence that these services are compliant with the Code.

There are also concerns that some services, such as the IAS, still require a diagnosis to access them. In Gwent it was therefore identified as good practice that adults on the IAS waiting list can access advice and support via the IAS virtual hubs. Some voluntary sector groups were reported to accept self-diagnosis, which was also seen as good practice, although this is sometimes felt by practitioners to be a difficult area, and there are concerns

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[51] 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.

about how reliable self-diagnosis is and the impacts it may have (see for example, David and Deeley, 2024).

The perception that a diagnosis is needed to access services and support appears to remain prevalent. In response, for example:

- in West Wales, the children's ND service offers pre-diagnostic support via telephone or virtual means for parents and carers awaiting diagnostic assessments
- the Powys ND services report that staff will identify what people want and expect from a diagnostic assessment and (where appropriate) will refer people to support services before a diagnostic assessment

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

As in 2023, 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 [footnote 52] and the Children's Commissioner's campaign for 'no wrong door' to services (No Wrong Door: bringing services together to meet children's needs), which drew upon existing good practice in regions, such as the SPACE-WB [footnote 53] panel in Gwent
- advice and training for CAMHS staff, which has helped increase practitioners' skills and confidence in supporting autistic children

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 [footnote 54], into wider policy (see boxed text).

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[52] 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" (NEST framework (mental health and wellbeing): introduction).

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

[54]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' (What is gender mainstreaming?).

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 individuals who may have care and support 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 [footnote 55]
- 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 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.

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.

Factors shaping access to services for adults with co-occurring conditions

Progress in relation to access to services for adults with complex needs has been uneven. As outlined in Table 5.1. it is notable that in Cwm Taf Morgannwg and Gwent the assessment of compliance in 2025 with the duty to ensure that ‘where autistic individuals 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’, was lower than in 2024. In both cases, in part, this was because additional information (which was not available in 2024) was provided in 2025, which led to the assessment to be revised. This scrutiny of practice and openness about the challenges facing each region was highlighted in their assessments of compliance as good practice, and represents an example of ‘non-linear’ progress, which may be hidden when a RAGG scale is used it illustrate progress [footnote 56]. However, in addition, in one of the two regions, it appeared that the pathways to AMHS that had been established and were

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[55] 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.

[56] ‘Non-linear’ progress describes progress that does not advance in a straight line, and may instead involve, for example, a plateauing or even regression, while overall, progress is still being made towards the desired outcome

operating in 2024, were no longer operating effectively, and this also contributed to the downgrading of compliance from ‘good progress’ to ‘mixed or limited’ progress.

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 mental health difficulties or mild learning disability). However, it is important to note that, in line with the national model, the IAS does not support autistic adults who are accessing secondary MH or LD services
- awareness raising work, training and consultations, particularly with AMHS (discussed below)

However, in the absence of equivalent panels such as SPACE-WB, it is reported that some adults with complex needs can still struggle to access services and support.

Examples of good and emerging practice

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

- a single point of access to services, to reduce the risks that people get ‘bounced’ between services
- 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 (SPOAs) 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 SPoA to both the ASD and IAS services in West Wales. Similarly, Gwent IAS are currently reviewing the pathways into the services as they move to become an ND service with ADHD. The new Adult ND Service is working to introduce a ‘front door’ system. This would mean all referrals for adult ND services will come into one place and be triaged to decide which neurodevelopmental service/pathway provides the best patient journey for the individual to meet their need.

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 Community Mental Health Teams (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 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.

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

As the ministerial forward to the Code identifies, ‘it is important that the way in which autistic individuals and those with other neurodiverse conditions communicate and interact with the world is understood’ (Code of Practice On The Delivery Of Autism Services). This is vital to ensure that services and society are ‘kinder’ and more inclusive (for example, 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)’
- ‘health and social care practitioners have the skills, knowledge and confidence to adapt their practice to better meet the needs of autistic individuals; and, where required as part of their role, advise and train others and/or undertake diagnostic or needs assessments’

As in sections 3, 4, and 5, the assessment of compliance is ranked on a four point RAGG scale [footnote 57], using the colour codes illustrated by figures 3.1 and 3.2; for each duty, the tables present:

- the baseline assessment in 2023
- the updated assessment of compliance in 2025
- where applicable, feedback from autistic adults and/or the parents and carers of autistic children and young people

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[57] The benchmarks against which compliance is judged are included in appendix A.

Table 6.1.1. Section 3. Workforce development and training
Duty: 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.

Notes	**Cardiff & Vale**	**CTM**	**Gwent**	**N Wales**	**Powys**	West Glam	West Wales
LA 2023	Good	Mixed / limited	Good	Mixed / limited	Good	Mixed / limited	Good
LA 2025	Good	Not known	Good	Mixed / limited	Good	Mixed / limited	Not known
LHB 2023	Mixed / limited	Not known	Good	Not compliant	Not known	Not known	Good
LHB 2025	Mixed / limited	Not known	Good	Not compliant	Not known	Not known	Good

Table 6.1.2. Section 3. Workforce development and training (assessing the autism training needs of all staff)
Duty: 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.

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
LA 2023	Good	Mixed / limited	Mixed / limited	Mixed / limited	Mixed / limited	Mixed / limited	Mixed / limited
LA 2025	Good	Good	Mixed / limited	Mixed / limited	Mixed / limited	Mixed / limited	Mixed / limited
LHB 2023	Mixed / limited	Mixed / limited	Mixed / limited	Mixed / limited	Mixed / limited	Not known	Mixed / limited
LHB 2025	Mixed / limited	Not known	Mixed / limited	Mixed / limited	Mixed / limited	Not known	Mixed / limited

Table 6.1.3. Section 3. Workforce development and training (the knowledge and training in autism to undertake roles)
Duty: 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.

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
202	Not known	Mixed / limited	Mixed / limited	Mixed / limited	Not known	Not known	Mixed / limited
2025	Good	Mixed / limited	Mixed / limited	Mixed / limited	Mixed / limited	Not known	Good

Table 6.1.4. Section 3. Workforce development and training (support for individuals in the secure estate is provided by appropriately trained practitioners)

Duty: LA and LHBs must: ensure that health and social care support for autistic individuals detained in the secure estate is provided by appropriately trained practitioners.

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
Children 2023	Not known	Not known	Not known	Mixed / limited	Not known	Not known	Not known
Children 2025	Good	Good	Good	Good	Not known	Not known	Not known
Adults 2023	Not known	Not known	Good	Mixed / limited	N/A	Not known	N/A
Adults 2025	Good	Good	Good	Good	N/A	Not known	N/A

Table 6.1.5. Section 3. Workforce development and training (commissioned services are provided by appropriately trained and skilled staff)

Duty: LAs must: ensure that where services are commissioned LAs must ensure autism services are provided by appropriately trained and skilled staff

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
2023	Good	Not known	Not known	Mixed / limited	Not known	Not known	Mixed / limited
2025	Good	Not known	Good	Mixed / limited	Good	Not known	Mixed / limited

Table 6.1.6. Section 3. Workforce development and training (all staff can access training)
Duty: 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.

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
LA 2023	Good	Not compliant	Mixed / limited	Mixed / limited	Mixed / limited	Mixed / limited	Mixed / limited
LA 2025	Good	Good	Good	Good	Mixed / limited	Mixed / limited	Mixed / limited
LHB 2023	Good	Not compliant	Mixed / limited	Mixed / limited	Mixed / limited	Mixed / limited	Mixed / limited
LHB 2025	Good	Mixed / limited	Good	Good	Not known	Not known	Good
Lived Experience [footnote 58]	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant

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[58] Based upon the proportion of autistic adults and the parents and carers of autistic children and young people who when asked ‘how confident are you that health workers, like GPs and nurses, understand the impact of autism upon your life?’ responded ‘not at all confident’.

Table 6.1.7. Section 3. Workforce development and training (staff receive appropriate training)
Duty: LHBs must: ensure that staff receive appropriate training in autism and associated behaviour and sensory needs at a level appropriate to their involvement.

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
Children's ND and IAS 2023	Good	Not known	Mixed / limited	Mixed / limited	Mixed / limited	Not known	Mixed / limited
Children's ND and IAS 2025	Good	Mixed / limited	Good	Mixed / limited	Good	Not known	Good
Other LHB services 2023	Mixed / limited	Not compliant	Not known	Not known	Not known	Not known	Mixed / limited
Other LHB services 2025	Mixed / limited	Not compliant	Mixed / limited	Not known	Not known	Not known	Mixed / limited

Table 6.1.8. Section 3. Workforce development and training (training provision takes account of NICE guidelines)
Duty: 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.

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
2023	Not known	Not known	Good	Not known	Not known	Not known	Not known
2025	Good	Not compliant	Good	Not known	Not known	Not known	Mixed / limited

Table 6.1.9. Section 3. Workforce development and training (the knowledge, skills and competence required to undertake the assessment and provide a diagnosis)

Duty: 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.

Notes	**Cardiff & Vale**	**CTM**	**Gwent**	**N Wales**	**Powys**	**West Glam**	**West Wales**
Children’s ND service 2023	Mixed / limited	Not known	Good	Mixed / limited	Not known	Not known	Good
Children’s ND service 2025	Mixed / limited	Good	Good	Mixed / limited	Good	Not known	Good
IAS 2023	Good	Good	Good	Mixed / limited	Not known	Good	Good
IAS 2025	Good	Good	Good	Good	Good	Good	Good
LD & MH services 2023	Mixed / limited	Mixed / limited	Not known	Mixed / limited	Not known	Mixed / limited	Not known
LD and MH services 2025	Mixed / limited	Not known	Not known	Mixed / limited	Not known	Mixed / limited	Mixed / limited

Table 6.1.10. Section 3. Workforce development and training (sufficient knowledge and skills to understand the impact of autism)

Duty: 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 wellbeing without care and support.

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
2023	Good	Mixed / limited	Good	Good	Not known	Good	Good
2025	Good	Good	Good	Good	Mixed / limited	Good	Good
Lived Experience [footnote 59]	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant

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[59] Based upon the proportion of autistic adults and the parents and carers of autistic children and young people who when asked ‘how confident are you that social care staff like social workers, care workers, and family and parenting support services understand the impact of autism upon your life?’ responded ‘not at all confident’.

Table 6.1.11. Section 3. Workforce development and training (autistic individuals and their parents and carers are involved in the development and delivery of autism training)

Duty: LAs and LHBs should: ensure that autistic individuals and their parents and carers are involved in the development and delivery of autism training. This may include consultation on training or involvement in delivery of training.

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
2023	Good	Mixed / limited	Good	Good	Not known	Good	Mixed / limited
2025	Good	Mixed / limited	Good	Good	Not known	Good	Mixed / limited

Staff skills, knowledge and confidence

As Table 6.1 illustrates, compliance with the Code's duties in relation to staff training varies, and in general more progress has been made since 2023 by LAs compared to LHBs. In part this may reflect the more limited engagement of LHB, compared to LA, workforce development leads [footnote 60], which limited the extent to which assessments of LHB's compliance could be made with confidence.

As in 2023, the most progress has been made in:

- offering general autism awareness training to health and social care workforces and it is reported that
    - in several LAs such as Anglesey, Bridgend and Monmouthshire, this training is now mandatory for social care staff
    - in Hywel Dda UHB's this training is mandatory for all staff (and the UHB is now recognised as an 'Autism Understanding' organisation by the NNT)
    - in Cardiff and Vale UHB, this training is mandatory for staff within the Mental Health Directorate
- offering higher level training to those undertaking social care assessments [footnote 61]
- ensuring that staff in children's ND services and the IAS undertaking diagnostic assessments have the skills and competence required [footnote 62].

The development of training by the NNT (formerly the NAT) has been vital in supporting this. Nevertheless, there have also been important local initiatives, often driven by autism leads, that predate the national training framework (see, for example, Evaluation of the Integrated Autism Service and Autistic Spectrum Disorder Strategic Action Plan: final report, for details). It is also reported by stakeholders interviewed for this study, that the legal duties

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[60] As outlined in section 2, a survey of workforce development leads in LA and LHBs was developed and shared in the autumn of 2024 with the help of the NNT. 21 responses were received, including responses from workforce development leads in 17 LAs: Cardiff, Blaenau Gwent, Bridgend, Carmarthenshire (n=2 responses), Ceredigion (n=2 responses), Conwy, Denbighshire, Flintshire, Gwynedd (n=2 responses), Monmouthshire, Neath Port Talbot, Newport, Pembrokeshire, Powys, Swansea (n=2) responses, the Vale of Glamorgan and Wrexham (n=4 responses); and 4 LHBs: Aneurin Bevan, Cwm Taf Morgannwg, Hywel Dda and Powys.

[61] 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' (Code of Practice On The Delivery Of Autism Services, p.30).

[62] 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' (Code of Practice On The Delivery Of Autism Services, p.30). 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 rest with individuals, rather than services as such).

articulated in the Code have helped raise the profile and importance of awareness raising and training with workforce development managers.

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

Feedback from autistic adults and parents and carers

As Table 6.1 also illustrates, feedback from autistic adults and parents and carers suggests that people with lived experience of LA and LHB services still have little confidence in the skills and knowledge of health and social care staff (we discuss their feedback in more detail in section 8). As sections 2 and 4 outline, this data is not considered directly comparable with, primarily, the practitioners' assessment of compliance [footnote 63]. Nevertheless, as section 2 also outlines, there is no suggestion that their responses are not genuine and the experiences they reported, were often recognised by stakeholders (for example, as consistent with anecdotal data on people's experiences). Therefore, it signals a sharp note of caution on the impact of the progress that LA and LHBs report and the importance of monitoring and evaluating people's lived experiences of interacting with LA and LHB services.

The co-production of training

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

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[63] As section 4 outlines, their responses may have been shaped by historical experiences, and it may be too early to judge the impact of improvements in workforce development and training. These responses may also not be entirely representative.

Examples of good and emerging practice

Monmouthshire council provides autism training to the whole LA workforce (beyond social care). They use the NNT/NAT questionnaire as part of staff induction to assess autism awareness and use the NNT/NAT autism training framework with the training team for social care. The NNT/NAT online training and communication module is mandatory across the LA and staff are required to have autism awareness certificates. 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.

In two LAs in Cwm Taf Morgannwg the autism training needs of all social care staff has either been assessed (RCT) or is being developed as part of their training plan (Bridgend) [footnote 64], in order to identify the level of training required according to staffs’ job roles. In addition;

- training provision is available at level 1 (understanding autism) and level 2 (autism skilled) on a continuing basis, including for new staff and existing staff who change their job roles and for those who cannot access learning online
- arrangements have been made to ensure that all social care staff can access the training identified to meet their autism knowledge and awareness training needs (principally by making training available online) and, in Bridgend, autism training is now mandatory for the social care team (an example of good practice)
- the take up of the different levels of autism training offered to staff is either monitored (Bridgend), or plans for this are being developed (RCT)
- plans are being developed to make autism training provision available at level 3 (autism enhanced) and level 4 (autism expertise) for those staff who need it

Information about, and awareness of, autism and signposting to services

Stakeholders reported examples of events to raise public awareness of autism. 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.

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[64] In Bridgend a TNA was circulated last year but received very few returns, so they are considering how this can be improved going forward.

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

Regional Partnership Boards (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 individuals to inform service development' and appointing a regional 'autism champion'
- ensuring that the 'needs of autistic individuals are considered in the development of Population Assessments and Area Plans'
- encouraging 'innovation' and the provision of specialist services
- monitoring and data collection

As in sections 3, 4, 5 and 6, the assessment of compliance is ranked on a four point RAGG scale [footnote 65], using the colour codes illustrated by figures 3.1 and 3.2. For each duty, the tables present:

- the baseline assessment in 2023
- the updated assessment of compliance in 2025
- where applicable, feedback from autistic adult and/or the parents and carers of autistic children and young people

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[65] The benchmarks against which compliance is judged are included in appendix A.

Table 7.1.1. Duties related to planning and commissioning services

Duty: LA and LHBs must jointly: develop strategic and operational teams which include autistic individuals to inform service development.

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
2023	Good	Not compliant	Good	Mixed / limited	Mixed / limited	Good	Mixed / limited
2025	Mixed / limited	Not compliant	Good	Good	Mixed / limited	Good	Mixed / limited
Lived experience Parents and carers [footnote 66]	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant
Lived experience autistic adults [footnote 67]	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant	Not compliant

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[66] Based on response to the question: ‘do parents or carers of autistic children have a say in the development of autism services in your area?’

[67] Based on response to the question: ‘do autistic adults have a say in the development of autism services in your area?’

Table 7.1.2. Duties related to planning and commissioning services (an autism champion role is appointed)

Duty: LHBs and LAs must jointly: ensure an autism champion role is appointed in each RPB area and is included in the governance structure of the board.

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
2023	Good	Not compliant	Good	Good	Mixed / limited	Good	Mixed / limited
2025	Good	Mixed / limited	Good	Not compliant	Mixed / limited	Mixed / limited	Not compliant

Table 7.2.3. Duties related to planning and commissioning services (compliance with relevant duties in the SSWBW Act parts 2 and 9)

Duty: LHBs with LAs must: jointly comply with relevant duties in the SSWBW Act parts 2 and 9, to ensure that needs of autistic individuals are considered in the development of Population Assessments and Area Plans.

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
2023	Mixed / limited	Mixed / limited	Mixed / limited	Mixed / limited	Not known	Not known	Mixed / limited
2025	Good	Not compliant	Good	Good	Mixed / limited	Good	Mixed / limited

Table 7.2.4. Duties related to planning and commissioning services (specialist service provisions are identified)

Duty: LA and LHBs must: ensure that where needs for specialist service provisions are identified, where possible these are made available.

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
2023	Good	Mixed / limited	Mixed / limited	Good	Mixed / limited	Not known	Mixed / limited
2025	Mixed / limited	Mixed / limited	Good	Mixed / limited	Mixed / limited	Good	Mixed / limited

Table 7.2.5. Duties related to planning and commissioning services (encourage innovation in the development of autism services)

Duty: LA and LHBs must: encourage innovation in the development of autism services.

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
2023	Good	Mixed / limited	Mixed / limited	Good	Mixed / limited	Not known	Mixed / limited
2025	Good	Mixed / limited	Good	Good	Mixed / limited	Good	Mixed / limited

Table 7.2.6. Duties related to planning and commissioning services (compliance with Welsh Government data collection and monitoring requirements)

Duty: LHBs and LAs must: ensure compliance with Welsh Government data collection and monitoring requirements.

Notes	Cardiff & Vale	CTM	Gwent	N Wales	Powys	West Glam	West Wales
2023	Good	Good	Good	Good	Good	Good	Good
2025	Good	Good	Good	Good	Good	Good	Good

Strategic and operational teams

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 [footnote 68] and in other regions, such as Cardiff and Vale and North Wales, the capacity of the group has increased over the period coved by the evaluation. Their membership has either been widened, and/or engagement from existing members has increased. However, there can still be challenges in identifying who needs to attend and having identified them, getting them to attend, in addition:

- in the past, the strategic groups have focused on the children’s ND service and IAS (which are important autism services but not the only ones that matter) and, as the Code has helped shine a spotlight on practice in other autism services, such as IAA, AMH and LD services, by 2025 they have generally taken a wider view. Nevertheless, as outlined in sections 3, 4 and 5, scrutiny of, and a role in developing, autism services such as IAA, AMH and LD services, were generally limited and while links are being developed with LA and LHB workforce development leads, these generally remain inchoate
- in 2025, although the relationship between the autism strategy group and the RPB was generally much clearer, there is still often a somewhat uneasy fit between an autism strategic group focused upon a specific condition for all ages and other regional strategic groups with a much wider cross cutting remit but for a particular age group, such as children and young people, adults or older people [footnote 69]
- as in 2023, 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

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 helped some staff, such as autism leads and/or regional coordinators, who can point to the legal duties placed upon LA and LHBs. The Code has also helped give some groups a clearer purpose (as they focused upon assessing compliance) although, as outlined in the conclusions, 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
- 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

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[68] Operational groups were much less visible.

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

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 individuals and can inform service improvement’. However, (somewhat confusingly) the duty says that LAs and LHBs must ‘develop strategic and operational teams which include autistic individuals to inform service development [footnote 70]’ (Welsh Government 2021a, pp. 34, 36). Moreover, the supporting guidance, which includes a diagram on page 70 outlining the relationships between different groups, does not mention operational groups (Welsh Government, 2021b). 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.

In 2023, 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. As Table 7.1 illustrates, in 2025 a number of regions were struggling to ensure continuity and had, for example, autism champions who had either stood down and not yet been replaced, or who were not members of the full RPB.

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 Neurodivergent 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.

Population Needs Assessments and data collection

As Table 7.2 illustrates, as in 2023, where autism is considered in PNAs in most cases, the assessment is not sufficiently in-depth. For example, PNAs do not include a thorough 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
- how autism services will be delivered taking into consideration population, culture and language with specific reference to the Welsh language (Code of Practice On The Delivery Of Autism Services)

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

This, in turn, means there is little evidence that the PNA is informing the development of autism services, including specialist services and innovation. Nevertheless, there are exceptions to this, such as such as Cardiff and Vale and North Wales' PNAs.

Examples of good and emerging practice

North Wales PNA has one of most comprehensive discussions of autism, for example it includes: a discussion of autism services; quantitative data (for example, 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.

In Cardiff and Vale, processes for providing advice and wider signposting for people requesting support will be reviewed during 2025/26. This will include IAA, adult and children first point of contact teams in Cardiff Council, and ND support workers. This is important given the feedback from autistic adults and parents and carers in Cardiff and Vale on their access to information about autism services (discussed in section 8). The review of progress will be included in the RPB plans for 2025/26.

As Table 7.2 illustrates, as in 2023, all regions are complying with the duties around data collection [footnote 71]; however:

- the use of the data by regional strategic autism groups to inform decisions about service development is not consistent
- as outlined in sections 3 to 6, regional strategic groups' knowledge and oversight of different areas covered by the Code is patchy
- groups' knowledge of autistic individuals' lived experience (for example, of accessing services and support) is often fragmented and anecdotal

It is also important to bear in mind that the data collection duties in the Code are narrow, and weakness in the data that is collected, including the gaps in the data about people's lived experiences and variable understanding of practice in different autism services, contributes to the weakness in PNAs. Without action to improve data collection and use, neither PNAs nor autism strategic groups' understanding and ability to plan strategically will improve.

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[71] 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 NNT (via Data Cymru).

8. Feedback from autistic adults and parents and carers

Introduction

As section 2 outlines, just over 440 autistic adults and parents and carers of autistic children and young people completed one of four questionnaires distributed by surveys in 2023 and 2024. These were:

- the main survey in 2024, open to autistic adults and the parents and carers of autistic children and young people
- the 2024 Families First survey of the parents and carers of autistic children and young people accessing Families First
- the 2023 Families First Pilot Survey of the parents and carers of autistic children and young people accessing Families First
- the 2023 STAND Survey of the parents and carers of autistic children and young people accessing STAND in North Wales

We discuss their responses in this section.

As section 2 also outlines, the autistic adults and parents and carers of autistic children and young people completing one of these four survey questionnaires reported accessing a wide range of different voluntary sector, LA and LHB services in the last three years. Therefore, they do not appear to be groups who were not accessing (or not trying to) access services or support. The results from across Wales were also consistent, suggesting a commonality of experience in different parts of Wales. Nevertheless, (as section 2 outlines) it is not possible to confidently judge how representative their experiences are of all autistic adults and of the parents and carers of autistic children and young people in Wales.

Awareness of and engagement with the Code

As outlined in Table 8.1, there was a very divided response when respondents were asked about their engagement with the Code. Almost a fifth of the 440 respondents had read the Code, suggesting quite a high degree of engagement with the Code. However, almost half of the respondents had not heard of the Code.

Table 8.1. Responses to the question ‘What best describes what you know about the Autism Code of Practice for Wales?’ and ‘What do you know about the Autism Code of Practice for Wales?’

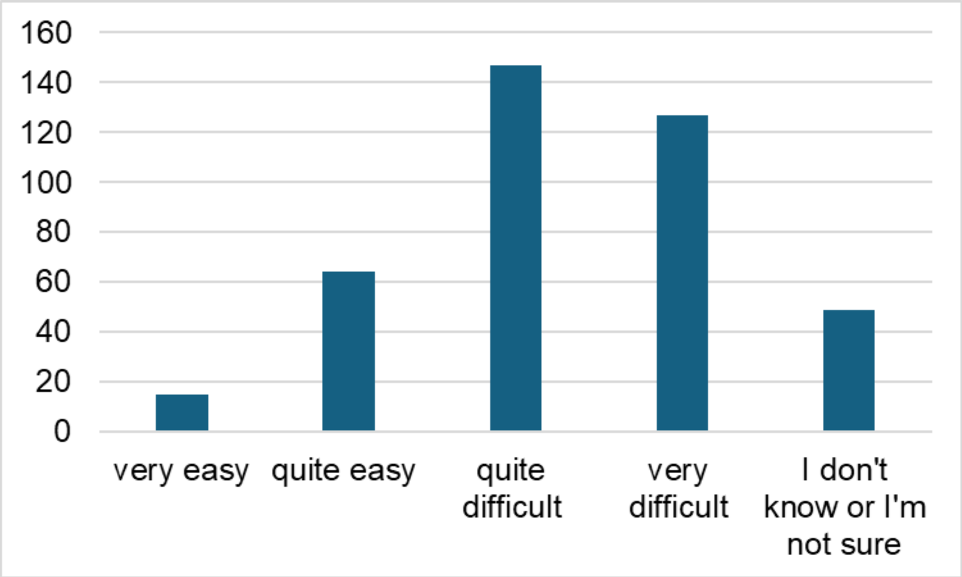
	(No.)	(%)
I have read it	82	19
I have heard of it	118	27
I have never heard of it	208	47
I am not sure/ don't know	32	7

Sources: Main Survey (2024) + FF (2024), + FF Pilot (2023) + STAND (2023). Total N= 440 responses

Access to information about autism services

As Chart 8.1 and Table 8.2 illustrate, almost 70% of respondents said that it was either quite or very difficult to get information about the autism services in their area. As Table A1 in the appendix illustrates, responses to the two smaller surveys conducted in 2023 were broadly similar.

Chart 8.1. Responses to the question ‘How easy is it to get information about the autism services in your area?’



Description of Chart 8.1: A bar chart outlining responses to the question "How easy is it to get information about the autism services in your area?". The majority of responses report it being quite difficult or very difficult.

Source: Main Survey (2024) + Families First Survey (2024), N= 402 responses

Table 8.2. Responses to the question 'How easy is it to get information about the autism services in your area?'

	Main Survey (2024)	FF Survey (2024)	Total (No.)	Total (%)
very easy	14	1	15	4
quite easy	59	5	64	16
quite difficult	133	14	147	37
very difficult	117	10	127	32
I don't know or I'm not sure	45	4	49	12

Written comments supported this and were overwhelming negative about access to information or support. They included those who said that there was little or no support from LA or LHB services, leaving them struggling and feeling alone or isolated, for example comments included:

- 'never offered help'
- 'support for autistic individuals in Wales is pretty much non-existent'
- ' I've not asked but only true support are forums of other parents struggling'
- '… it takes a lot to reach out for help; and then when no one gets back to you it's incredibly distressing'

Less commonly, respondents reported that it was difficult to identify and understand the support that was available, for example:

- 'there are so many different groups and agencies each purporting to offer something different. It's confusing'
- 'I never know what is available to us, what we can and can't attend without being referred into and what services are there to support us'
- 'it is difficult even for a neurotypical person!'
- 'seems disjointed and difficult to find anything unless you specifically know what you're looking for'
- '….even finding information is difficult, looking online directs you to multiple differently places and it is frustrating and complicated. There seems to be no help, no partnership working, no collaboration and a woeful lack of knowledge in both Health and Social Services about neurodiversity'

A small number of comments focused upon the practical difficulties they faced accessing information and support, given their circumstances, for example:

- ‘I am aware of neurodivergence Wales and certainly appreciate the resources available. I visit the website frequently to watch online training / sessions and read resources. This is of course difficult to juggle with work and taking care of my child (and sibling), I am unable to attend live sessions’
- ‘I am proactive and therefore search for services. Have been sent some information for courses but unable to attend due to work and issues caring for my child. I access online training that is posted in neurodevelopmental Wales website and watch in the evenings but [I] am often unable to attend’

Moreover, as many of the comments discussed below outline, the parents and carers of autistic children and young people or sometimes adults, linked the difficulties they faced caring and coping with their difficulties finding out about services and support. It was felt that this could create a vicious cycle that was difficult to escape from, for example:

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

Access to support

As Tables 8.3 and 8.4 illustrate, feedback from autistic adults and the parents and carers of autistic children when asked how easy it was to access support was very negative.

Table 8.3. Responses from autistic adults and the parents and carers of autistic children to the question: ‘in the last three years, if you needed to access autism advice or support services, how easy was it was to get this support?’

	Main Survey (2024) (no.)	Main Survey (2024) (%.)	FF Survey (2024) (no.)	FF Survey (2024) (%)
Very easy	5	2	8	2
Quite Easy	31	8	45	13
Quite difficult	85	17	111	32
Very difficult	110	31	158	46

I have not needed this support	11	3	25	7

Written comments supported this; many of them focused upon the lack of support and/or the ‘battle’ to access support, for example:

- ‘everything is difficult. Constant fighting and battling. LA just focussed on money which is obviously an issue but no one seems to have any insight into how spending the money in a wiser way would help in the long run’
- ‘every little thing has been a battle!’
- ‘I’m a carer at my wits end. No support comes without me instigating it & it is always on the parent to fight for support. Feels like a constant battle’
- ‘I have had to fight every step of the way. Following diagnosis she [my daughter] was discharged with no plan going forward and no support’
- as I understand it there are no autism services available for us’
- ‘I do not know who to go to as I am not officially diagnosed I'm left on my own to (not) cope’

Some of the written comments linked their difficulties accessing services to waiting lists, the pressure upon services and/or funding cuts. For example:

- ‘I feel that the NHS is at breaking point and so leave it down to schools. If you try to access anything for yourself or your child it is often pushed to one side as a minor concern’
- ‘support is non-existent! Waiting lists are huge and no information about where to seek support is shared with parents whilst they are waiting to be seen!’
- ‘you can beg for help and they will say oh sorry there’s a 9 month wait’

This lack of support, and the fight to access support, meant that a number of comments described people experiencing exhaustion, which in some cases felt close to desperation, including fears of family breakdown as a result. For example:

- ‘the fight I have had with my husband and son for support for them is just indescribable. I have felt suicidal and my husband has attempted suicide. Now we're going through it with my daughter, because she's younger it is a different process again. Every day can be a challenge. This just adds to that. Like pouring petrol on the fire’

- ‘I am a EU [European Union [footnote 72]] Mum, on my own with two autistic children, it's really hard at times to just get through a day. When things go wrong, I not only have to deal with my children's needs but the prejudice of every one else’
- ‘‘very very very difficult to the point I can’t take this any more and considering moving away from [name of LA omitted]’
- ‘it’s an appalling system for children. Honestly its driven me to an actual mental breakdown, because kids who don't have any learning difficulties fall through the cracks. no one wants to help and you end up feeling desperate and hopeless’
- ‘Parents/Caregivers need so much more support than is out there. So many of us are at breaking point which means our children on edge of care’
- ‘access to services, help and even knowing what is out there is difficult and often I feel like I'm drowning not knowing who I need to turn to’
- ‘I’m burnt out, at times suicidal and need support services fit for purpose. The services are underfunded, understaffed and just as overwhelmed as the autistic community are. I was late diagnosed in my 50’s. My now adult undiagnosed child is involved with drugs and is abusive. Their children are out of the school system and as a result are forgotten by services. As long as they don’t impact on a schools attendance register they become invisible. What have we come to?! It’s heartbreaking and hopeless’

However, as this final quote illustrates, it also important to note that many of the concerns related to access to support in educational settings (which are not covered by the Code) and many of the descriptions related to children who were home educated [footnote 73], given the difficulties they had experienced at school, had left parents even more isolated and alone. This is an important concern and partly beyond the scope of the Code (which does not cover education). Nevertheless, as this written comment illustrates, this does not necessarily mean that the Code is irrelevant, as health and social services may still have a role:

> My child is 8 years old, has autism and ADHD. Hasn[‘]t attended a school setting for 2 years. The support is non[-]existent and his case is now closed. Homelife is pretty hard, the outbursts, violence, struggles, mental health declining, being trapped at home, sleepless nights. You're expected to get on with it and that is that. There is support out there but it is not something that is given, and how as a parent can you get this support if no one is willing to help you?????

A small number of comments focused upon the type of support, rather than the lack of support; for example: ‘Support groups are not the answer to every problem’.

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[72] This is our inference based upon the comment. We believe she was describing her status as a probably fairly recent immigrant from an EU country.

[73] It was striking that in one region, a number of people described withdrawing their children from school and home educating them which appeared in some cases to have increased their isolation.

A number of the written comments focused upon the important role respondents felt the voluntary sector played:

- ‘the voluntary/charity organisations are fantastic in this area such as Stand NW, NEWCIS young carers and Daffodils’
- ‘The volunteers at the parent led groups are by far the best in terms of advice, support, activities etc, compared to the NHS’
- I ‘always go to STAND NW CIC for help as they know what they are talking about’

There were also occasional positive comments about health and/or social care services, for example:

- ‘I speak to a psychiatric nurse at my GP surgery who is very knowledgeable and understanding of Autism. I have attended a wellbeing event organised by the NWIAS (it was very good), and I have also met with someone from the service to discuss how I can support my autistic brother’
- ‘things have improved in the last 12 months’
- ‘I am lucky as my child receives support through social services and has regular assessments. His social worker is fantastic and checks on him and myself’
- ‘I have found the Autism Service in Swansea to be excellent, they have provided kind & consistent support’

Access to diagnostic assessments

Although no specific question was asked about access to diagnostic assessment services, many of the written comments referred to difficulties in accessing diagnostic assessment services, particularly for children, for example:

> [W]e had to pay privately for an initial diagnosis due to the NHS’s inability to diagnose effectively
>
> [T]he system for referring and diagnosing children is broken. You cannot make a child wait three or more years for a diagnosis. The early years are vitally important to children and these missed opportunities to support them. [This] Will have far-reaching and detrimental effects on children in years to come. My son’s diagnosis is three years overdue and he faces an uncertain future going to secondary because of the delay and the lack of help and support. Autism has an impact on the whole family not just the child in question. Some of these affects will be long-lasting, the stress on families is unprecedented. Something needs to be done to fix this nightmare of a system that we are having to battle on a daily basis.

Access to social services

As Tables 8.4 to 8.6 illustrate, awareness of rights to an assessment were variable.

Table 8.4. Responses from autistic adults to the question: 'do you know that if you may need help or support from social services, you have a right to an assessment of those needs?'

	Main Survey (2024) (no.)	Main Survey (2024) (%)
Yes	61	50
No	51	42
Not sure	10	8

Table 8.5. Responses from parents of carers to the question: 'do you know that if your child/children may need help or support from social services, you have a right to an assessment of those needs?'

	Main Survey (2024) (no.)	Main Survey (2024) (%.)	FF Survey (2024) (no.)	FF Survey (2024) (%)
Yes	155	22	177	52
No	114	8	122	36
Not sure	39	4	43	13

Table 8.6. Responses from parents or carers to the question: 'do you know that if you may need help or support from social services as a carer, you have a right to an assessment of those needs?'

	Main Survey (2024) (no.)	Main Survey (2024) (%.)	FF Survey (2024) (no.)	FF Survey (2024) (%)
Yes	142	21	163	48
No	135	11	146	43
Not sure	32	2	34	10

Written comments focused the difficulty people experienced getting a social care assessment, for example:

- ‘getting an assessment is impossible’
- ‘have waited over a year after contacting social services for an assessment of needs, it still hasn’t happened!’
- I ‘know that they should be [a right] however the last 2 times I’ve requested an assessment I’ve been told they only have capacity to prioritise children with a terminal or life limiting illness!!’
- ‘I did request a Carers Assessment a few years ago as there was a poster in The Carers Centre reception. However, the woman who answered the phone said they don't do them. She passed me on to a social worker who said to just put on my daughter's GP records that I am her carer’

And, more commonly, there was frustration with the outcome of assessment, for example:

> I had a carer’s needs assessment and a care and support plan assessment- both were awful. I told the social worker that I was so burnt out that I was feeling suicidal (and that this had progressed to the point where I wasn’t sure how long I could keep myself safe) she told me that since I wasn’t abusing my children, there was really nothing she needed to do about that.

Often this frustration was linked to the feeling that there was very little money available to meet their needs, for example:

- ‘ assessments are done to prove you don’t need support, not to help’
- ‘ there is NO MONEY for DP's [Direct Payments] - local authorities are broke and are skimming the surface just above bankruptcy’
- ‘….I don't think services have the time, resources, energy or staffing to meet this need. It's a great idea but in practice it is not realistic with the current state of services’

and/or a lack of understanding of autism, for example: ‘Social Services have very little understanding of Autism’.

Consequently, written comments suggested that even when people were aware of their right to an assessment, they felt this was of limited value, for example:

- ‘legally there is a right[,] but there is no funding for actual support’
- ‘I don’t bother because they are useless’
- ‘[yes, I know I have a right] But it took 3 years to get a carers assessment’

As we touch upon in section 5, a small number of people reported that they were reluctant to seek support from social services, particularly in relation to children, for example, comments included:

- ‘yes [I’m aware of the right] but then there’s also the stigma around having social services involvement’

- I ‘really feel they only get involved when you're doing something wrong as a parent. They're not approachable in the same way adult social services is for support’

A small number of people commented that they did not know how to access an assessment or how social service could help, for example:

- ‘I don’t actually know how to request for an assessment from social services’
- ‘I do not know where to request this from and have looked online’

Nevertheless, there were occasional positive comments, for example:

- ‘social care has been compassionate and responsive’
- ‘social care services have been brilliant and provided wonderful support’

Access to diagnostic assessments and pre- and post-diagnostic support

Although no specific question was asked about access to diagnostic assessments or pre- or post-diagnostic support, many of the written comments expressed concerns about this, particularly in relation to children. There were many concerns about limited access to support for those waiting for a diagnostic assessment, which it was often felt meant opportunities for early intervention were being lost, for example:

- our ‘daughter was referred for ASD assessment from primary school in 2022. We had an online screening early 2024 but haven’t heard anything since. She has started secondary school and things are getting more difficult’
- ‘my son isn't currently diagnosed, he is on the pathway. He faces many challenges daily, and so do we as a family as a result of this. We have tried to find support for this but have faced nothing but barriers due to him not being diagnosed. This is such a shame, as if my son had the diagnosis, I feel he would thrive’
- ’the ND assessment takes far too long and when you do eventually get a diagnosis, it doesn't change anything’
- both my children were diagnosed as autistic within a fortnight of each other two years ago we have received no offers of support, everything we have had we have had to search for and fight for’
- ‘there is very little help and support out there for my husband and children who are all awaiting an asd [sic] diagnosis and are all in great need of mental health support. There is also no help for carers like myself[,] who are trying to support and navigate this’

The comments also suggest that many parents, and carers in particular, still anticipate that a diagnosis will unlock access services and support. They are left bitterly disappointed when, after what may be years of waiting [footnote 74], they finally get a diagnosis, this does not happen.

As noted above, this was often linked to a lack of support in schools (which is not covered by the Code). There were also widespread concerns expressed about the lack of post-diagnostic support, for example:

- ‘I feel like our child has been lost in the system. Once you have a diagnosis you are not pointed in the direction of any services and you have to do your own research’
- ‘I feel since my child’s diagnosis 2 years ago we haven’t received the support needed as a family, let alone him, almost as if we’ve been given a diagnosis and told to get on with it’
- ‘had a diagnosis after 2 years on the list but no support offered just given a leaflet’
- ‘as a parent of a child with autism, when we fought for assessment, finally got a diagnosis, there was no support as a follow up’

Access to services for people with co-occurring conditions

As tables 8.7 and 8.8 illustrate, amongst the parents and carers of autistic children and among autistic adults who needed to access services like mental health or learning disability services, over 80% reported that it was either ‘very’ or ‘quite’ difficult to do so.

Table 8.7. Responses to the question: ‘autistic children sometimes have other needs. In the last three years, if you needed to access support from services like mental health or learning disability services, how easy was it to get this support?’

	Main Survey (2024)	FF Survey (2024)	Total (Main + FF) (No.)	Total (Main + FF) (%)
Very easy	3	1	4	1
Quite easy	30	3	33	11
Quite difficult	72	12	84	27
Very difficult	103	31	134	44
I have not needed to access advice or support	37	15	52	17

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[74] It should be noted that for many parents and carers, the time they feel they are waiting is not calculated from the time before they are accepted onto a waiting list for a diagnostic assessment, as they may count the period of time they had concerns, but these were either not recognised, or referrals for assessment were not accepted, as part of their wating time (Evaluation of the Integrated Autism Service and Autistic Spectrum Disorder Strategic Action Plan: final report).

Table 8.8. Responses to the question: 'autistic adults sometimes have other needs. In the last three years, if you needed to access support from services like mental health or learning disability services, how easy was it to get this support?'

	Main Survey (2024)	FF Survey (2024)	Total (Main + FF) (No.)	Total (Main +FF) (%)
Very easy	2	3	5	4
Quite easy	7	4	11	9
Quite difficult	15	14	29	24
Very difficult	22	29	51	42
I have not needed to access advice or support	13	12	25	21

A large number of written comments described concerns about access to mental health services for autistic children and adults, and a feeling that services were only accessible when mental health difficulties had escalated to a 'crisis' point. Several people described mental health services as 'broken', for example:

- 'Need to hit crisis point to get help. Otherwise it's another waiting list, signposting to a website address or handout. Not until my son became suicidal, began self harming and started having compulsive thoughts of harming others (harm OCD [Obsessive-compulsive disorder]) that the urgent support he needed came. Lost 2 years of education as a result.'
- 'I have repeatedly tried to get help for crippling anxiety and depression since 2010 [name of IAS Team manager omitted] aside, all of it has been an unhelpful torture, mis-handled, mis-understood, mis-diagnosed and poorly handled.'
- 'I am so depressed about our experience [with mental health services]. And the truth is our experiences are probably the norm. The system is totally broken.'
- 'Every single person I ever speak to about their experience with Cahms [sic] is negative.'

Other comments focused upon difficulties accessing mental health services that were perceived as reluctant to, or in some cases unable to, work with autistic individuals, for example:

- 'I went round in circles for a long time as was under a CMHT and kept being referred to IAS but they wouldn't see me as I was under a CMHT. I now attend their advice hub and third sector support.'
- 'Anxiety in Autism is just expected, something to live with without any support. Our child was being supported by primary mental health then the support was stopped after an

Autism diagnosis as there was an expectation that we would get other support after a diagnosis, but we didn't! A long battle to get referred to CAMHS, no support after initial assessment, only parenting courses! Had already been on several parenting courses, unfair to expect parents to support children without help. Another battle to get more help from CAMHS, a long waiting list but eventually offered a nurse therapist who comes to the house. A child should not have to struggle for years without help and reach crisis point before getting help. There needs to be a much more proactive and preventative approach. There is a lack of Welsh language support.'

- 'CAMHS: online consultation that our son didn't want to access as he has anxiety about new people. They concluded that his issues were autism based.'
- 'Discharged by MH service as you can't have anxiety and depression if you have autism.'
- 'It was difficult to access CAMHS before my children were diagnosed as autistic and then they were discharged soon after receiving the diagnosis.'
- Refused cahms [sic] support on the basis my daughter is autistic 3 times and wasn't accepted until the m.p [sic] got involved.'
- 'Mental health support for autistic adults does not exist.'

Concerns were also raised that even if you could access it, the support offered by mental health services was not adequate, for example:

- 'While CAMHS have been relatively quick to support what they can offer does not so far fit with my child.'
- 'CAMHS' menu of services/therapies fail to support Autistic children.'
- 'Neuro[-]affirming mental health care does not exist in my area.'

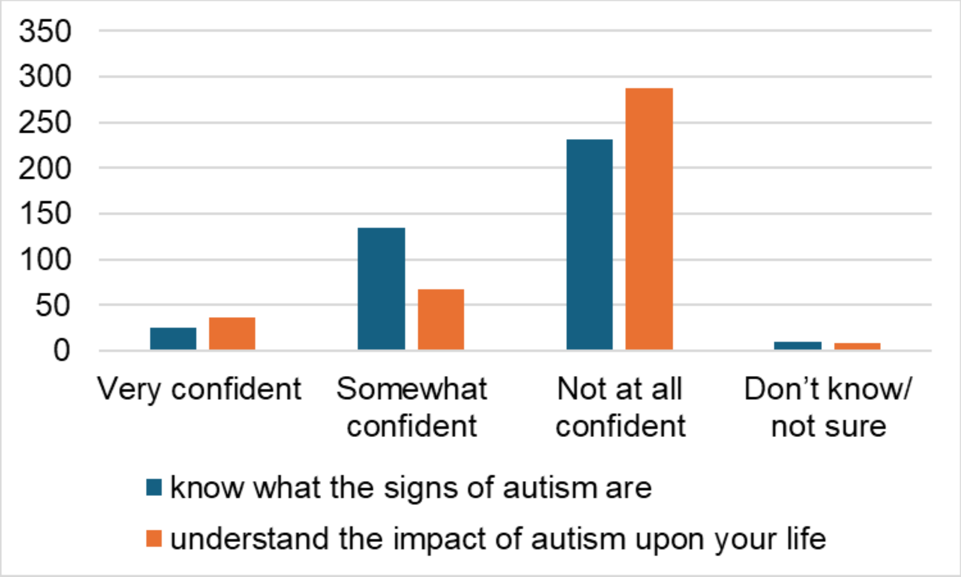
The main written comment (complaint) about LD services was that they could only be accessed by those with a low IQ, for example:

- 'All determined by IQ - shameful.'
- 'Getting help for adults with learning disabilities is another nightmare (I am a carer for one and the local authority and social services 'support' is non-existent). The learning disabilities social services team don't want to know and the adult care team don't either. I have been on the phone in tears begging for help and have been told there is no funding.'

Confidence in health and social care staffs' awareness, knowledge and skills

As Chart 8.2 illustrates, just over 70% of respondents were 'not at all confident' that health care staff, such as GPs and nurses, understood the impact of autism upon their lives. As Chart 8.3 illustrates, respondents were more confident in relation to social care staff but even so, just over half were 'not at all confident' that social care staff understood the impact of autism upon their lives. Further details are provided in Tables 8.10 and 8.11 and in Tables A3 and A4 in the appendix.

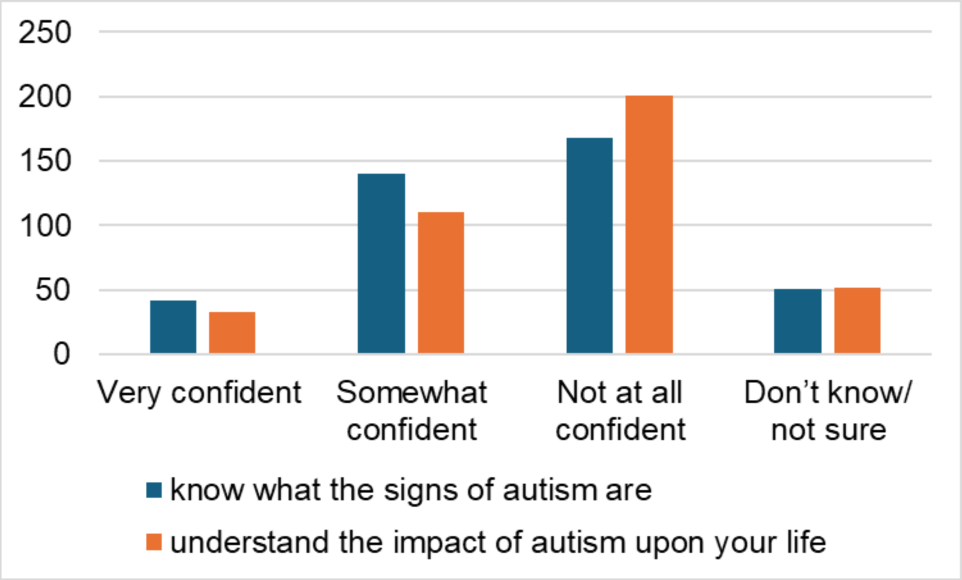
Chart 8.2. Reponses to the questions: how confident are you that health care staff, such as GPs and nurses 'know what the signs of autism are' and 'understand the impact of autism upon your life'



Description of Chart 8.2: A bar chart outlining the responses to the questions: how confident are you that health care staff, such as GPs and nurses 'know what the signs of autism are' and 'understand the impact of autism upon your life'. The majority of responses report being "not at all confident" to both statements.

Source: Main Survey (2024) + Families First Survey (2024), N= 402 and 401 responses

Chart 8.3. Reponses to the questions: how confident are you that social care staff like social workers, care workers, and family and parenting support services ‘know what the signs of autism are’ and ‘understand the impact of autism upon your life’



Source: Main Survey (2024) + Families First Survey (2024), N= 401 and 396 responses

Description of Chart 8.3: A bar chart outlining the responses to the questions: how confident are you that health care staff, such as GPs and nurses ‘know what the signs of autism are’ and ‘understand the impact of autism upon your life’. The plurality of responses report being “not at all confident” to both statements.

Table 8.9. Responses to the question: ‘how confident are you that health workers, like GPs and nurses, know what the signs of autism are?’

	Main Survey (2024)	FF Survey (2024)	Total (Main + FF) (No.)	Total (Main + FF) (%)
Very confident	24	2	26	6
somewhat confident	120	15	135	34
Not at all confident	214	17	231	57
Don’t know/ not sure	10	0	10	2

Table 8.10. Responses to the question: ‘how confident are you that health workers, like GPs and nurses, understand the impact of autism upon your life?’

	Main Survey (2024)	FF Survey (2024)	Total (Main + FF) (No.)	Total (Main + FF) (%)
Very confident	34	2	36	9
Somewhat confident	61	7	68	17
Not at all confident	263	25	288	72
Don’t know/ not sure	8	0	8	2

Written comments suggested particular problems in accessing health services, reflected in their comments about reasonable adjustments (outlined below) and concerns about health staff knowledge and understanding, which in turn limited their access to health services such as dentists and GPs, for example:

- ‘It’s really hard to know who to contact. I had concerns about my son’s eating for example and spoke to GP. It was almost impossible to get an appointment and only then if I was reporting weight loss. I felt I was dismissed as an overly worried parent and I just wanted someone to speak to who understood how autism affects eating and to provide some really basic encouragement.’
- ‘I am a highly educated, articulate, white middle class person who is generally able to navigate the systems in place. I find the lack of understanding about autism in Wales in the healthcare system more generally to be really poor and I’m constantly having to battle for and be an advocate for my child. I dread to think how people who present differently from me or have language barriers for example, manage. It feels like the code of practice is non-existent in Wales so what’s the point of having one?’
- ‘In my experience the vast majority of health care staff have a very fixed and outdated idea of what autism looks like.’
- ‘Most medical and social care professionals are not able to communicate with autistic individuals effectively’

There were also many written comments expressing frustration that autism was not felt to be understood by social care staff, for example:

- ‘Social workers do not understand that people with high functioning autism still needs to support but they limited to the bare minimum and make them struggle at home.’
- ‘It seems there is a general ignorance across the board about Autism and ADHD and the issues both of them cause on a daily basis.’
- I’ve always come across people who are dismissive, so it’s incredibly challenging to try and “convince” someone and often don’t feel listened to unless in destress [sic].’

- ‘The Integrated Disability team in [name of LA omitted] have staff that have no training is Neurodiversity.’
- ‘To be perfectly honest, I have always been too nervous to contact Social Services for fear that they will not be neurodiverse informed.’
- ‘I have met very few people in the social services who have had any ideas at all’

The net effect of feeling that staff did not understand autism and were working in a system that was ‘broken’, given, for example, as one person put it, ‘limited services, poor funding, little support for child[ren], unacceptable waiting lists’ was that people trying to access services ‘don't feel valued or cared for’.

However, several of the comments went further, expressing the view that the lack of understanding led professionals to ‘blame’ parents or carers, for example:

- ‘Social Services have very little understanding of Autism, do not see Autism as a disability and are very discriminatory. They believe every autistic child is the same! There are several research papers on autism and parental blame by Social Services and Systems Generated Trauma by Cerebra and Luke Clements.’
- ‘Several ‘professionals’ have said our child is ‘stubborn’! We have been gobsmacked by how little understanding there is and the very outdated viewpoints by professionals. Significant amount of parental blame’.

Nevertheless, occasional positive comments were also made, although these were often qualified in some way, for example:

- ‘Some health workers and social workers know about autism, understand my daughter’s difficulties and come up with some good guidance and advice. Other workers know very little and I feel we are being treated as if on a check list and no help or advice is given.’
- ‘This [awareness and understanding] is improving and professionals within adult services trying to improve their understanding and attitudes are definitely changing. [H]owever there are still some social workers particularly within mental health services who hold stereotypical attitudes and beliefs… In children’s services it depends very much on the individual workers however there is still a lack of knowledge and people still hold the stereo type and out of date info as factual…such as everyone is a little bit autistic. Autism is a learning disability...all autistic individuals do not have social imagination’

Confidence that health and social care staff know how to refer people for an assessment

As Tables 8.11 and 8.12 illustrate, respondents were somewhat more confident that health and social care staff knew how to refer people for an assessment, but even here, a plurality of respondents (around 40 per cent) were ‘not at all confident’. As tables A4 and A5 in the appendix illustrate, this was comparable to the responses in 2023.

Table 8.11. Responses to the question: ‘how confident are you that health workers like GPs and nurses know how to refer people for an assessment?’

	Main Survey (2024)	FF Survey (2024)	Total (Main + FF) (No.)	Total (Main + FF) (%)
Very confident	25	5	30	7
Somewhat confident	156	12	168	42
Not at all confident	158	16	174	43
Don’t know/ not sure	28	1	29	7

Table 8.12. Responses to the question: ‘how confident are you that social care staff like social workers, care workers, and family and parenting support services know how to refer people for an assessment?’

	Main Survey (2024)	FF Survey (2024)	Total (Main + FF) (No.)	Total (Main + FF) (%)
Very confident	31	5	36	9
Somewhat confident	128	11	139	35
Not at all confident	145	14	159	40
Don’t know/ not sure	63	3	66	17

Very few written comments on referrals were made, with most comments being upon waiting lists, difficulties accessing assessments or meeting thresholds and the lack of support, rather than a lack of staff knowledge about how to refer people to that support; for example, as one person commented, ‘I think they know how to refer people for assessment but delay doing this because of the long waiting lists’.

Nevertheless, comments occasionally highlighted examples where referrals were either missed or misidentified or because services failed in some way (for example, paperwork was lost, not sent etc.), for example:

> ‘It took a long time before the paediatrician referred my child to Cahms [sic] This was such a relief once it was done. Then they lost the paperwork after I waited over six months to hear from them. Then once I was told he was in the system they still hadn’t found the paperwork, so this was another three months. Then, we had to wait the normal amount of time for an appointment. In this time we were in crisis. In the meantime we went private. Had we not done this? We would have been in crisis as a family for two years, my son did not get any education during this time.’

People’s confidence that health and social care staff would make reasonable adjustments

As Tables 8.13 and 8.14 illustrate, respondents were generally not confident that health care staff would make reasonable adjustments. Over two thirds of respondents were ‘not at all confident’ and half of respondents ‘were not at all confident’ that health care staff would make reasonable adjustments to ensure that they could access autism services.

Table 8.13. Responses to the question: ‘how confident are you that health workers, like GPs and nurses make reasonable adjustments to ensure that autistic individuals are able to access health services?’

	Main Survey (2024)	FF Survey (2024)	Tota (Main + FF) l (No.)	Total (Main + FF) (%)
Very confident	14	0	14	3
Somewhat confident	85	8	93	23
Not at all confident	248	25	273	68
Don’t know/ not sure	21	1	22	5

Table 8.14. Responses to the question: ‘how confident are you that social care staff like social workers, care workers, and family and parenting support services make reasonable adjustments to ensure that autistic individuals are able to access services?’

	Main Survey (2024)	FF Survey (2024)	Total (Main + FF) (No.)	Total (Main + FF) (%)
Very confident	24	5	29	7
Somewhat confident	101	5	106	27
Not at all confident	178	21	199	50
Don’t know/ not sure	63	3	66	17

Written comments focused particularly upon health services such as GPs and hospitals and the behaviour of staff, for example:

- ‘Accessing hospital appointments can be awkward as I don't feel reasonable adjustments are made and the wait times are very lengthy’
- ‘It very much depends who you get on the day. I have encountered some lovely staff members but more often than not they approach the same as they would with a NT child. Most healthcare settings I/we have accessed do not even have the basics such as quiet rooms, let alone ensuring they have a communication plan in in place, or making adjustments such as home visits to ensure the person feels comfortable’
- ‘No reasonable adjustment made have been in A&E for 20+ hours with an autist[ic] young man who cannot be in a group of people in full fight or flight putting himself in danger and others’

- ‘We have not seen such consideration at any health services, and if I try to explain that my children are autistic, I either get dismissed that it is irrelevant in to the health care provider or they pretended that my children are not there?!’
- ‘Access to health in general is very disabling for neurodivergent people. Needing to advocate for yourself, getting info out face to face when asked, clinical settings are a sensory nightmare’

As a result, some people described how the failure to make (what they felt were) reasonable adjustments, such as changes to the sensory environment and/or mode of communication, restricted their or their child’s access to health care, for example:

- ‘Because appointments are timed, often there is no time for my children to adjust to the new and often frightening environment. There are little or no areas that are quiet enough. Practitioners don't seem to understand the level of gentleness needed or the time that is required to prepare the child and ensure they are comfortable enough to have treatment’
- I ‘have been unable to access GP support since 2019 when Dr [name omitted] left my practice. Since then I have been spoken to disgustingly by reception staff, who treat me as though I am a child / being awkward’
- ‘I have multiple chronic health conditions but cannot access the correct medical support because no one will give me the time I need to describe my conditions and my GP will not make reasonable adjustments such as email contact’
- ‘Being autistic with anxiety and selective mutism has been a complete barrier for my daughter to services such as GP, paediatrician, OT, CAMHS because they don’t understand how to make reasonable adjustments’

Fewer comments were also made about social care staff’s failure to make reasonable adjustments, although those that were made were generally negative, for example:

- ‘Social workers are unable to help because of their lack of experience or knowledge with children with autism’
- ‘Social and Health Workers seem blissfully unaware that a neurodiverse personal does not necessarily fit their stereotypical view of what neurodiversity looks like. Teams seem well set up for Learning Disabilities, but training in Autism/neurodiversity is woefully inadequate, "Autism awareness " is just not good enough’

Some people also commented about their wider experiences (that is not just health and social care), for example:

> ‘I always tell a service that I am autistic if I have to have an assessment or whatever and never get a reply offering any kind of adjustment. You have to know and advocate for yourself and this can be really difficult for a number of reasons, including the admin side of contacting people, not wanting to feel like a burden or being “difficult” etc.’.

Nevertheless, there were also occasional positive comments, for example:

> ‘Our son's GP has been holding person centred appointments with him since he was 4 years old, I just add any information that he missed out that are relevant, this GP has autistic relatives but knows enough to not assume all autistic individuals are the same, she's incredibly caring and consistent’.

Having a say in the development of autism services

As Table 8.15 illustrates, over two thirds of the parents and carers of autistic children or young people who responded to the question: ‘do you think that parents or carers of autistic children have a say in the development of autism services in your area?’, said no. As Table 8.16 illustrates, the proportion of autistic adults who felt that they did have a say in the development of autism services in their area was higher at just over 50 per cent. However, the proportion of adults who did not know (just over one third) was also higher when compared to responses from the parents and carers of autistic children or young people.

Table 8.15. Responses from the parents and carers of autistic children or young people to the question: ‘do you think that parents or carers of autistic children have a say in the development of autism services in your area?’

	Main Survey (2024)	FF Survey (2024)	FF Survey (2023)	STAND Survey (2023)	Total (No)	Total (%)
Yes	34	5	5	0	44	12
No	228	21	19	2	270	71
Don't know	46	8	13	1	68	18

Table 8.16. Responses from autistic adults to the question: ‘do you think that autistic adults have a say in the development of autism services in your area?’

	Main Survey (2024) (no)	Main Survey (%)
Yes	17	15
No	57	51
Don't know	38	34

Written comments suggested that there was little confidence that autistic adults or the parents or carers of autistic children have a say in the development of autism services, for example:

- ‘They don’t listen to parents as much; always asked for my views but they aren’t actively taken into consideration and efficiently actioned to provide provision for my child. I find cost saving is above children’s needs in [name of LA omitted].’
- We ‘are know[n] to local authority and NHS [but] never asked to take part. [We] have been involved in the past but felt like no one wanted to hear what it not working and how things could be better due to costs’
- ‘If they did [listen to us] then there would be a lot more support available than there is’

People’s responses were often shaped by their personal experience of the difficulties in accessing services (which suggested that services were not listening or responding to them), for example:

- ‘If they did [have a say on the development of services] they WOULD NOT be so terrible. Every parents of autistic I speak to is drained by the ‘disability admin tax’ of having multiple inaccessible cases, processes and fights to get their children the support the law says they’re entitled to.’
- ‘I don’t think the lived experiences of families are listened to’

Other comments reflected a general pessimism that things would or could improve, even if they made their voices heard, for example:

- ‘You gather opinion but it seems ignored after that’
- I keep filling out surveys but I doubt anything will change’
- ‘I've never seen anything, anywhere, other than this survey that has asked for input from ND people’
- ‘I have been advocating for changes for years. No one listens.’
- ‘No one listens. And there is no funding’
- ‘There aren't many services anyway- so not much to influence. Plus I don't think the NHS and social services are in any shape to listen to and implement any of what we say right now. They are just trying to stay afloat as it is so it's not a good time to be making demands or big changes as they cannot be sustained and staff are already stressed out enough. I honestly believe our services are doing the best they can with what they have and that the staff are brilliant but I don't think they have the time/energy/resources to change things in any big way right now’

Nevertheless, there were a small number of more positive comments, although even these tended to be qualified in some way, for example:

- ‘I am a lived experience advisor with the [name of service omitted] and feel that they do much to include. I just wish I could do more when asked.’
- ‘I think there are very proactive parents that take time to work their way into services to influence and tell their story, but if speaking up about the challenges is difficult, you are left out of the conversation’

9. Assessing the likely impact of the Code

The Code directly addresses the three priorities outlined in the 2016 Autism Strategic Action Plan:

- ‘Assessment and Diagnosis’
- ‘Meeting Support Needs’
- ‘Awareness Raising, Information and Training’ (Refreshed Autistic Spectrum Disorder Strategic Action Plan, p. 6)

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’ (Refreshed Autistic Spectrum Disorder Strategic Action Plan). Although this evaluation has not systematically assessed whether these remain priorities for autistic children, adults and their families and carers, previous evaluations and reviews (see, for example, Evaluation of the Integrated Autism Service and Autistic Spectrum Disorder Strategic Action Plan: final report) and feedback from stakeholders (including autistic adults and the parents and carers of autistic children and young people, discussed in section 8), suggest they do remain priorities. Improvements in these areas can therefore be expected to contribute to ensuring that (as the Refreshed Autistic Spectrum Disorder Strategic 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’ (Refreshed Autistic Spectrum Disorder Strategic Action Plan, p.5).

However, as outlined in sections 4 to 7:

- the extent to which LAs and LHBs are compliant with the Code varies
- 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

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

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

- some impact upon planning and commissioning of services (unlike 2023, where we identified little impact)

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.

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 [footnote 75]
- 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 [footnote 76] and carers, including those provided by the third sector, have improved access to IAA support for children and families
- the IAS continues to play a central role in providing access to information and support for autistic adults who are not eligible for support from secondary services (that is LD and MH services); for 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
- the Code has further raised the profile of autism and the importance attached to it by LAs and LHBs at regional and service levels [footnote 77]. 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)

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[75] 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.

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

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

- access to services and support for children and adults in the secure estate
- the role that people with lived experience can and should play in shaping training and service design and delivery

10. Conclusions

Addressing the evaluation aim and objectives

As outlined in section 2, the aim of this evaluation was 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. The objectives of the second phase were:

- to examine whether the recommendations in meeting the duties of the Code identified in phase one have been addressed and identify any challenges service providers have had in implementing the recommendations
- to further assess the extent to which the duties of the Code are being met
- to assess whether service users are aware of the Code and its duties
- to assess and develop further recommendations for improvements in meeting the duties of the Code

In response:

- we discuss the progress each region has made in addressing the recommendations made at the end of phase one, and their compliance with the Code, in section 4 to 8, and the barriers and enablers to compliance, in section 9
- we consider service users' awareness of the Code and their experiences in section 8we assess the extent to which the Code has made a difference to the development and delivery of autism services in section 9

In this concluding section, we reflect upon the progress made in complying with the code (including service users' experiences and enablers and barriers) and the impact of the Code. In the following section (11) we then outline recommendations for improvements in meeting the duties of the Code.

Compliance with the code

Although the Code is a restatement of existing duties within the SSWBW Act and NHS Wales Act (rather than the creation of new duties) the evaluation identifies that LAs and LHBs are still embarking on the journey toward full compliance [footnote 78], for example:

- in relation to parts of the Code, regions were already generally compliant with the Code's duties (and the Code has had little impact). The clearest example of this was in relation to duties addressing access to diagnostic assessment services via children's ND services and the IAS, where, with the exception of the waiting time target, regions were generally compliant

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

- the regional assessment of compliance (supported by this evaluation) 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. However, this has not yet provided assurance that LAs and LHBs are compliant with the duties in the Code, nor identified further actions that may be required to ensure compliance in these areas

- the regional assessment of compliance has also highlighted a number of specific duties that LA and LHBs:

    - were struggling to meet in 2024, most notably the waiting time for children's diagnostic assessment. However, as noted in section 3, progress is being made, and additional investment to support further reductions in waiting times, was announced in November 2024 (Written Statement: Reducing Long Waiting Times (17 November 2024))

    - find (appropriately) challenging (or stretching), as they potentially require change across health and social care systems. The clearest examples of this are duties like the duty to 'ensure that reasonable adjustments are in place for autistic individuals to ensure they are able to access services in the same way as everyone'

    - disagree about 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 they may have care and support needs, are not necessarily consistent with the letter (or text) of the Code 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 somewhat counter to the duty on LAs and LHBs to 'ensure that awaiting a diagnosis is not a reason to be refused support and other services'. Although, as outlined above, steps taken to open up IAS's support offer to those awaiting a diagnosis are welcome, they do not yet provide parity of support for those awaiting diagnosis. In addition, it was also observed that the duty does not require the IAS to offer pre-diagnostic support; instead, the duty requires LA and LHBs to do so, through for example, IAA and access to primary health services

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 is significant. Engagement with other LA and LHB leaders and strategic groups to 'mainstream' autism into wider policy will be required, to transform mental health, wellbeing and support services for children, young people, parents, carers and their wider families across Wales. This will involve reviewing policies and practice from equality and diversity 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.

Finally, it is striking that in almost all the areas examined, the feedback from autistic adults and parents and carers is much more negative than practitioners’ assessments of compliance. A direct comparison should not be made however, given the considerations outlined in section 2; for example, it is not clear how representative these experiences are of all autistic adults and/or all parents and carers of autistic children or young people. Moreover, in part the negativity appears to reflect wider difficulties in services not covered by the Code (most notably education) and also historical experiences that continue to cloud or blight people’s perceptions of services, but which may not fully represent services today. Nevertheless, as section 2 also outlines, there is no suggestion that their responses are not genuine and the experiences they reported were often recognised by stakeholders (for example, as consistent with anecdotal data on people’s experiences). Therefore, it signals a sharp note of caution on the impact of the progress that LA and LHBs report and the importance of monitoring and evaluating people’s lived experiences of interacting with LA and LHB services. This may also highlight priorities for action beyond those covered by the Code. Equally, it is important to note that the feedback included examples of people with positive experiences. Approaches such as appreciative inquiry, where the focus is upon identifying and building on what is working well (rather than what is not working well), are also appropriate to identify how services and support can be strengthened.

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

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

Enablers and barriers to compliance

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. As in 2023, the important factors that have supported compliance (enablers) include:

- the profile and legal force of the Code (although even here, it is reported that the Code is sometimes seen more as guidance rather than a statutory requirement) and the ways in which it has supported 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 (for example, in relation to access to IAA services and social care assessments) and the Equality Act (in relation to reasonable adjustments)

- Welsh Government funding to develop national autism services such as children's ND services and the IAS and, more recently, additional funding support from the NDIP

- the support from the NNT/NAT, particularly around training and resources

As in 2023, the main factors that have hampered compliance (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 (for example, when 'dashboards' are filled with red or amber 'lights', signalling non-compliance [footnote 79]) and can encourage what some stakeholders' described as a 'tick box' approach to compliance [footnote 80]

- linked to this, it has sometimes proved difficult to get all of the stakeholders engaged and, in some cases, to even identify in LAs or LHBs who has responsibility for specific duties

- the financial pressures health and social services face as result of high levels of demand and constraints upon their capacity, including problems recruiting and retaining staff, which can encourage services to turn inward and focus upon what they see as their 'core' role. This can undermine systems leadership [footnote 81] and can make prioritising action to support compliance with the Code challenging (when services face other competing priorities demanding attention and resources)

- linked to this, the short term nature of some funding, such as some NDIP monies, and delays in confirmation of funding, were reported to be limiting RPB's scope to use the money as effectively as they would like

- weakness in regional leadership and co-ordination where, for example, there have been delays or senior individuals or groups have not taken responsibility for assessing compliance and identifying the actions required

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

[80] 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.

[81] 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 individuals' experiences.

The impact of the Code

As section 9 outlines, the Code is starting to make a difference in areas such as the provision of information for autistic adults and the parents and carers of autistic children and young people, and regional planning. Nevertheless, the scale of the challenge facing LAs, LHBs and RPBs is starkly illustrated by the often distressing experiences of autistic adults and the parents and carers of autistic children and young people when interacting with services (discussed in section 8). Their accounts also highlight the need for action beyond the existing Code duties, in health and social care and also in areas beyond the current Code, most notably education in the case of parents and carers and, to a lesser degree, employment in relation to autistic adults [footnote 82].

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[82] It is likely that this issue did not feature more prominently because no questions were asked about employment. There is, however, ample evidence from other research highlighting the barriers that autistic adults face in relation to employment (see, for example, The Buckland Review of Autism Employment: report and recommendations).

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

Recommendations for LAs and LHBs

A series of recommendations have been made to each LA and LHB to address specific areas where they are either not compliant or where there is insufficient evidence to judge compliance with the Code. Importantly, the feedback from autistic adults and the parents and carers of autistic children discussed in this report suggests that poor experiences and outcomes are often best understood as systemic failures or weaknesses, rather than as failures to meet individual duties. This suggests the need for a systems wide response, and that reviewing individual duties may mean that the interrelationship between different duties is missed.

The recommendations 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[footnote 83]
    - enhance the scrutiny of practice that has been overlooked or neglected by regional strategic groups (for example, in relation to diagnostic assessments in LD and AMH services) and, where needed, identify actions to address gaps or weaknesses
    - ensure that a systems-wide approach to developing autism services, that is informed by better data on services' practice and autistic individuals' experiences, helps ensure that resources (including additional funding such as the NDIP) support innovation and the development of specialist services (where needed) and helps 'mainstream autism' within wider policy development
- awareness raising and training: ensuring that autism is considered in 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 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 adults' disability services,

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[83] 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.

education settings (such as schools, colleges and universities), third sector organisations, stakeholder groups and networks and autism officers

- improving access to diagnostic services: taking action to address demand-capacity challenges facing ND services, drawing upon the Review of Neurodevelopmental Services (Welsh Government, 2023a) and the recent review of children's ND services undertaken by the NHS Delivery Unit

Recommendations for the Welsh Government

The evaluation of the impact of the Code, including the limits of its likely or possible impact in areas like education, not covered by the Code, and the enablers and barriers to implementation identified by this report are likely to be relevant for the Welsh Government when considering the forthcoming Code of Practice on Neurodevelopmental Services. For example, in considering:

- how awareness of and the profile of the Code amongst autistic individuals and their families, can be raised (given the relatively modest levels of awareness identified in the surveys of autistic individuals and the parents or carers of autistic children, discussed in Section 8) consideration could be given to working with people with lived experience to identify how best to communicate the most important messages. For example, this could be through documents such as The leaflet for autistic people and their families: what does the code of practice mean? and/or other forms of media such as videos or podcasts
- how to encourage a system wide response, through duties that are often narrowly focused upon one small part of the system the current duties in section 4 of the Code, focused upon 'Planning and Monitoring Services and Stakeholder Engagement', which encourage a systems wide perspective, could be strengthened
- how funding streams such as the NDIP, the Regional Integration Fund and advice, support and challenge from the Welsh Government Neurodivergence Improvement Team and NNT can encourage and support systems wide change including:
    - continuing to support the sharing of practice through, for example, funding and facilitation of events (such as the event in 2024 focused upon the design of neurodevelopmental services), networks and communities of practice. These could be particularly valuable in developing practice in areas such as the secure estate, where there are gaps and shortcomings across Wales, and there may be a desire for the development of a national model, rather than a series of regional models
    - identifying whether there is a demand for national leadership in developing new approaches (e.g. in relation to diagnostic assessment pathways and in broadening

the range of professionals involved in diagnostic assessments or formulations [footnote 84]). Partners, such as NHS Executive, are likely to have an important role here

- developing models and tools that can be used across Wales, such as the NNT's National Autism Training Framework and training materials
- moving from short (one year) to medium term (three year+) funding commitments, to support a shift from pilots and projects to the development of sustainable services
- integrating NDIP reporting requirements, and any future reporting requirements on compliance with the Code, with Welsh Government reviews of RPB annual reports [footnote 85] , PNAs and Area Plans
- exploring how autism (and neurodiversity more broadly) can be more effectively mainstreamed into the delivery of wider policies, such as the NYTH/NEST framework, the ALN transformation programme; the Mental health and wellbeing strategy 2025 to 2035 and parenting support programmes such as Families First
- clarifying the roles that regional autism champions, regional strategic and operational groups, local stakeholder groups and local ASD leads are expected to have in ensuring compliance with the Code, and how these different groups and roles can best complement each other
- considering how the new ND Code can be streamlined (given the way in which the number of duties in the autism Code became a barrier to compliance); simplified (given the ambiguity around what some duties required, or in some cases tensions between what is considered good practice and what the Code footnote[86] or other guidance requires footnote[87]) and restructured (given the way in which closely related duties often appear in different sections of the Code, rather than being grouped together)

Looking forward to the proposed ND Code, it is notable that the (current) Code of Practice on the Delivery of Autism Services, includes a mix of process and outcome requirements.[88] For example, in Section 1, the Code requires:

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[84] A formulation has been defined as 'a provisional explanation or hypothesis of how an individual comes to present with a certain disorder or circumstance at a particular point in time'. (Formulation: A Multiperspective Model*, p. 351).

[85] The current Code outlines that 'Welsh Government will request an annual report on the delivery of the regional area plan including compliance with the requirements contained within this Code'. However, as this evaluation outlines, RPBs understanding of compliance is often patchy.

86 For example, the Code requires that 'Ensure IQ is not considered as part of the eligibility criteria' for health services (p. 22), whereas LD services often report using IQ as one of their eligibility criteria. It was also observed that ineligibility for LD services was one of the eligibility criteria for the IAS.

87 For example, one of the 'Principles' in the Supporting Guidance for the IAS is that 'With the exception of diagnostic assessment of adults, the service may only be accessed by those who have received a formal autism diagnosis.' Although, the supporting guidance also makes it clear that 'the IAS may work with adults on their waiting list for Diagnostic Assessment' (p. 6), this still runs counter to the ethos that a diagnosis should not be needed to access services and support.

88 In this context, 'process' requirements focus on what LA and/or LHBs must do, and 'outcome' requirements focus upon the results or end goals that need to be achieved. The distinctions between the two can be blurred.

- LAs and LHBs to ‘Designate an individual with lead responsibility for maintaining, reviewing and promoting diagnostic pathways for children, young people and adults’ (p. 13). In effect, the Code identifies what LAs and LHBs must do, without specifying the outcome of this
- LHB’s to ‘Comply with current national waiting time standards for assessment and diagnosis’ (p. 12). In effect, the Code identifies the outcome required (that is to say compliance with the waiting time standard) without specifying how this outcome is to be achieved

Each approach offers strengths. For example:

- a focus upon process requirements can provide greater clarity on what LAs and/or LHBs must do and can aim to enable or contribute to a range of outcomes. For example the duty to ‘Designate an individual with lead responsibility for maintaining, reviewing and promoting diagnostic pathways’ provides the basis for fulfilling a number of other duties
- a focus upon outcomes, provides greater flexibility to address local contexts and also provides greater focus upon the intended result. For example, the duty to ‘comply with current national waiting time standards’, gives LHBs and ND services the freedom to develop different approaches and encourages them to focus upon the effectiveness of what they do

In any future ND code, we recommend that consideration is given to whether a particular desired outcome is best achieved by:

- directly and clearly articulating what LAs and LHBs must do (using process requirements) and/or
- directly and clearly articulating the outcomes that LAs and LHBs must achieve (using outcome requirements), and wherever possible, outlining how the desired outcome is to be measured. Wherever possible we suggest these are based upon existing or planned outcome measures, such as those proposed for the NDIP

In many cases, it may be appropriate to include both process and outcome requirements. Process requirements are likely to be appropriate where there is a strong evidence base of what works and consensus on what should be done or how it should be done. Conversely, outcome requirements are likely to be appropriate where the evidence base is weaker and there is less consensus on what should be done or how it should be done, in order to achieve the desired outcome.

Given the ambiguity about what some of the duties in the current Autism Code requires (an issue that is discussed in Section 2), being as clear and direct about what is

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For example, the duty in section 1 of the Code ‘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’ could be interpreted as focusing upon processes, given the requirement to make referrals, but the duty does not specify how the referrals are to be made, and ensuring that referrals are made, could also be interpreted as focusing upon an outcome.

required, will be important in any future ND Code. This should aim to improve compliance and make it easier to audit compliance in the future.

12. Bibliography

David, A.S. and Deeley, Q. (2024) ‘Dangers of self-diagnosis in neuropsychiatry’, Psychological Medicine, Volume 54, Issue6, pages1057 to1060

Annex A. Additional Survey Data

Table A1. Responses to the question: ‘is it easy to gain information on the autism services in your area?’

	FF Pilot Survey (2023)	STAND Survey (2023)	Total (no.)	Total (%)
Yes	3	1	4	13
No	16	2	18	58
I am unsure	9	0	9	29

Table A2. Responses to the question: ‘how confident are you that health workers, like GPs and nurses know what the signs of autism are?’

	FF Pilot Survey (2023)	STAND Survey (2023)	Total (no.)	Total (%)
Not at all confident	8	0	8	20
slightly confident	12	3	15	38
somewhat confident	11	0	11	28
quite confident	5	0	5	13
extremely confident	1	0	1	3

Table A3. Responses to the question: ‘how confident are you that health workers, like GPs and nurses understand the impact of autism upon your life?’

	FF Pilot Survey (2023)	STAND Survey (2023)	Total (no.)	Total (%)
Not at all confident	11	1	12	30
Slightly confident	4	1	5	13
Somewhat confident	12	1	13	33
Quite confident	6	0	6	15
Extremely confident	4	0	4	10

Table A4. Responses to the question: ‘how confident are you that health workers, like GPs and nurses know how to refer people for an assessment?’

	FF Pilot Survey (2023)	STAND Survey (2023)	Total (no.)	Total (%)
Not at all confident	15	0	15	38
Slightly confident	6	1	7	18
Somewhat confident	7	1	8	20
Quite confident	8	1	9	23
Extremely confident	1	0	1	3

Table A5. Responses to the question: 'how confident are you that social care staff like social workers, care workers, and family and parenting support services know how to refer people for an assessment?'

	FF Pilot Survey (2023)	STAND Survey (2023)	Total (no.)	Total (%)
Not at all confident	8	0	8	20
Slightly confident	10	1	11	28
Somewhat confident	12	0	12	30
Quite confident	7	2	9	23
Extremely confident	0	0	0	0

Table A6. Responses to the question: 'how confident are you that social care staff like social workers, care workers, and family and parenting support services make reasonable adjustments to ensure that autistic individuals are able to access services?'

	FF Pilot Survey (2023)	STAND Survey (2023)	Total (no.)	Total (%)
Not at all confident	7	0	7	18
Slightly confident	12	1	13	33
Somewhat confident	11	1	12	30
Quite confident	5	1	6	15
Extremely confident	2	0	2	5

Table A7. Responses to the question: ‘how confident are you that health workers, like GPs and nurses make reasonable adjustments to ensure that autistic individuals are able to access health services?’

	FF Pilot Survey (2023)	STAND Survey (2023)	Total (No.)	Total (%)
Not at all confident	13	2	15	38
Slightly confident	8	0	8	20
Somewhat confident	10	1	11	28
Quite confident	4	0	4	10
Extremely confident	2	0	2	5

Annex B. Benchmarks

Table B1.1 Benchmarks for compliance: duties related to access to diagnostic assessment services (multidisciplinary involvement)
Duties: 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.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**
- Detail of multidisciplinary involvement in diagnostic assessments (for example, multiple disciplines involved in history / observation / clinical interview and/or decision on diagnosis) in the service offering diagnostic assessments for children and adults (for example, children's ND, IAS, AMHS, LD).	- Detail of multidisciplinary involvement in diagnostic assessments (for example, multiple disciplines involved in history / observation / clinical interview and/or decision on diagnosis) in the service offering diagnostic assessments for children and adults (for example, children's ND, IAS, AMHS, LD).	- Detail of multidisciplinary involvement in diagnostic assessments, but significant gaps or weakness in teams (for example, due to staff vacancies).	- Clear evidence that NICE best practice guidance for multidisciplinary involvement is not followed.
- Each services' team has adequate capacity to undertake thorough diagnostic assessments (for example, in terms of numbers of staff and staff skills and competence).			

Table B1.2. Benchmarks for compliance: duties related to access to diagnostic assessment services (in the secure estate)
Duty: LHB and NHS trusts must: ensure that autism assessment and diagnostic services are accessible by individuals detained in the secure estate.

Full compliance + (including going above and beyond the Code requirements)	Good progress (but not full compliance)	Limited or uneven progress to date	Not compliant
- Details of the pathways for young people and adults in different secure estate settings in the region (for example, LA secure children's homes, YOIs, prisons) - Evidence that autism assessment and diagnostic services are accessible by individuals detained in the secure estate (for example, examples of this happening).	- Details of how young people and adults in different secure estate settings in the region could access a diagnostic assessment service.	- Discussion of how young people and adults in different secure estate settings in the region could potentially access a diagnostic assessment service.	- Clear evidence that autism assessment and diagnostic services are not accessible by individuals detained in the secure estate.

Table B1.3. Benchmarks for compliance: duties related to access to diagnostic assessment services (referral pathways)

Duty: LHBs must: ensure that primary and secondary care practitioners are notified of assessment referral pathways for children, young people and adults.

Full compliance + (including going above and beyond the Code requirements)	Good progress (but not full compliance)	Limited or uneven progress to date	Not compliant
- Details of how primary and secondary care practitioners are notified of assessment referral pathways to the service	- Details of how primary and secondary care practitioners are notified of assessment referral pathways to the service	- Details of how primary and secondary care practitioners are notified of assessment referral pathways to the service	- Evidence that primary and secondary care practitioners have not been notified of assessment referral pathways for children, young people and adults.
- Evidence that primary and secondary care practitioners understand and use pathways (for example, analysis of referral rates and rates of inappropriate referrals to different services by different staff groups; surveys of staff awareness).	- 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.	- 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.	

Table B1.4. Benchmarks for compliance: duties related to access to diagnostic assessment services (waiting times)

Duty: LHBs must: comply with current national waiting time standards for assessment and diagnosis.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**
- 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.

Table B1.5. Benchmarks for compliance: duties related to access to diagnostic assessment services (waiting times and data collection)

Duty: 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.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**
- The Children's ND service provides waiting time data to the WG	- The Children's ND service provides waiting time data to the WG	- 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 (for example, autism strategy and operational groups).		- However, concerns are raised about the data that is provided.	

Table B1.6. Benchmarks for compliance: duties related to access to diagnostic assessment services (prompt referral)

Duties: 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

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**
- 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.	- 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.	- 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 or child or adult has given consent.

- These referrals are always made following a diagnostic assessment (irrespective of the outcome), when indicated/appropriate and the parent or child or adult has given consent. - Referrals (where appropriate) for post-diagnostic support assessments are routinely accepted by other services (for example, SLT, OT, social care) - Referrals (where appropriate) for further investigation (for example, for another ND condition) are routinely accepted by other services (for example, AMHS / ADHD services).	- These referrals are sometimes made by the services following a diagnostic assessment (irrespective of the outcome) when indicated/appropriate and the parent or child or 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 (for example, 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 or child or 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 (for example, referrals being rejected by other services); AND/OR - The capacity of the service to offer post-diagnostic assessments is very limited.	

Table B1.7. Benchmarks for compliance: duties related to access to diagnostic assessment services (designate an individual with lead responsibility)

Duty: LAs with LHBs must: designate an individual with lead responsibility for maintaining, reviewing and promoting diagnostic pathways for children, young people and adults.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**
- Name of designated individual with lead responsibility for maintaining, reviewing and promoting diagnostic pathways for the service is provided.	- 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 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.	- No one is responsible for maintaining, reviewing and promoting diagnostic pathways for the service.
- The designated individual has lead responsibility for maintaining, reviewing and promoting <u>all</u> autism diagnostic pathways (for different services for example, 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.		

Table B1.8. Benchmarks for compliance: duties related to access to diagnostic assessment services (the provision, publication and regular review of assessment and diagnostic pathways)

Duty: 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 best practice guidance.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**
- Copy of / link to the diagnostic pathways for the service is provided	- 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 compliant 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 compliant 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' (for example, if there is evidence 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	- Services provide assurance that the diagnostic pathway takes into account NICE best practice guidance.		

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 (that is within last 12 months) including results of the review (for example, audit against the national guidelines for children's ND services and the IAS; and equivalents for other services for example, AMHS).			

Table B2.1. Benchmarks for compliance: Duties related to access to social care assessments (information and signposting to access assessment services)

Duties: LAs must ensure there is information and signposting to access assessment services

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited progress to date**	**No / insufficient evidence to evaluate compliance**
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.	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.	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 etc.	- There is no or clearly inadequate information and signposting to access assessment services.
Websites also provide information on: - How social care and support systems operate with regards to autism services in the area; - the types of care and support available to autistic individuals; and - how to access the care and support that is available; and - LAs publicise how to access social care assessment via a range of media (for example, websites, posters, leaflets in GP surgeries, libraries etc.).			

Table B2.2. Benchmarks for compliance: Duties related to access to social care assessments (information and signposting to access assessment services continued)

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**
LA staff (including but not limited to IAA services) can provide advice on: - How to access a social care assessment; - the types of care and support available to autistic individuals; - 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.	LA IAA services can provide advice 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.	LA IAA services can provide: - access to assessment services.	
- The numbers of people seeking a social care assessment is monitored against benchmarks (for example, expected /projected rates) and when this is lower than expected/projected this is investigated and action is taken to raise rates.			

Table B2.3. Benchmarks for compliance: Duties related to access to social care assessments (aware of the right to an assessment)

Duties: LAs must ensure that autistic individuals 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.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**
- In services that undertake diagnostic assessments, where it appears than an individual may have a need for care and support, all 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 need for care and support, all 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 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.	- Substantial evidence that people are not or are unlikely to be aware of their right to access a needs assessment and a carer's assessment for a carer.
- 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 (for example, by working with the third sector, support groups, social media campaigns etc.).			

Table B2.4. Benchmarks for compliance: Duties related to access to social care assessments (prompt sharing of information)
Duties: 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, 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 / are not diagnosed but where it is indicated necessary that a referral for further assessment is required.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**
- 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 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 (for example, if high numbers of referrals are not accepted).	- 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 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.	- 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 nor advised to self-refer for an assessment.

Table B2.5. Benchmarks for compliance: Duties related to access to social care assessments (secure estate)
Duties: 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.

Full compliance + (including going above and beyond the Code requirements)	Good progress (but not full compliance)	Limited or uneven progress to date	Not compliant
- 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.	- 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.	- 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.	- There is clear evidence that pathways for further assessment after referral within the secure estate are not adequate in design and/or operation.
- 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.	- 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.		

Table B3.6. Benchmarks for compliance: duties related to related to information about and access to autism services (practitioners and services are aware of autism services and have clear referral pathways)

Duties: 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.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited progress to date**	**Not compliant**
- In the judgment of the evaluation team, adequate steps have been taken to ensure that Health and LA staff know how to refer autistic individuals to autism services (for example, training, awareness-raising activity). Note: this could for example, be via the IAA or a 'front door' to services.	- In the judgment of the evaluation team, adequate steps have been taken to ensure that Health and LA staff know how to refer autistic individuals to autism services (for example, training, awareness-raising activity). Note: this could for example, be via the IAA or a 'front door' to services.	- There is a basic knowledge about how to refer to core autism services (for example, the IAS).	- 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.
- Local autism services have been mapped; and - information about autism services is provided on LA and/or LHB websites.	- Local autism services have been mapped; and - information about autism services is provided on LA and/or LHB websites.		

- Clear referral pathways to autism services are published (with copies provided). Note: this could, for example, be via the IAA or a ‘front door’ to services. - Health and LA staff routinely refer autistic individuals to autism services. - The numbers of people referred to autism services is monitored against benchmarks (for example, expected /projected rates) and when this is lower than expected/projected this is investigated and if appropriate, action is taken to raise rates.			

Table B3.7. Benchmarks for compliance: duties related to related to information about and access to autism services (awareness of the IAA service)

Duties: LAs with LHBs should ensure that health and local authority staff are aware of the IAA service and how to refer autistic individuals to the service.

Full compliance + (including going above and beyond the Code requirements)	Good progress (but not full compliance)	Limited or uneven progress to date	Not compliant
- The IAA service and how to access it, is clear on LA websites.	- The IAA service and how to access it, is clear on LA websites.	- 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 individuals 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 individuals 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 individuals to the service.		
- Health and LA staff are aware of the IAA service and how to access it is monitored (including, for example, the appropriateness and numbers of referrals they make to IAA services).			

Table B3.8. Benchmarks for compliance: duties related to related to information about and access to autism services (IAA service information is available on local autism services)

Duties: LAs must ensure that as part of their IAA service information is available on local autism services. As part of their duties under the SSWBW Act, ensure the IAA service provides information on local autism services.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**
- Local autism services have been mapped; and - IAA services provide information on: - the types of autism services available; and - how to access 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 weaknesses; 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 individuals) 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 (for example, expected /projected rates) and when this is lower than expected/projected this is investigated and if appropriate, action is taken to raise rates.			

Table B3.9. Benchmarks for compliance: duties related to related to information about and access to autism services (information, resources and training is made publicly available).

Duties: LAs with LHBs should make arrangements to ensure a range of autism awareness information, resources and training is made publicly available.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**
- A range of autism awareness information, resources and training is made publicly available (for example, on websites).	- A range of autism awareness information, resources and training is made publicly available (for example, on websites).	- A range of autism awareness information, resources and training is made publicly available (for example, on websites).	- No arrangements have been made to ensure a range of autism awareness information, resources and training is made publicly available.
- In the judgment of the evaluation team, the information, resources and training are comprehensive, clear and easy to find and access.	- In the judgment of the evaluation team, the information, resources and training are comprehensive, clear and easy to find and access.		
- There is a comprehensive description of autism information, resources and training offered to different groups [footnote 89], including:			

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

- health care staff - social care staff - other LA staff (i.e. housing, leisure services) - autistic individuals - parents and carers - there is a comprehensive description of material and training designed to raise the awareness of autism amongst LA and LHB staff and the wider public. This includes promoting a social model of disability [footnote 90]. - Evidence of steps taken to ensure accessibility for different groups (for example, link to website where it is publicly available; leaflets and posters in GP surgeries, libraries etc.).			

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[90] 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 individuals, 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 individuals, removing barriers to inclusion. This can be achieved by: i. supporting autistic individuals 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 individuals, their families or carers about their rights iv. providing information about local opportunities tailored for autistic individuals v. providing information about local training available which can support autistic individuals and their family or carers vi. providing information to help autistic individuals and their family or carers to prepare for the future vii. providing the contact details of the Information, Advice and Assistance service.’ (Welsh Government 2022b, pp 25 to 26).

- The take up, and experiences of those taking up information, resources and training, and its impact (for example, upon awareness and understanding) is monitored and used to inform development of information, resources and training			

Table B3.10. Benchmarks for compliance: duties related to related to information about and access to autism services (information, resources and training is made publicly available continued).

Duty: LAs with LHBs should make arrangements to ensure a range of autism awareness information, resources and training is made publicly available.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**
- There are effective LA and the LHB policies on identifying and then making reasonable adjustments.	- There are effective LA and the LHB policies on identifying and then making reasonable adjustments.	- There are effective 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 individuals 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.	- 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; for example, by strengthening training and awareness-raising work).			

Table B4.1. Benchmarks for compliance: duties related to access to needs based services (awaiting a diagnosis)
Duties: LA and LHBs must ensure that awaiting a diagnosis is not a reason to be refused support and other services.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited progress to date**	**Not Compliant**
- Support is consistently offered to people on the basis of need rather than diagnosis. This includes support for those awaiting assessment.	- Support is consistently offered to people on the basis of need rather than 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 individuals 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.			

Table B4.2. Benchmarks for compliance: duties related to access to needs based services (co-occurring conditions)

Duties: LA and LHBs must [ensure that] Where autistic individuals 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.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**
- 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 of Access (SPoA) to help with access to services and support. - A referral for a diagnostic assessment of autism or a diagnosis of autism does not prevent, delay, or hinder referral to other services (for example, MH, LD services) or the provision of support; for example, if ADHD is suspected, information on exercise, sleep	- 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 of Access (SPoA) to help with access to services and support. - A referral for a diagnostic assessment of autism or a diagnosis of autism does not prevent, delay, or hinder referral to other services (for example, MH, LD services) or the provision of support; for example, if ADHD is suspected, information on exercise, sleep	- Support is available from a range of sources including other health and social care services (for example, ADHD, MH, eating disorder and substance 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 individuals; AND/OR - demand-capacity pressures ND services face delay access to support / joint working with other services (for example, MH services).	- There is evidence that autistic individuals with co-existing conditions cannot access support services which can meet their additional support needs in relation to autism.

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 [footnote 91] (see table A5 for detail). Support services make reasonable adjustments for autistic individuals (see table A4 for details).	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 [footnote 91] (see table A5 for detail). - Support services make reasonable adjustments for autistic individuals (see table A4 for details).		
- Referrals for further assessment do not cause delays in providing immediately necessary support - The experiences of and outcomes for autistic individuals with co-occurring conditions are evaluated and this is used to inform service development.			

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

Table B4.3. Benchmarks for compliance: duties related to access to needs based services (co-occurring conditions and Children or Adults Mental Health Services)

Duties: LHBs must ensure that people with an Autistic Spectrum Condition with co-occurring conditions are not excluded from CAMHS or AMHS.

Consideration of core ASC indicators and their influences on individuals must inform the care and support offered and its outcomes.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**
- There are pathways for autistic individuals 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 individuals with co-occurring MH conditions can access an assessment by MH services; for example, reasonable adjustments to services are made; practitioners involved in assessments have the necessary skills and knowledge and understanding of autism through training and/or access to expert	- There are pathways for autistic individuals 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 individuals with co-occurring MH conditions can access an assessment by MH services; for example, reasonable adjustments to services are made; practitioners involved in assessments have the necessary skills and knowledge and understanding of autism through training and/or access to expert	- There are pathways for autistic individuals 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 individuals with co-occurring MH conditions can access an assessment by MH services; for example, reasonable adjustments to services are made; practitioners involved in assessments have the necessary skills and knowledge and understanding of autism through training and/or access to expert	- There is evidence that autistic individuals with co-occurring conditions are excluded from CAMHS/ AMHS.

advice and consultations (for example, by the IAS).	advice and consultations (for example, by the IAS).	advice and consultations (for example, by the IAS).	
- A referral for a diagnostic assessment of autism 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.	- A referral for a diagnostic assessment of autism 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 referral being made or being accepted.	
- The numbers of autistic individuals with co-occurring conditions accessing other services (for example, MH, LD services) is monitored against benchmarks (for example, 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 raises concerns, action is taken.			

Table B4.4. Benchmarks for compliance: duties related to access to needs based services (IQ and eligibility criteria for a needs assessment)

Duties: LAs must ensure that IQ is not considered as part of the eligibility criteria for a needs assessment under the SSWBW Act.

LHBs must ensure IQ is not considered as part of the eligibility criteria.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**
- 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) - Services and support focus upon people's needs and 'what matters to them', rather than their diagnosis, IQ or condition.	- 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) - 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.
- There is effective monitoring to ensure that IQ is not considered as part of eligibility criteria.			

Table B5.1. Benchmarks for compliance: duties related to workforce development and training

Duties: 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.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not Compliant**
• 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 all staff working in health and social care • There are minimum training standards for staff in other LA departments (for example, housing) • Take up of training is monitored (and action is taken to raise take up if required).	• Level 1 autism awareness training (or equivalent) is included in general equality and diversity training programmes offered for all 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 training, have not been publicised; and/or - take up is not monitored.	- 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.

Table B5.2. Benchmarks for compliance: duties related to workforce development and training (assessing the autism training needs of all staff)

Duties: As part of workforce planning [LAs 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.

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.
- Ensure that health and social care support for autistic individuals 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:

- Where the need for specialist training is identified, ensure that training provision takes account of NICE guidelines.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**

- As part of workforce training needs analysis, an analysis of autism training needs has been carried out for <u>all</u> health and social care staff (including those in the secure estate)
- Specialist training needs for staff in <u>all</u> services that undertake diagnostic assessments and/or provide post-diagnostic support have been assessed.
	- The National training framework <u>Job profile and tasks</u> or an equivalent is used to identify training needs.
	- Training for specific roles is mandatory.
		- There is an offer of training at different levels (for example, autism aware – autism enhanced)
		- But, for example the training is:
		  - not mandatory,
			- Clear evidence that, for example:
			  - The training needs of staff who are working in health and social care have not been assessed

- 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 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 NICE guidelines.	- Specialist training needs for staff in the children's ND service and IAS have been assessed (for example, sensory profiles for OTs), but not other services that undertake diagnostic assessment. - Training is delivered to meet identified needs and regularly updated.	- not monitored or has very low take up - is not adequate/sufficient for different roles; and/or - is not regularly updated.	- Staff lack the knowledge and training in autism they need to undertake their roles and/or - health and social care support for autistic individuals detained in the secure estate is not provided by appropriately trained practitioners.

Table B5.3. Benchmarks for compliance: duties related to workforce development and training (the knowledge and training in autism to undertake roles)

Duties: 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.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**
• An autism training needs analysis has been carried out for all health and social care staff undertaking diagnostic assessments (including for example, 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 (for example, DISCO, ADOS etc.) and the wider understanding of autism required, and training is regularly updated.	• An autism training needs analysis has been carried out for all health and social care staff undertaking diagnostic assessments (including for example, 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 (for example, 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 (for example, as part of annual reviews).			

Table B5.4. Benchmarks for compliance: duties related to workforce development and training (commissioned services)

Duties: LAs must [ensure] where services are commissioned, local authorities must ensure autism services are provided by appropriately trained and skilled staff.

Full compliance + (including going above and beyond the Code requirements)	Good progress (but not full compliance)	Limited or uneven progress to date	Not compliant
• An autism training needs analysis (using The national training framework Job profile and tasks or an equivalent) is part of the commissioning process • training requirements are specified as part of the process; and • training requirements monitored by the LA or LHB [footnote 92].	• The skills, knowledge in relation to autism required by staff delivering commissioned services is considered. This uses the national training framework Job profile and tasks or an equivalent; and • training requirements are specified as part of the process.	• The skills and knowledge in relation to autism required by staff delivering commissioned services is considered, but for example; - it is not clear how training requirements are identified; and/or - there is little/no consistency in the specification of minimum standards across different contracts.	- There are examples of (including evidence) that commissioned services are not provided by appropriately trained and skilled staff.

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[92] This should 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 B5.5. Benchmarks for compliance: duties related to workforce development and training (autistic individuals and their parents and carers are involved in the development and delivery of autism training)

Duties: LAs and LHBs should ensure that autistic individuals 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.

Full compliance + (including going above and beyond the Code requirements)	Good progress (but not full compliance)	Limited or uneven progress to date	Not compliant
• 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 groups have a role in the development and oversight of LA and LHB training.	• 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 individuals 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 individuals and their parents and carers in the development and delivery of autism training.	- In the judgment of the evaluation team, it is clear that autistic individuals 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.

Table B5.6. Benchmarks for compliance: duties related to workforce development and training (sufficient knowledge and skills to understand the impact of autism)

Duties: 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.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**
• Social workers are registered with Social Care Wales (and therefore have approved qualifications) [footnote 93].	Social workers are registered with Social Care Wales (and therefore have approved qualifications) [footnote 98].	Social workers are registered with Social Care Wales (and therefore have approved qualifications) [footnote 98].	- 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 wellbeing. without care and support.
• Where specialist skills are required, staff are either (i) trained to the appropriate level (for example, in line with the NAT training framework or equivalent) or	• Where specialist skills are required, staff are either (ii) trained to the appropriate level (for example, in line with the NAT training framework or equivalent) or	• 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.	

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[93] 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 the duty, suitably skilled, practitioners should have ‘appropriate understanding and training in autism and related behaviour support’ (Welsh Government 2021b, p.32).

(ii) able to consult someone who has these skills.	(ii) able to consult someone who has these skills.		
• 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 been trained to ensure they meet this requirement. • As part of each assessment, the LA determines if the assessor requires specialist skills (for example, 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 • 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 B6.1. Benchmarks for compliance: duties related to related to the planning, commissioning, monitoring and evaluation of autism services (compliance with the SSWBW Act parts 2 and 9)

Duties: LHBs and LAs must jointly comply with relevant duties in the SSWBW Act parts 2 and 9 to ensure that needs of autistic individuals are considered in the development of Population Assessments and Area Plans.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited progress to date**	**Not compliant**

- Autistic individuals/parents and groups/organisations are actively involved and engaged in the process of developing the PNA and Area Plans.
- In the judgment of the evaluation team, the PNA includes a rigorous 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.
	- Autistic individuals/parents and groups/organisations are actively involved and engaged in the process of developing the PNA and Area Plans.
	- In the judgment of the evaluation team, the PNA includes a rigorous 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 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.
			- There is evidence that the needs of autistic individuals 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 goodassessment of regional progress (including alignment with the Welsh Government autism strategy).			

Table B6.2. Benchmarks for compliance: duties related to related to the planning, commissioning, monitoring and evaluation of autism services (specialist service provisions are identified)

Duties: LA and LHBs must ensure that where needs for specialist service provisions are identified, where possible these are made available.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**
The need for specialist services can be identified through assessment processes and, where appropriate, specialist services can be commissioned.	The need for specialist services can be identified through assessment processes and, where appropriate, specialist services can be commissioned.	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 is 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.	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.			

Table B6.3. Benchmarks for compliance: duties related to related to the planning, commissioning, monitoring and evaluation of autism services (include autistic individuals to inform service development)

Duties: LA and LHBs must jointly develop strategic and operational teams which include autistic individuals to inform service development.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**

- 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
	- 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
		- 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.

seniority to inform service development - ASD leads - IAS and ND service leads and specialist practitioners - third sector representative(s) - the autism champion and autistic individuals.	seniority to inform service development - ASD leads - IAS and ND service leads and specialist practitioners - third sector representative(s) - the autism champion and autistic individuals.		
- 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 vital role in identifying:			

- gaps and weakness in service provision and - potential innovations			

Table B6.4. Benchmarks for compliance: duties related to related to the planning, commissioning, monitoring and evaluation of autism services (an autism champion role is appointed)

Duties: LHBs and LAs must jointly ensure an autism champion role is appointed in each RPB area and is included in the governance structure of the board.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**
An autism champion has been identified	An autism champion has been identified	An autism champion has been identified	- No autism champion has been identified.
The autism champion attends RPB meetings and reports on the development of autism services in the region	The autism champion attends RPB meetings and reports on the development of autism services in the region	- An autism champion has been identified, but no information on the role is available.	
- The autism champion: - has a role within the governance structure of the RPB 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 - works alongside LA and health ASD leads	- 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 (for example, as they are still new to the role).		

Table B6.5. Benchmarks for compliance: duties related to related to the planning, commissioning, monitoring and evaluation of autism services (encourage innovation in the development of autism services)

Duties: LA and LHBs must encourage innovation in the development of autism services

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**
- Individual autism services are supported and encouraged to innovate (for example, through funding, invitations to submit SBARs [footnote 94], developing networks of practice, commissioning reviews etc.)	- Individual autism services are supported and encouraged to innovate (for example, through funding, invitations to submit SBARs [footnote 100], developing networks of practice, commissioning reviews etc.)	- Individual autism services are supported and encouraged to innovate (for example, through funding, invitations to submit SBARs [footnote 100], 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 examples of this (i.e. innovations in the development of services)	Strategic and operational groups' remit includes encouraging innovation in the development of autism services and there are examples 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)			

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[94] Situation, background, assessment, recommendation.

- There is good monitoring and evaluation of autism services and where, for example, weaknesses or opportunities are identified, innovative responses are considered.			

Table B6.6. Benchmarks for compliance: duties related to related to the planning, commissioning, monitoring and evaluation of autism services (compliance with Welsh Government data collection and monitoring requirements)

Duties: LHB and LAs must ensure compliance with Welsh Government data collection and monitoring requirements.

Full compliance + (including going above and beyond the Code requirements)	**Good progress (but not full compliance)**	**Limited or uneven progress to date**	**Not compliant**
- The children's ND service provides waiting time data to the WG - The IAS provides quarterly data to the NNT (via Data Cymru) The RPB provides reports on neurodiversity for RIF funding purposes.	- The children's ND service provides waiting time data to the WG - The IAS provides quarterly data to the NNT (via Data Cymru) The RPB provides reports on neurodiversity for RIF funding purposes.	- The children's ND service provides waiting time data to the WG - The IAS provides quarterly data to the NNT (via Data Cymru) The RPB provides reports on neurodiversity for RIF funding purposes.	- The RPB, LHB or individual services (for example, the IAS) are not complying with Welsh Government data collection and monitoring requirements.
- Data on other services that undertake diagnostic assessments (for example, AMHS, LD services) are collected - Data from different services are 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 (for example, autism strategy and operational groups).		- However, there are concerns about the data that is collected and shared with the Welsh Government or NNT (for example, in terms of quality, timeliness etc.).	