Welsh Government
Consultation Document

Code of Practice on the Delivery of Autism Services

Date of issue: 30 November 2018
Action required: Responses by 1 March 2019

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

How to respond
You can respond to this consultation by completing and returning, by midnight on the closing date,

Alternatively the consultation response form is available on our website and can be returned to us, by midnight on the closing date, via e-mail to: Autism.CodeofPracticeConsultation@gov.wales

Further information and related documents
MS Word, Large print, Braille and alternative language, easy read versions of this document are available on request.

Contact details
For further information:

Autism Policy Branch
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

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The Welsh Government will be data controller for any personal data you provide as part of your response to the consultation. Welsh Ministers have statutory powers they will rely on to process this personal data which will enable them to make informed decisions about how they exercise their public functions. Any response you send us will be seen in full by Welsh Government staff dealing with the issues which this consultation is about or planning future consultations. Where the Welsh Government undertakes further analysis of consultation responses then this work may be commissioned to be carried out by an accredited third party (e.g. a research organisation or a consultancy company). Any such work will only be undertaken under contract. Welsh Government’s standard terms and conditions for such contracts set out strict requirements for the processing and safekeeping of personal data.

In order to show that the consultation was carried out properly, the Welsh Government intends to publish a summary of the responses to this document. We may also publish responses in full. Normally, the name and address (or part of the address) of the person or organisation who sent the response are published with the response. If you do not want your name or address published, please tell us this in writing when you send your response. We will then redact them before publishing.

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Cathays Park
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CF10 3NQ

e-mail:
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The contact details for the Information Commissioner’s Office are:
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

Tel: 01625 545 745 or 0303 123 1113
Website: https://ico.org.uk/
Ministerial Foreword

The Welsh Government is firm in our commitment to improve autism services.

We published the first ASD Strategic Action Plan in 2008, an independent evaluation showed that strategy was successful in raising awareness of autism and in providing training and development tools and resources.

We listened when we were told that despite progress many autistic people and their families and carers were still struggling to access the support they need. The national strategy was renewed in 2016 with a comprehensive delivery plan which takes a holistic and needs based approach to the development and provision of autism services.

To address gaps in support in 2016 we commenced the rollout of the National Integrated Autism Service, this is now available in five regions in Wales and will be available in Western Bay and West Wales this financial year. At the same time we made significant investment in neurodevelopmental services for children and young people to improve assessment and diagnostic waiting times.

Autistic people often do not fit neatly into services. It is essential that staff have the right level of knowledge and skills to provide the best support they can. We are issuing this consultation on the Delivery of Autism Services so that we can take the necessary steps to ensure the local health boards and local authorities and their partners understand their existing duties to provide needs based services, including support for carers. In this consultation document we suggest where the Code can place specific duties on local authorities and health boards to take action. We would welcome views on our proposals and whether there is more it could include to strengthen support for autistic people. The Code will set out the requirements placed on public authorities in the following areas.

1. Arrangements for assessment and diagnosis.
2. Arrangements for accessing care and support.
3. Arrangements for awareness raising and training.
4. Arrangements for planning, monitoring and stakeholder involvement.

Both service providers and autistic people will understand the standards of service which should be delivered in all of these areas. Crucially through existing legislation, the Code will have strong remedial powers enabling Welsh Ministers to take action to intervene where services do not meet satisfactory standards. This includes ensuring staff training, compliance with requirements to undertake assessments in a timely manner and to collect data as required. We will require local authorities and health boards to consider autism as a stand alone key theme when undertaking future population needs assessments, to be published in local area plans.
The publication of this consultation document takes place at a time when there is significant discussion and debate about autism specific legislation in Wales. This Code, alongside powerful legislation such as the Additional Learning Needs Act and the Social Services and Wellbeing (Wales) Act gives the government all the statutory power it needs to drive change. It is not additional legislation which is needed to make faster progress, but rather effective implementation of the new plans and services that are currently being put into place. The Code that we are consulting on is key to guiding this.

Vaughan Gething
Cabinet Secretary for Health and Social Services
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Introduction
This consultation is seeking views on what we should include in the Code of Practice including the range of duties we believe it should contain, which will enable services to develop but will not stifle innovation as the services we are putting in place evolve. The proposed aims of the Code are to raise awareness of the needs of autistic people and provide clarity on what level of support they should expect to receive.

Purpose

The purpose of the Code of Practice on the Delivery of Autism Services is to secure the implementation of Welsh Government’s autism policy priorities, currently published in the Autistic Spectrum Disorder Strategic Action Plan 2016. Guidance will be provided to local authorities and NHS health bodies on the level and range of services and support they are expected to provide for people with autism under existing legislation.

Where individuals with autism have eligible care and support needs under the Social Services and Well-being Wales Act 2014 (SSWBW Act), the relevant guidance and Codes of Practice which accompanies this Act will apply. Where autistic children and adults have additional educational support needs the Additional Learning Needs and Educational Tribunal Act 2018 and associated Code of Practice will apply and where there are additional mental health needs the relevant duties in the Mental Health Act 1997 and Mental Health Wales measure 2010 must be observed.

The Code will also reflect the Welsh Government’s values as set out in the Well-being of Future Generations Act 2015, which is aimed at improving the economic, environmental and cultural well-being of Wales. The Act requires public bodies in Wales, including local health boards and local authorities to think about the long-term impact of their decisions, to work better with people, communities and each other, and to prevent persistent problems such as poverty, health inequalities and climate change. It sets out five ways of working needed for public bodies to achieve seven well-being goals (A Prosperous Wales, A Resilient Wales, A Healthier Wales, A Equal Wales, A Wales of Cohesive Communities, A Wales of Vibrant Culture and Thriving Welsh Language and a Globally Responsible Wales). This approach provides an opportunity for innovative thinking, reflecting the way we live our lives and what we expect of our public services.

Background and Context

Autistic Spectrum Disorder Strategic Action Plan

The ASD Strategic Action Plan was updated in November 2016, and accompanied by a delivery plan setting out the actions the Welsh Government and partners will take to improve autism services. Central to the delivery is the roll out of a new Integrated Autism Service backed by £13 million up to 2021. The first annual report was published in June 2018 and in September an updated Delivery Plan was also published, which contained new commitments, which included issuing a Code of Practice on autism services this Assembly term and to improve monitoring through developing a GP autism diagnosis register.
The National Autism Development Team

The National Autism Development Team provides strategic and operational support for the successful delivery of the ASD Strategic Action Plan. The team develops and maintains the ASDinfoWales Website, which is a free on-line resource providing a wide range of materials and advice for people with autism and their parents and carers, local authorities, education settings, health boards, employers and other service providers. The full range of resources available include development programmes for schools and other settings, advice for health and social care settings, post diagnostic guidance for parents, children and for adults. The website can be found at [www.asdinfowales.co.uk](http://www.asdinfowales.co.uk).

The National Integrated Autism Service

The Strategic Action Plan acknowledged gaps in services for some autistic people, particularly as many may not be assessed as having eligible social care support needs under the SSWBW Act. We recognise that many autistic people may none the less have significant support needs, which if not addressed could escalate and result in the need for more intensive service interventions. The National Integrated Autism Service offers an all age often preventative service which provides targeted support and assistance for autistic people and their families and carers.

This new service is creating specialist community based autism teams in every region which is providing a range of information, advice and support services. This includes diagnostic assessment for adults and interventions and support for parents, families and adults. This service is intended to add to existing services, particularly for those who may not have to access formal social care services. More information on the IAS, including regional contact details can be found on the ASDinfowales website.

We developed the Integrated Autism Service in response to feedback from autistic people and their parents and carers who told us they need more support but were often not eligible to receive formal social cares services. Their feedback told us more services and support were needed in the following areas, which the service is now providing.

- Adult Assessment services.
- Behavioural issues.
- Emotional issues such as anxiety and anger.
- Developing social and daily living skills.
- Accessing leisure and recreational activities.
- Support for parents and carers.

Children and Young People Neurodevelopmental Services

Improvements are being secured for neurodevelopmental services for children and young people as part of the Together for Children and Young people Programme (T4CYP). This programme is improving assessment and diagnostic services for all neurodevelopmental conditions and services are linked at the local level to ensure that
there is a strong relationship with the IAS. We are also working to address any gaps in provision which may have been created for a small group of individuals who may not be eligible to access support from either service. We are seeking ways to achieve closer join up between this service and the IAS in the longer term. More information on the developments achieved can be found in Section One on arrangements for assessment and diagnosis for children, young people and adults.

Additional Learning Needs Reform

To improve educational support for children and young people up to 25, our Additional Learning Needs reform, underpinned by the Additional Learning Needs and Education Tribunal (Wales) Act 2018, introduces a new system focused on ensuring all children and young people that require support, including those with autism, have that support properly planned for and protected, and will have a statutory plan with equal rights of appeal. The Act puts learners at the heart of the decision making process, Although it extends to meet the needs of autistic children and young people it does not differentiate between different additional learning needs because it seeks to ensure that all needs are met equitably and comprehensively.

National Institute of Health and Care Excellence

The National Institute of Health and Care Excellence (NICE) is a widely recognised body providing authoritative advice and information on a range of health issues. In recent years NICE has produced several guidelines on the diagnosis and management of autism. The purpose of the NICE guidance is to drive and measure quality improvements and describe what a good service should look like. Health boards and local authorities should take the guidance into account when planning autism services as they are the accepted benchmark of what good services should aim to provide. These include:

- **Autism spectrum disorder in adults: diagnosis and management (CG142)**
- **Autism spectrum disorder in under 19s: recognition, referral and diagnosis (CG128)**
- **Autism spectrum disorder in under 19s: support and management (CG170)**

NICE has also published a **Quality Standard on Autism**, which covers health and social care services for adults, young people and children with autism. It includes assessment and diagnosis of autism spectrum disorders, and care and support for people diagnosed with an autism spectrum disorder. It describes high-quality care in priority areas for improvement.

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1 NICE (2016) Autism spectrum disorder in adults: diagnosis and management (CG142)
2 NICE (2017) Autism spectrum disorder in under 19s: recognition, referral and diagnosis (CG128)
3 NICE 2013 Autism spectrum disorder in under 19s: support and management (CG170)
Equality of Access

The Equality Act 2010 places clear duties on public sector bodies to prevent discrimination and promote equality for people with certain Protected Characteristics. These are – age, disability, gender reassignment, race, religion or belief, sex, sexual orientation, marriage and civil partnership, pregnancy and maternity. There are specific duties around the provision of reasonable adjustments for disabled people, including autistic people, to assist them to access the services they need. This could mean offering a service in a different way or providing additional support, such as by taking into account difficulties autistic people may have with sensory processing and verbal or written communication. These duties are re-enforced through the SSWBW Act and NHS Act.

The Code of Practice also supports the United Nations Principles and Conventions and Covenants as set out in the SSWBW Act Part 2 Code of Practice. The Welsh Government works alongside the UK Government to ensure Wales is fully represented in the presentation of international reports. It also ensures we meet our obligations to human rights. The UK State party has signed and ratified the following United Nations Conventions and Covenants:

- Covenant on Economic, Social and Cultural Rights
- Covenant on Civil and Political Rights
- Convention on the Elimination of All Forms of Racial Discrimination
- Convention on the Rights of Disabled People
- Convention on the Elimination of All Forms Discrimination Against Women
- Convention Against Torture
- Convention on the Rights of the Child


Women and Autism and Gender Identity

The rate of autism diagnosis in girls and women has historically been much lower than for boys and men. Although the research is limited, evidence and anecdotal clinical evidence suggests that the disparity in diagnostic rates is caused by a number of factors. These include the way girls and women present themselves, they are often more able to mask behaviour through observing and mimicking others around them. It is also suggested that standard diagnostic tools are more tailored towards recognising classic autism more commonly seen in boys and men, whereas girls and women presentation of autism may be more subtle making it more difficult to understand how they are managing the challenges of autism in their day to day lives. It is important that professionals understand how autistic girls and women may present differently and that they can have different support needs. For example girls may appear to be more able

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5 National Autistic Society ‘Gender and Autism. [https://www.autism.org.uk/about/what-is/gender.aspx](https://www.autism.org.uk/about/what-is/gender.aspx) accessed 29 October 2018
to sustain social relationships but in reality experience exhaustion when trying to adapt their own behaviour to mirror that of others and what is more acceptable.

There is also increasing literature linking autism with gender identity/dysphoria, with a higher incidence of autistic people reporting a psychological identity with a gender other than the one they were born with. The Welsh Government has recognised the need to improve gender identity services in Wales and have established the All-Wales Gender Identify Partnership Group to provide advice, and Wales Gender Team is being created which will operate from Cardiff University Hospital.

**Autistic people from black and ethnic minority (BAME) communities including Asylum Seekers and Refugees**

Autistic people from BAME communities or who are asylum seekers and refugees and their parents and carers can face additional challenges in accessing services and support. In the report *Diverse perspectives: The challenges for families affected by autism from Black, Asian and Minority Ethnic communities (2014)* the National Autistic Society highlighted the difficulties which can be experienced by autistic people living in BAME communities. In general terms they experience the same difficulties accessing services and support as in other parts of the community but issues are compounded by factors such as cultural views on disability in some communities. In some groups there may be serious stigma associated with having a disabled child, and parents reported they experienced feelings of shame as the community blame them for the perceived poor behaviour in their autistic children and the communities were often looking to finding a cure. Cultural assumptions and bias could also have a negative impact, for example black boys being seen as more likely to be disruptive and language difficulties being wrongly attributed to a child speaking English as their second language. Service providers should be aware that cultural differences can have an impact on how people with autism are perceived and supported and adapt their practice to recognise these differences.

**Welsh Language Services**

Local health boards and local authorities should make sure Welsh language services are built into planning and delivery and that Welsh language services are offered to Welsh speakers without them having to request it. The Welsh Government has established a Strategic Framework for Welsh Language Services in Health, Social Services and Social Care (*More than just words*).

**Terminology**

The Code of Practice will continue to use the World Health Organisation’s definition of autism as set out in the Strategic Action Plan.

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“The term autistic spectrum disorders (ASD) is used to describe the group of pervasive developmental disorders characterised by qualitative abnormalities in reciprocal social interactions and in patterns of communication and by restricted, repetitive repertoire of interests and activities.”

The terms Autistic Spectrum Disorder, autism and autistic people will be used interchangeably for individuals on all parts of the autism spectrum, including those currently described as having Asperger Syndrome.

This guidance does not extend to other neurodevelopmental conditions but recognises that some individuals will have autism with other co-occurring conditions which may impact on their care and support needs.

A glossary of terms is provided
Power to Issue a Code of Practice on the Delivery of Autism Services

The Code of Practice on the delivery of autism services will be issued under sections 145 and 169 of the SSWBW Act 2014 and sections 1 and 2 of the National Health Service (Wales) Act 2006.

The Welsh Government wants to ensure the Code has comparable force in relation to both local authorities and local health boards. Welsh Ministers are able to and will be exercising a power of direction over health boards which would require them to comply with the duties contained in this Code of practice.

Powers

The SSWBW Act is available at:


And National Health Service (Wales) Act 2006


Local authorities, when exercising their social services functions, must act in accordance with the requirements contained in this guidance. Section 147 of the SSWBW Act (departure from requirements in guidance) does not apply to any requirements contained in this guidance. In addition, local authorities must have regard to any guidelines set out here.

Local Health Boards when exercising their health functions must act in accordance with the requirements contained in this guidance. In addition health boards must have regard to any guidelines set out here.

In this guidance and statutory guidance, a requirement is expressed as “must” or “must not”. Guidelines are expressed as “may” or “should/should not”.

This guidance should be read in conjunction with the relevant Code of Practice and statutory guidance issued under the SSWBW Act to require local authorities to consider people’s needs for care and support. These are:

- Part 2 Code of Practice (General Functions)
- Part 3 Code of Practice (Assessing the Needs of Individuals)
- Part 4 Code of Practice (Meeting Needs)
- Part 11 Guidance (Miscellaneous and General)
- Part 9 Statutory Guidance (partnership arrangements)

This document was developed in consultation with the Welsh Government’s Autistic Spectrum Disorder Implementation Advisory Group, established in March 2017 to provide expert advice and feedback on the delivery of the ASD Strategic Action Plan. Membership includes representative third sector groups and individuals with autism and
parents and carers. Advice was also provided by the Regional Integrated Autism Services, Local authority ASD Leads, who work with autistic people in local communities and specialist clinicians from the Adult ASD Diagnostic Community of Practice.

**Remedies**

There are built in mechanisms within the SSWBW Act for intervention and enforcement of the local authority to the Code. Section.150 provides for Welsh Ministers to be able to intervene in the event that local authorities fail to comply with a duty that is a social services function, act unreasonably in the exercise of a social services function, or fail to perform a social services function to an adequate standard. There is then provision for a warning notice to be issued and further steps to be taken by Welsh Ministers by way of enforcement against a local authority.

Similarly, under the NHS (Wales) Act 2006, there is provision to make an intervention order and for further steps to be taken in the event that a local health board is not performing one or more of its functions adequately or at all, or that there are significant failings in the way the body is being run, and the Welsh Ministers are satisfied that it is appropriate for them to intervene.

The Welsh Government can and has taken action under these Acts to require statutory bodies to review and improve services which are found to be unsatisfactory. Stand alone legislation would be reliant on individuals taking forward Judicial Review to challenge compliance.

**Principles**

The Code will provide guidance for statutory services in the following areas:

1. Arrangements for assessment and diagnosis.
2. Arrangements for accessing care and support.
3. Arrangements for awareness raising and training.
4. Arrangements for planning, monitoring and stakeholder involvement.

**Understanding the duties in the Code**

The Code will be made under both the SSWBW Act and the NHS (Wales) Act, the Welsh Government is able to place a range of duties on each organisation to require them to act. For clarity the duties made under different legislation and with different force have been set out in coloured boxes as follows:
Requirements placed on local authorities under the SSWBW Act section 145

**Local Authorities Must/Must not**

Requirements placed on local health boards under the NHS (Wales) Act 2006

**Local Health Boards must/must not**

Guidelines for local authorities under the SSWBW Act section 145

**Local Authorities should/should not**

Guidelines for local health boards under the NHS (Wales) Act 2006

**Local Authorities and Local Health Boards may/should/should not**

Requirements placed on health boards and local authorities jointly under the SSWBW Act section 169

**Local Health boards and Local Authorities must/must not jointly**
SECTION 1. - Arrangements for assessment and diagnosis

Access to assessment and diagnostic services is an important step in understanding the needs of children who are presenting with behaviours which maybe causing concern for families and/or for health and education and care services. For adults who have not been diagnosed in childhood, access to assessment can provide an insight into self understanding and can be one way to access appropriate support.

Diagnostic Teams

In Wales neurodevelopmental teams undertake the assessment and diagnosis of autism for children and young people. These teams are also able to assess for other co-occurring neurodevelopmental conditions, such as attention deficit hyper activity disorder. Teams take a multidisciplinary approach to assessment and diagnosis.

Adult diagnostic services are provided by the National Integrated Autism Service in each region in Wales. The service accepts self referrals and referrals from GPs or other practitioners. Contact details for each service can be found in the Asdinfowales website www.asdinfowales.co.uk

Diagnostic pathways

Arrangements for accessing diagnostic assessment for autism currently have different pathways for children and young people and for adults. Children and young people can access dedicated neurodevelopmental assessment services and adults are able to access assessment services through the ASD Integrated Autism Service. These two services work alongside each other and it is critical the pathways are aligned as much as possible, this will be of particular importance for those that are over 16.

Information about pathways and how to access services should be readily available to those that need to access them, this should include parents, children and young people. Access to assessment should be timely and in line with targets set to support the effective delivery of services. Services should expect performance to be monitored however this should not only relate to specific waiting time targets but to the quality and impact of the services received.

Children and Young People’s Assessment Services

The NHS led Together for Children and Young People Programme, neurodevelopmental work stream has developed, in conjunction with key stakeholders, including those with lived experience and the third sector, a diagnosis and assessment pathway and guidance document. To support the delivery of equitable services across Wales, the most up to date research and evidence have informed its content.

To promote access, health boards and partners should ensure there is a single point of access for the diagnostic assessment for all neurodevelopmental disorders including ASD. Referrals should detail signs and symptoms, pervasiveness, impact on

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functioning and risk factors, as described in NICE guidelines. There should be a ND team discussion of the referral and a decision made as to whether to proceed or whether further information is required. To ensure equity of access, all efforts should be made to facilitate a diagnostic assessment if appropriate, even if some information is not available initially.

When referrals are not accepted the referrer should be provided with a rationale for this, alongside advice about what additional information is needed to progress the referral and/or other service to refer to. It is expected a local protocol will be developed to ensure this information will be shared with the child and family.

Children referred to a ND team for an assessment should have the assessment started within 26 weeks of the referral being received by the ND service. Some children may need to be seen more quickly and teams should develop prudent ways to identify those that are in need of an expedited assessment.

Assessments should be planned by the multidisciplinary ND team in a child centred way, ensuring sufficient information to create a profile of the child’s needs is gathered, whilst ensuring a prudent, flexible approach to the use of resources. Children having an assessment should also be assessed for any related physical and mental health needs. Assessing staff will need to be alert to the impact of adverse childhood experiences and/or any safeguarding considerations.

Professionals (or a professional) who have been involved in the assessment process will normally communicate face to face the outcome of the assessment to the family and where appropriate the child. When this does not occur, clear reasons should be given. This will be followed up in writing and where consent is given, will be shared with other professionals who support the child.

To support a continued person centred approach, a profile of the child’s strengths and difficulties should be produced; any advice and or recommendations will be included.

For children with a diagnosis of ASD, a follow-up appointment with an appropriate member of the team should be offered if clinically indicated.

Post assessment consideration should be given to the following:

- The assessment and profile may identify the need for some specific interventions. Those interventions should be proportionate to identified need, evidence-based to achieve identifiable outcomes in a stated timescale and not solely driven by diagnosis.

- Information and education should be provided on the core features of the child’s diagnosis. This may include written information, one to one sessions or workshops. If no ND diagnosis is given, other relevant information should be given. Information on seeking a second opinion should be provided if required.
- Signposting to relevant support and other information may also be provided. This could include any additional learning needs identified.

- Interventions advised and offered by neurodevelopmental services should be based upon the best possible evidence.

Each region should have a designated lead role to ensure the national pathway is maintained and developed in partnership with families to maintain consistent standards and to promote further improvement. This will ensure that a child or young person’s neurodevelopmental needs and those of their family are central to the pathway.

The guidance also suggests information to be collected by health boards to provide a clear picture of service demand, uptake and delivery. Mechanisms should be put in place to review, adapt as needed, and maintain the diagnostic pathway. It is important that outcome measures demonstrate and highlight the quality of services and not solely the number of diagnosis made.

**Adult assessment services.**

Through increasing awareness of autism many adults, who were not recognised as being autistic in childhood may find access to diagnostic services very helpful as a diagnosis can help them make sense of and understand their own perceptions of not coping well in social situations and perhaps having sensory difficulties. It may also be possible that their needs have been addressed inappropriately through mental health or learning disability services.

In Wales the first ASD Strategic Action Plan recognised that autism diagnosis for adults was poorly understood and provision of assessment services was patchy. Action was taken to improve support through the clinical adult diagnostic network and a community monitoring scheme designed to provide low level support for autistic adults. The learning from this work and good practice drawn from other services formed the basis of the Integrated Autism Service now being rolled out across Wales, establishing a dedicated ASD assessment and diagnosis service.

A key element of this service is to create a national approach to adult diagnostic services and a clinical adult diagnosis community of practice has been established to enable expert clinicians to work collaboratively, to share their experiences and expertise to improve the quality of diagnostic assessment and post diagnostic services. An adult diagnostic pathway has been developed and in the same way as the children’s pathway it should be reviewed and updated to reflect improvements and good practice.

**Who should know about the pathways?**

NICE guidance advises that relevant professionals (healthcare, social care, education and voluntary sector) are aware of the local autism pathway and how to access diagnostic services. Health boards should ensure that all primary care services are aware of the local pathway and the local referral process in their areas and should designate an individual with lead responsibility for developing maintaining, reviewing and promoting diagnostic pathways for both children and young people and for adults.
Children and Young People Assessment Waiting Time Standard

We have recognised the need to improve diagnostic services, and there must be a mechanism to measure improvements. In November 2017 we introduced a 26 week waiting time standard for children’s and young people’s assessment as a robust approach to collecting reliable and consistent information. The NICE Quality Statement\(^{11}\) states that ‘evidence of local arrangements to ensure that people with possible autism referred for a diagnostic assessment by an autism team have the assessment started within 3 months of their referral’. As health boards varied in their perception of when an assessment would be deemed to have started, it was agreed that the most consistent and unquestionable measure would be to record the date of the first face to face appointment after referral being within 26 weeks. It is expected, in the weeks before the first assessment appointment, health boards would have already collected relevant information from schools and other services involved in the child’s development, to support practitioners and the families during the first appointment. Some services have also developed pre assessment support and information.

The feedback we have received from the pilot stage is enabling us to develop the standard for the future, with the aim of extension to adult assessment services.

Access to Diagnosis in the Secure Estate

Individuals detained in prisons who appear to require access to autism assessment should have access to diagnostic services and post diagnostic support. It is essential that staff within the secure settings, particularly health staff have the right level of knowledge and skills to recognise when an individual could be referred for assessment. The WLGA National Autism Team has worked with HM Prison and Probation Service locally to develop staff training in some secure establishments, and the team are also working with the emergency services to produce and rollout a training package for emergency services staff.

Referral for Social Care Assessment

It may become apparent that during a diagnostic assessment that the individual may have eligible care and support needs. Depending on the complexity of the needs these may be met through the provision of information and advice or preventative services for lower level needs, which can be provided through dedicated or general services.

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Draft Duties

Local Authorities Must

- Ensure that people with autism are aware of the right to access a needs assessment and a carer’s assessment for a carer. The process of obtaining one should align with the diagnosis process and be offered at the diagnosis stage and a referral made if needed.

Local Health Boards must

- Provide access to services which can diagnose autistic spectrum disorder and associated conditions which take account of NICE best practice guidance for multidisciplinary involvement.

- Ensure the provision, publication and regular review of assessment and diagnostic pathways for children and young people and adults which take into account NICE best practice guidance.

- Ensure the primary care practitioners including GPs are notified of assessment referral pathways for children, young people and adults.

- Ensure waiting times from referral to first assessment appointment for children, young people and adults comply with current national waiting time standards for autism assessment and diagnosis.

- Designate an individual with lead responsibility for developing maintaining, reviewing and promoting diagnostic pathways for both children and young people and for adults.

- Where a diagnosis of autism is made, with the individual’s consent (or for most children their parent or carer) a referral is made to the National Integrated Autism Service promptly to ensure post diagnostic support assessments can be undertaken if appropriate.

- Where a diagnosis of autism is made, with the individual’s consent (or for most children their parent or carer) a referral is made to social care services, promptly to enable care and support assessments to be undertaken if appropriate.

- Where an assessment of autism is undertaken but a diagnosis is not made, if the assessment indicates 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.
Where autistic people have co-existing conditions, including mental health and or learning disabilities, pathways should be in place to enable access to support services which can meet their additional support needs in relation to autism.

Ensure that autism assessment and diagnostic services are accessible by individuals detained in the secure estate.

Local Authorities and Local Health Boards should

- Ensure prompt sharing for information between autism diagnostic services and social care services about the needs of children and adults diagnosed with autism where indicated additional support may be required.

- Ensure prompt sharing for information between autism diagnostic services and social care services about children and adults not diagnosed but where indicated necessary a referral is made.

- Ensure there are pathways within the secure estate to ensure young people and adults who are detained can access assessment services and social care support.

Health Boards and Local Authorities must jointly

- Where autistic people have co-occurring mental health and or learning disabilities, pathways should be in place to enable access assessment services, which can meet their additional support needs in relation to autism.
SECTION 2. Arrangements for accessing care and support

The impact of autism is very varied and each autistic person will have unique needs and preferences. Some individuals may be able to live independently whilst others, particularly where they have other co-occurring conditions or mental health needs will require specialist support.

This section of the Code will describe how the duties placed on local authorities and local health boards set out in the SSWBW Act and associated Codes of Practice will apply to autistic children, adults and their carers. It summarises pathways to access mental health services and support for those with co-occurring conditions.

For social care services the SSWBW Act and associated Codes provides detailed guidance on the arrangements which local authorities and their partners must have in place to ensure all people can access social care services which meet their identified needs in three key areas

- information, advice and assistance.
- assessment for care and support.
- meeting needs and care and support planning.

A central aim of the SSWBW Act is to provide an emphasis on preventative services, to support individuals to live fulfilling lives and to prevent, reduce or delay the need for more intensive interventions and support. The Integrated Autism Service (IAS) has been specifically designed to provide early interventions to prevent an escalation of needs. The IAS can help to build and maintain individual resilience and offer support if difficulties arise. It is recognised that some people with autism, particularly if they have additional health needs, may require statutory care and support services.

This section of the autism Code will be underpinned by the SSWBW Act Codes of Practice on Part 2, Part 3 and Part 4, which provide more detail on the duties placed on local authorities and local health boards in relation to all Welsh citizens, including autistic people who may be in need of care and support. In summary these are:

Part 2 Code of Practice (General Functions) contains:

- Provisions relating to the general functions of a local authority, including assessment of the needs of a population for care and support such as those that promote well-being, and the promotion of social enterprises, co-operatives user led services and the third sector.
- Provisions on those exercising functions under the Act, local authorities should ensure they meet their duties to promote the well-being of people who need care and support and carers who need support.
- Provision and guidance on how local authorities must provide a range of preventative services.
• Provisions and guidance on how local authorities should discharge their duties in relation to the provision of the service providing people with information and advice relating to care and support; and assistance in accessing care and support.

_The Information, Advice and Assistance service_

Local authorities are required to provide a bi-lingual Information, Advice and Assistance Service (IAA), which enables everyone to access relevant, clear information and advice about all of the services available in the area. Local authorities should ensure that staff providing IAA services have the appropriate skills to assist autistic people.

Part 3 Code of Practice (assessing the needs of individuals) which sets out:

• A process for assessing the needs of an individual for care and support, or support in the case of carers.

• A common process of assessment that applies to all people – children, adults and carers.

• A common process of review and re-assessment.

Part 4 Code of Practice (Meeting Needs) which:

• Determines the point at which an individual will have an enforceable right to support from the local authority and the authority has a legal duty to provide or arrange care and support.

• Sets eligibility criteria that will apply to all people – children, adults and carers.

• Sets out the requirements of a care and support plan.

• Sets out the circumstances required by a local authority when making direct payments.

_Assessment of Needs_

Part 3 of the SSWBW Act Code of Practice (section16) states that any individual or family with care and support needs has a right to an assessment on the basis of that need and the assessment undertaken should be proportionate to the request and/or the presenting need. A local authority must ensure that practitioners have the knowledge and skills to provide an assessment which reflects the extent of the care and support needs being presented, such that the depth and detail of the assessment and care and support planning process is appropriate to the individual’s needs. The assessment process will often start when a person accesses the IAA. However, this isn’t the only way a referral can be made.
The purpose of an assessment for care and support is to work with the individual, carer, family and other relevant individuals to understand the person’s needs, capacity, resources and the outcomes they wish to achieve, and to identify how they can best be supported to achieve them. The process requires practitioners to work co-productively with the individual or connected persons to identify what really matters to them and help them achieve it.

Effective assessments are valuable experiences in themselves as well as being the catalyst for helping get the care and support and individual or family need. The assessment should build a better understanding of someone’s situation, identify the most appropriate approach to addressing their particular circumstances and establish a plan for how they will achieve their personal outcomes.

*Eligibility for Care and Support*

The SSWBW Act and its associated regulations introduced assessment and eligibility criteria based on an analysis of five inter-related elements to ensure that a local authority considers the person’s circumstances in the round. This requires a local authority to:

- assess and have regard to the person’s circumstances.
- have regard to their personal outcomes.
- assess and have regard to any barriers to achieving those outcomes.
- assess and have regard to any risks to the person or to other persons if those outcomes are not achieved.
- assess and have regard to the person’s strengths and capabilities.

The assessment will be a product of the conversation between the individual, family, connected persons and the practitioners designed to identify how to meet the persons care and support needs. The assessment process must focus on understanding the individual’s personal outcomes, identify risks to the person or others, explore and address barriers to meeting their outcomes and consider what strengths and capabilities the person has which will help meet their outcomes. Through this the assessment must identify what solutions they need and how they will be delivered. A specialist involved in an assessment should be involved in the care and support planning.

All five elements listed above must be taken into account during the assessment process, from this a judgement will be reached about whether each of the identified needs is an eligible need and must be met by the provision of care and support whether they can be met through information, advice or preventative services.

Part 3 Code of Practice paragraphs 80-91 identify additional considerations for assessing the needs of children and needs being met by carers.
An assessment will conclude with one of the following:

- there are no needs to be met.
- a more comprehensive assessment is required, which may include more specialist assessments.
- needs can be met through the provision of information, advice or assistance;
- needs can be met through the provision of preventative services.
- needs can be met, wholly or in part, by the individual themselves (with or without the assistance of others).
- other matters can contribute to the achievement of the personal outcomes, or otherwise meet the needs.
- needs can only be met through a care and support plan, or a support plan.

It is essential that social care assessors understand the needs of autistic people, so they are able to provide the most appropriate advice and support. Local authorities should ensure that practitioners undertaking an assessment of need with an autistic person has relevant autism training, which meets their professional needs as set out in the National Training Framework described in section 3 of this consultation.

**Eligibility and IQ**

In some areas concerns have been raised about autistic people who may be prevented from an assessment of needs because they have high IQ. The national eligibility criteria for care and support under the SSWBW Act makes no reference to IQ and this should not be a factor in the assessment of an individual’s need for care and support. In each case, the criteria includes a requirement about how the need in question arises, about whether it relates to one of the well-being-related factors, about whether or not the need can be met by the person alone or with assistance, and about whether or not a person is likely to achieve personal outcomes without provision of care and support by the local authority.

**Transition**

Every person will experience a range of transitions during their lives, all of which can be stressful, and these points can be especially difficult for autistic people, not least because of changes to their environment but also there can be changes to the services and support. Transitions must be carefully planned for in advance to make them as seamless as possible. One of the most important transitions will be the move into adulthood, when young people move into adult services or leave school.

The transition from children to adult social care services constitutes a significant change in the individual’s circumstances and creates a right to a re-assessment of needs. A local authority must review an assessment where changes in circumstances are such that the five key elements of an assessment need to be re-considered. Individuals themselves can also request a review and reassessment, when personal outcomes have changed.

For children and young people experiencing transition during their education, particularly when they leave school for further education or other service, the Additional Learning Needs and Education Tribunal (Wales) Act 2018 contains a chapter devoted to
transition. The ALNET code, in the section devoted to multi-agency working, will explicitly reference the Integrated Autism Service and other support available. This code will impose a requirement on local authorities and governing bodies to use the appropriate standard form of an Individual Development Plan as set out in the additional learning needs code.

*Mental health services for children and adults with autism.*

Child and Adolescent Mental Health Services (CAMHS), in common with wider NHS provision, do not provide priority treatment to any specific group or cohort. Rather, the central tenet of NHS provision is that it is provided on the basis of the clinical need of the individual, with priority given to those with the greatest clinical need.

For young people with co-occurring mental illness CAMHS services will provide for their mental health needs (either at a primary care level in Local Primary Mental Health Support Services) or in specialist services for those with more severe mental ill-health. The Welsh Government has also introduced new waiting time targets of 28 days to access specialist CAMHS services.

It is estimated that 40% of autistic people also have some learning disabilities. Children with co-occurring learning disabilities and autism access diagnostic services through local children’s teams, or through the newly established neurodevelopmental services. The constitution of the children’s teams do vary, some may have a generic role and be constituted of paediatricians and other practitioners, including children's nurses, others may be specialist learning disability children's team with psychiatrists and learning disability nurses.

*Services for children and adults with autism and co-occurring conditions.*

For children with learning disability and autism who need health care, services are generally provided by the same teams which undertake diagnosis. Adults usually access community learning disability teams where they have healthcare needs. Some children will go to special schools and access some of their specialist input through the school and will have a special schools nurse to support them. Both children and adults may access social care such as a residential service.

For some people with very profound or severe learning disabilities who may also have additional behavioural issues and mental health problems, there are some specialist health placements which may be in the independent sector.
Local Authorities Must

Duties

- Ensure that people with autism are aware of the right to access a needs assessment and a carer’s assessment for a carer. The process of obtaining one should align with the diagnosis process and be offered at the diagnosis stage and a referral made if needed.

- Ensure that as part of their Information, Assistance and Advice Service information is available on local autism services.

- Ensure that IQ is not considered as part of the eligibility criteria for a needs assessment under the SSWBW Act.

Local Health Boards Must

- Make arrangements to ensure that primary health services are aware of the autism services available in their local areas and have clear pathways for referral.

Local Authorities and Local Health Boards should

- Encourage innovation in the development of autism services.
- Ensure that reasonable adjustments are in place for people with autism and with learning disabilities to ensure they are able to access services in the same way as everyone else.
- Ensure that where they identify the need for specialist services provision, they are available.

Health boards and Local Authorities must jointly

Ensure that an autism lead role is appointed in each regional partnership board area at a sufficiently senior level to represent the needs of autistic people. This will include:

- Regularly report to the board on the delivery of autism services.
- Oversee joint commissioning and delivery of the arrangements for autism services.
- Ensuring effective local stakeholder involvement in planning and delivery of autism services.
- Where autistic people have co-occurring mental health and or learning disabilities, pathways should be in place to enable access assessment
services, which can meet their additional support needs in relation to autism.

**Health, Education and Improvement Wales should**

Should ensure they are involved in the development of local workforce planning and GPs and primary care practitioners are engaged in the training agenda in relation to autism.
SECTION 3. Arrangements for awareness raising and training

Raising Awareness of Autism

There is a welcome increase in awareness of autism in the community and many more professionals now understand the need to adapt their practice to meet the specific needs of autistic people. The ASD National Development Team has been very successful in raising awareness of autism in the community and this work is being developed at pace with a specific aim of involving autistic people in the development and dissemination of resources. The ASDinfowales website provides awareness raising resources suitable for different audiences, a leaflet on the the resources available is at appendix one. For example the Can You See Me programme provides resources including resources explaining the experience of autistic people and the adaptations which can be put in place to provide assistance.

Assessing Workforce Training Needs

Through the implementation of the ASD Strategy and the work of the ASD National Development Team, many more professionals have participated in training and development to understand autistic people’s needs and how to adapt their practice to provide tailored support. All professionals supporting autistic people should have an appropriate level of knowledge and skills in autism to undertake their roles effectively. Autistic people must also have confidence that they will receive high quality, evidence based advice and support.

To ensure good quality and appropriate training is available, the Welsh Government has invested in the development of a wide range of training resources aimed at different professional groups. The full range of resources can be found on the ASD infowales website, a leaflet is provided at appendix one, which includes:

- The Autism Learning with Autism programme – for early years to further education settings.
- Working with Autism - employment resources.
- Living with Autism - independent living resources.
- Growing with Autism – children’s resources.
- Diagnostic toolkits for professionals.
- A practitioner toolkit for professionals.

It is important that local health boards and local authorities and their partners are confident that all their staff has an appropriate level of knowledge and skills to be able to provide effective support for autistic people they work with. The WLGA has adapted existing good practice to develop the National Autism Training Framework\(^\text{12}\), which will assist organisations to assess autism training needs for a wide range of professional staff, helping to ensure they can access the right level of training required for their roles. Organisations are encouraged to adopt the Framework, when assessing the training and development needs of their all staff. It describes the level of autism knowledge

\(^{12}\) WLGA – National Autism Training Framework for Wales
appropriate for each type of role and links them to resources available on the ASDinfowales website.

The Framework is attached at appendix two. There are four levels of skills which are:

**Autism Aware**

- I am likely to work in a public facing role but would only recognise if someone had autism if I was made aware.

**Autism Informed**

- I am likely to work in a role where, as part of my day to day work, individuals may present with possible features of autism although I may not be aware of it.

- I may come across individuals with autism in my day to day work and may need to be able to identify when someone’s responses or behaviours appear unusual and to adapt my own behaviour.

**Autism Skilled**

- I work in a service where I may come across individuals with autism. My work may focus on specific aspects of the person, but I need to be able to identify possible autism to be able to adjust my practice.

- I need to be aware of autism in order to adapt my practice and to refer on if I am unsure or need clarification on diagnosis, the person's support, management or intervention.

**Autism Enhanced**

- As part of my role I may participate in team diagnostic assessments or conduct initial screening of assessment of individuals in my service for referrals to specialist service for differential diagnosis or 2nd opinion.

- I am likely to work in a team where, as part of my daily work, individuals are likely to present with possible features of autism.

- In my regular management and interventions, I may need to consider that someone has autism and conduct initial screening and assessment so as to adapt my practice.

- If it is a complex case, I may need to refer to a specialist services for a full assessment or obtain specialist supervision in my assessment.
Training for specialist health professions

The Government of Wales Act 2006, section 140 sets out that the regulation of health professionals is a reserved matter, which means that the Welsh Government is unable to legislate in this area with the exception of social care and social work professions. The Welsh Government does however have a role in promoting good practice and encouraging health boards and local authorities to ensure that staff have access to appropriate autism training. The National Autism Training Framework is a useful tool to enable health boards to assess the training needs of its workforce. The National Development Team has also developed information resources for some professions such as GPs. Skilled professionals in the National Integrated Autism Service in each region are also providing advice and training to other professional groups which also support autistic people to build local capacity and skills.

Primary Care Services

Primary care practitioners will often have to provide care for autistic people, these will include GPs, community pharmacists, opticians and dentists. It is important that local health boards and local authorities provide clear pathways for additional advice and signposting individuals to other services which can provide tailored support for autistic people to access services. The ASD National Development team has developed some resources aimed at providing key professionals with additional advice, for example guidance for GPs.

Knowledge and Training of Social Care and Social Work Staff

The service regulations under the Regulation and Inspection of Social Care (Wales) Act 2016 require that social care workers are suitably qualified and receive the training needed to carry out their roles. Social Care Wales, the social care workforce regulator and development body, is responsible for training and development of the social care workforce through the Social Care Workforce Development Programme.

Qualifications Wales, Social Care Wales and NHS Workforce Education Development Service (WEDS) have worked collaboratively to develop a new suite of qualifications for social care workers that will be implemented from September 2019 and will continue to offer a range of pathways for different service areas.

These qualifications will have specific units for different conditions, including autism, and decisions on units to be undertaken will be agreed between the learner, employer and learning provider and will reflect the learner’s needs in relation to their role. There are currently vocational units for workers supporting individuals with autism in the health and social care qualifications at level 2, 3 and 5. As part of the development of a new suite of qualifications, pathways related to autism will be included in levels 2, 3, and 5; and an additional specialist practitioner qualification will be available at level 4.

Access to Autism Training

Once organisations understand their staff training needs, arrangements should be made to ensure that suitable training is provided as quickly as possible. Training provision
must be high quality and evidence based and is essential that, where required it meets professional standards and is accredited to the relevant training bodies. The Welsh Government already offers a range of autism training programmes and there are third sector organisations such as the National Autistic Society which also offers a programme of training for professions and for parents and carers.

*Involving autistic people in training development*

Autism training should always be developed in partnership with autistic people, parents and carers. The Welsh Government is funding the development of an Adult Participation network to ensure that the voice of autistic people informs any future training and resources we provide. In addition, we are working closely with the National Parent Carer forum to gain the views of parent carers.

*Local stakeholder engagement and involvement*

The successful planning and delivery of autism services can only be achieved through direct engagement with those seeking support and their parents and carers. A co-production approach enables commissioners to identify what is working well, where there are gaps in service provision and where existing services and can be improved to meet the identified needs and demand for support.

In section 4 the role of the Regional ASD Champion is summarised, it is recommended that the champion also has an important role to ensure that stakeholders’ voices are sufficiently listened to and considered by regional partnership boards.

### Local Authorities Must

- 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 condition, the local authority must ensure that a person with that expertise is consulted.

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

- Ensure compliance with the Regulation and Inspection of Social Care (Wales) Act 2016 service regulations, requiring that social care workers, are suitably qualified and receive the training needed to carry out their roles.

### Local Health Boards Must

- Ensure healthcare professionals have the knowledge and training in autism they need to undertake their roles, where relevant engaging with specialist professional bodies.

- Ensure that any person carrying out an assessment of autistic spectrum disorder with an individual has the knowledge, skills and competence required, to undertake the assessment and provide a diagnosis.
• Ensure that primary health practitioners are aware of the autism services available in their local areas and have clear pathways for referral.

Local Authorities and Local Health Boards should

• Ensure that autism awareness training is included in general equality and diversity training programmes offered for all staff working in health and social care.

• As part of work force planning, assess the autism training needs of all their staff who are working in health and social care and identify the level of training required according to their job roles and responsibilities. The National Autism Training Framework provides a useful assessment tool.

• Make arrangements to ensure a range of autism awareness information, resources and training is made available to meet the identified needs

• Make arrangements to ensure that all staff can access the training identified to meet their autism knowledge and awareness training needs.

• Where the need for specialist training is identified ensure that training provision takes account of National Institute for Health and Care Excellence (NICE) guidelines.

• Ensure that appropriate training provision is made available on a continuing basis, including new staff and existing staff who change their job roles.

• Ensure that people with autism 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.

Health, Education and Improvement Wales Should

Ensure they are involved in the development of local workforce planning and GPs and primary care practitioners are engaged in the training agenda in relation to autism.
SECTION 4. Arrangements for Planning and Monitoring Services

Local authorities and health boards are required to plan and deliver health and social care services to meet the needs of their local population.

The SSWBW Act requires local health boards and local authorities to undertake a joint population assessment of care and support needs. Regional Partnership Boards must also produce area plans which set out how they will respond to the assessment through the provision of services and support\(^{13}\).

Part 9\(^{14}\) of the SSWBW Act established seven Regional Partnership Boards on an health board area footprint. These boards bring together health, social services, the third sector, citizens and other partners. Their purpose is to drive integration of health and social care in order to improve the outcomes and well-being of people and improve the efficiency and effectiveness of service delivery.

The boards have specific responsibility for the delivery of the Integrated Autism Service in each region. Co-production is a key principle in the SSWBW Act and regional partnerships are required to work with people to develop and deliver integrated services.

**Population assessments**

Part 2 of the SSWBW Act requires local authorities and local health boards to jointly undertake a population assessment of the extent to which there are people who need care and support and carers who need support, which should be undertaken in partnership. This assessment must also identify:

- The extent to which those needs are not being met.
- The range of level of services required to meet those needs.
- The range and level of services required to deliver the preventative services required in section 15 of the Act.
- How these services will be delivered through the medium of Welsh.

The purpose of the population assessment is to ensure that local authorities and local health boards produce a clear and specific evidence base in relation to the care and support needs and carer’s needs in their area. This will underpin the delivery of their statutory functions to inform planning and operational decisions.

Citizen engagement is a requirement in the development of population assessments, and a broad range of individuals, groups and organisations must be involved in the process of undertaking the population assessment. Population assessment reports must be published once per local government electoral cycle.

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Autism as a Core Theme

At present population assessments cover eight core themes, including learning disability/autism as a single theme as required by the Code of Practice on Part 2 of the Act. For more information, read the Part 2 Code of Practice (General Functions). At the next opportunity we will amend the Code of Practice to make autism a stand alone theme.

Area plans

Regional Partnership Boards are required to produce area plans in response to the population assessment, covering the same core themes as the population assessments, including learning disability/autism. The first area plans were published in April 2018. For more information, read the statutory guidance in relation to area plans under section 14A. The population assessments and area plans have both been published.\(^{15}\)

Regional partnership boards are required to review their population assessments and area plans and also to produce annual reports, setting out their progress against area plans.

Autism Data Collection

A successful population needs assessment is reliant on the availability of good quality data to understand the demand for and range of support needs which may be present in the local population. Similarly the development of health based services is also reliant on baseline information to assess the demand and scope of the services required. There has been a long standing debate on the data which should be collected to inform service planning and development. It is very difficult to determine the prevalence of autism as data can often only be sought for those who are seeking support from services and many individuals may not have received a diagnosis and or may not wish to access services. The Welsh Government recognises the widely agreed prevalence rate which is supported by the National Autistic Society, which estimates that 1% of the population has autism. Of this group we cannot be sure of the numbers of individuals who do not require support from statutory services.

Accepting 1% as the prevalence baseline it is important to understand the demand for existing services and to identify where there may be gaps in support. There is no one single way to collect this information, particularly for those not engaged with services.

Any approach to gathering individual data have careful regard to data security, now updated in the Data Protection Act 2018, particularly the General Data Protection Regulations (GDPR).

When planning autism services regional partnerships should take into account a wide range of data on service delivery. The Welsh Government collects high level data on autism as part of wider data collections. This includes:

\(^{15}\) [http://gov.wales/topics/health/socialcare/act/population/?lang=en](http://gov.wales/topics/health/socialcare/act/population/?lang=en)
Monitoring and Service Improvement

Data collection should not only focus on number of individuals diagnosed or receiving services as this alone cannot provide information on the outcomes achieved through service interventions or the quality of the services received. Richer, qualitative data is required to inform service improvement. To this end data outcome measures have been developed by the Together for Children and Young People, neurodevelopment work stream and the Integrated Autism Service which focus on how service interventions have assisted individuals and their families in their everyday lives. This approach also helps to identify where there may be gaps in service provision which need to be addressed.

This approach is being taken in the collection of data around the development and delivery of neurodevelopmental services is clearly set out in current guidance

“Guidance on the Delivery of Neurodevelopmental Services in Wales data collection questions.”

The National Integrated Autism Service is developing a robust shared approach to data collection which not only collects information on the numbers using services but more importantly aims to demonstrate how the interventions agreed have had a positive and lasting impact on the individual, which is aimed to build resilience and prevent the need for further or more intensive support.

Stakeholder Involvement

The development of autism services must be informed by local stakeholders, to provide feedback on existing services and to advise where there are gaps in provision which need to be addressed. Regional partnership boards should ensure that there is engagement with autistic people and their representative groups so stakeholders are listened to and involved in the planning and delivery of services to meet identified needs. Regional Partnership Boards have an essential role in facilitating this engagement. Many local authorities will also have local ASD Leads who will have established networks of stakeholders which can be accessed.

Regional autism champion role.

It is important that the needs of autistic people are adequately reflected in population assessments and areas plans and appropriate action is taken regionally. We propose that regional partnership boards can achieve this by appointing an ASD champion role on each board at a sufficiently senior level to be able to attend board meetings and report on the development of autism services in the region, particularly the delivery of
the Integrated Autism Service. The champion would have responsibility for oversight of any joint commissioning arrangements, including the delivery of the integrated autism service and other services for autistic people. The champion would also have a role in ensuring that there is effective local stakeholder involvement in the delivery of autism services and ensuring that stakeholders can take an active role in service development.

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<tr>
<th><strong>Local Health Boards Must</strong></th>
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<td>• Ensure compliance with Welsh Government ASD Waiting Time Data Standard collection requirements.</td>
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<th><strong>Local Health boards and local authorities must jointly</strong></th>
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<tr>
<td>• Comply with relevant duties in the SSWBW Act, Parts 2 and 9 to ensure that needs of autistic people are considered in the development of Population Assessments and Area Plans.</td>
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<td>• Ensure that stakeholders are involved in the planning and delivery of autism services.</td>
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<tr>
<td>• Ensure that an autism champion of suitable seniority is appointed to represent the needs of autistic people. This will include:</td>
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<td>• Reporting to the regional partnership board on the delivery of autism services.</td>
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<td>• Overseeing joint commissioning and delivery of the arrangements for autism services</td>
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<td>• Ensuring effective local stakeholder involvement in planning and delivery of autism services.</td>
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Appendix One – ASD Info Wales Resources Leaflet

ASDinfoWales_Resources-leaflet_CYM.pdf
ASDinfoWales_Resources-leaflet_ENG.pdf
Appendix Two - National Autism Training Framework

Glossary of Terms

ALN Additional Learning Needs
ALNET Additional Learning Needs and Education Tribunal Act 2018
ASD Autistic Spectrum Disorder
ASD SAP Autistic Spectrum Disorder Strategic Action Plan
CAMHS Child and Adolescent Mental Health Service
IAS Integrated Autism Service
LA Local Authority
LHB Local Health Board
LDD Learning difficulties/disabilities
NAS National Autistic Society
NICE National Institute of Health and Clinical Excellence
T4CYP Together for Children and Young People
SSWBW Act Social Services and Wellbeing (Wales) Act 2014
WLGA Welsh Local Government Association

**Are the proposed requirements in this section right for service providers?** If you think there is anything missing or unnecessary, please explain in the box below.

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Do you think that the proposals will have any unintended consequences, please explain.

Q2 - SECTION 2: Arrangements for Accessing Care and Support

**Are the proposed requirements in this section right for service providers?** If you think there is anything missing or unnecessary, please explain in the box below.

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Do you think that the proposals will have any unintended consequences, please explain.

Q3 – SECTION 3: Arrangements for Training Needs Assessment and Provision of
Training

**Are the proposed requirements in this section right for service providers?** If you think there is anything missing or unnecessary, please explain in the box below.

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Do you think that the proposals will have any unintended consequences, please explain.

Q4 – SECTION 4: Arrangements for **planning** of autism services

**Are the proposed requirements in this section right for service providers?** If you think there is anything missing or unnecessary, please explain in the box below.

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Do you think that the proposals will have any unintended consequences, please explain.

Q5 – SECTION 4: Arrangements for **monitoring** of autism services
Are the proposed requirements in this section right for service providers? If you think there is anything missing or unnecessary, please explain in the box below.

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Do you think that the proposals will have any unintended consequences, please explain.

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Q6 – SECTION 4: Arrangements for Stakeholder Engagement and Awareness Raising

Are the proposed requirements in this section right for service providers? If you think there is anything missing or unnecessary, please explain in the box below.

<table>
<thead>
<tr>
<th>Agree</th>
<th>Tend to Agree</th>
<th>Tend to Disagree</th>
<th>Disagree</th>
</tr>
</thead>
</table>

Do you think that the proposals will have any unintended consequences, please explain.

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Other Questions

The Welsh Government is interested in understanding whether the proposals in this consultation document will have an impact on groups with protected characteristics. Protected characteristics are: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex, and sexual orientation.
Do you think that the proposals in this consultation will have any positive impacts on groups with protected characteristics? If so, which and why/why not?
Please explain

Do you think that the proposals in this consultation will have any negative impacts on groups with protected characteristics? If so, which and why/why not?
Please explain

We would like to know your views on the effects that these proposals would have on the Welsh language, specifically on
i) opportunities for people to use Welsh and
ii) on treating the Welsh language no less favourably than English.

What effects do you think there would be? How could positive effects be increased, or negative effects be mitigated?
Please explain

Please also explain how you believe the proposed policy could be formulated or changed so as to have:

i) positive effects or increased positive effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language, and

ii) no adverse effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language.

Please explain
We have asked a number of specific questions. If you have any related issues which we have not specifically addressed, please use this space to tell us about them

Please explain