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**Welsh Government
Consultation Document**

Code of Practice on the Delivery of Autism Services

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Action required: Responses by 14 December 2020

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

Overview This consultation is seeking views on the Code of Practice on the Delivery of Autism Services under the Social Services and Well-being (Wales) Act 2014 and the NHS (Wales) Act 2006. It will support the delivery of the Welsh Government's autism priorities as set out in the Autistic Spectrum Disorder Strategic Action Plan published in November 2016.

How to respond You can respond to this consultation by midnight on the closing date using the consultation response form available on our website or 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.**

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Your response

Responses to consultations are likely to be made public, on the internet or in a report. If you would prefer your response to remain anonymous, please place a tick in the box on the responses form or confirm in your response.

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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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Data Protection Officer:
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Ministerial Foreword

To be included in the final published version of the Code of Practice.

Introduction

This Code of Practice on the Delivery of Autism Services (the Code) has been developed in response to feedback from autistic people and their families and/or carers, seeking clarity on the services they should expect to be available in Wales. It sets out the duties placed on local authorities and health bodies about the range and quality of services that should be available in their local areas. This Code reinforces the legal frameworks already in place by specifying provisions for autism services. More detail on the interpretation of duties is in a guidance document accompanying this Code.

This Code is for:

- autistic people, including those with other co-existing conditions
- providers of social care and health support for autistic people and their families and/or carers
- practitioners in social care and health who work with autistic people and their families and/or carers
- commissioners and people with a strategic role in assessing and planning local services for autistic people and their families and/or carers
- practitioners in other related services providing support for autistic people and their families and/or carers, for example employment, education and criminal justice
- service providers and practitioners providing services for autistic people with co-existing conditions.

Terminology

As an outcome from our consultation with engagement groups and technical groups this Code will refer to the following as a definition of autism:

“The term autistic spectrum condition (ASC) is used to describe the group of complex neuro developmental symptoms, of variable severity, that are characterised by challenges in social interaction and communication and by restricted or repetitive patterns of behaviour, thought and sensory feelings”.

The terms Autistic Spectrum Condition, 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 Code will use the term ‘autistic people’ rather than ‘people with autism’, this is to reflect the language preferences expressed by autistic people who have contributed to the development of this Code.

This Code will also use the term ‘practitioners’ rather than referring to individual professions. This is to reflect the language preferences expressed by all individuals who contributed to the development of this Code.

This Code 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.

In this Code, a **requirement** is expressed as “must” or “must not”. **Guidelines** are expressed as “may” or “should/should not”.

A glossary of terms is can be found at the end of the Code.

Purpose

The purpose of this Code is to secure the implementation of Welsh Government’s autism policy priorities, currently published in the Autistic Spectrum Disorder Strategic Action Plan 2016. Alongside the Code, there is a guidance document to assist local authorities and NHS health bodies on the services and support they are expected to provide for autistic people under existing legislation.

Where autistic individuals 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 accompany this Act will apply. Where autistic children and adults have additional educational support needs, the proposed 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 also takes account the requirements of the Equality Act 2010.

This Code reflects 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 the five ways of working needed for public bodies to achieve the seven well-being goals (A Prosperous Wales, A Resilient Wales, A Healthier Wales, A More 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.

Additionally, work to develop the Explanatory Memorandum and Regulatory Impact Assessment for the Code is underway. We are examining a number of options for securing our policy objectives for autism services in terms of potential costs and benefits. To ensure a robust analysis, this work, coupled with the responses received from this consultation, and the data collected as part of a demand and capacity review of neurodevelopmental services, will be used to inform the body of the Regulatory Impact Assessment in the Explanatory Memorandum. In considering the options, account will be taken of the likely impact in relation to equity or fairness for particular groups, for instance race, age, gender, sexual orientation, marriage and civil partnership, pregnancy and maternity, disability, religion and belief, gender reassessment.

Power to Issue a Code of Practice on the Delivery of Autism Services

This Code is issued under section 145 of the SSWBW Act 2014. It also constitutes guidance under section 169 of the SSWBW Act 2014 and guidance under section 2 of the National Health Service (Wales) Act 2006.

The Welsh Ministers want to ensure it has comparable force in relation to local authorities, local health boards and NHS trusts. Therefore, Welsh Ministers are able to and will be exercising a power of direction over health boards and NHS trusts which would require them to comply with the duties contained within this Code.

Powers

The SSWBW Act is available at:

<http://www.legislation.gov.uk/anaw/2014/4/enacted>.

And National Health Service (Wales) Act 2006 (NHS (Wales) Act).

http://www.legislation.gov.uk/ukpga/2006/42/pdfs/ukpga_20060042_en.pdf

Local authorities **must** act in accordance with the **requirements** contained in this Code. Section 147 of the SSWBW Act (departure from requirements in guidance) does not apply to any **requirements** contained.

Local health boards and NHS trusts, when exercising their functions under the NHS (Wales) Act have been directed to have regard to the **requirements contained within this Guidance** by **[insert reference to the title of the Directions Welsh Health Circular]**.

In addition, local authorities, local health boards and NHS trusts must have regard to any **guidelines** set out within the Code and accompanying guidance.

This Code should be read in conjunction with the relevant Codes 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)

Understanding the duties in the Code

This Code is made under the SSWBW Act and constitutes guidance under the NHS (Wales) Act but relevant NHS boards / NHS Trusts have been directed to have regard to the guidance. The Welsh Ministers are 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 and NHS trusts under the NHS (Wales) Act 2006

Local Health Boards and NHS Trusts Must/must not

Requirements for local health boards and NHS trusts under the NHS (Wales) Act 2006 and local authorities under the SSWBW section 145

**Local Authorities with Local Health Boards / NHS Trusts
Must/should/should not**

Requirements placed on health boards, NHS trusts and local authorities jointly in guidance issued under the SSWBW Act, section 169

Local Health Boards with Local Authorities Must jointly/must not jointly

Compliance with the Code

Welsh Ministers may direct local authorities, local health boards and NHS trusts to take any action which the Welsh Ministers consider appropriate for the purpose of securing the compliance of functions in accordance with the relevant requirements in this Code. Welsh Government will request an annual report on the delivery of the regional area plan including compliance with the duties contained within this Code.

SECTION 1: Arrangements for Autism Assessment and Diagnosis

This section describes the arrangements for:

- people who may be autistic to access assessment and diagnosis services
- the establishment of referral routes and assessment pathways
- access to *multidisciplinary* services, trained in the diagnostic techniques to identify autism
- support for people referred for diagnostic assessment and their families and/ or carers during this process.

1. Identification

Practitioners should be aware and be able to recognise a pattern of lifelong impairments in reciprocal social interaction and communication skills, together with unusual restricted and repetitive behaviours which may suggest the need for further investigation. Clear information and explanations should be given to the family/carer, young person or adult regarding the referral, assessment and diagnostic process, including consent, to ensure the process is understood, this should include the explanation that a positive autism diagnosis may not be made. Local authorities, local health boards and health trusts must ensure:

- i practitioners receive awareness training / information on the signs and symptoms and the presence of unusual features which may alert to the possibility of autism in a child, young person or adult
- ii practitioners receive guidance / training on referral pathways for assessment
- iii practitioners offer information (in an appropriate format and language), to the, young person or adult and family or carer which explains the referral process and that it does not mean a diagnosis of autism will always be made.

2. Referral to Autism Assessment services

An autism assessment must be clearly communicated so that all people can understand how to access an assessment, how it will be undertaken, who will be involved and what it means for them. There will be occasions where, because of their particular needs, people will need additional support to ensure that they understand what is available to them and how to access support;

- i. there must be nationally agreed autism referral pathways which must be followed
- ii. the autism referral pathways must be easily accessible to all, this must include family or carers, children, young people and adults and must offer details on self-referral

- iii. autism referrals must detail signs and symptoms, pervasiveness, impact on functioning and risk factors
- iv. practitioners must listen to and take into account the views of young people, adults, families and/or carers
- v. referrals must be arranged within agreed national timescales
- vi. people on the autism referral pathways must be offered support whilst awaiting assessment, this includes the provision of clear information on the diagnostic process and the autistic condition, in plain language format
- vii. when referrals to the diagnostic teams are not accepted, the referrer must be provided with a rationale for this, alongside advice about what additional information is needed to progress the referral. If other services are more appropriate details on access to these should be provided
- viii. performance will be monitored, however this must not only relate to specific waiting time targets but to the quality and impact of the services received.

3. Assessment and Diagnostic pathways for autism

There must be nationally agreed arrangements for accessing diagnostic assessments for autism for children and adults. These two services must work alongside each other and the pathways must be aligned. This will be of particular importance for transition between services.

- i. There must be nationally agreed autism assessment pathways which take into account best practice guidance
- ii. the autism assessment pathways must be holistic and must include access to assessment for co-occurring neurodevelopmental conditions
- iii. the autism assessment for children and adults must provide clear clinical information which can inform lifespan services
- iv. all practitioners involved in assessment and diagnostic services must be aware of the assessment and diagnostic pathways for autism
- v. pathways must be published electronically, kept up to date and be easily accessible.

Access to autism assessment and diagnosis in the secure estate

Individuals detained in secure hospitals, prisons, youth detention accommodation or their equivalent who appear to require access to autism assessment must have:

- i. access to diagnostic services and post diagnostic support in line with the requirements of this Code and relevant accompanying guidance
- ii. access to health and social care practitioners who have the right level of knowledge and skills to recognise when an individual should be referred to specialist services for autism assessment.

4. Autism assessment and diagnostic services

Assessment and diagnosis for children, young people and adults must be through multidisciplinary teams who are appropriately trained. To promote access, local health boards with local authorities must ensure:

- i. pathways will have a single point of access for the assessment and diagnosis of autism
- ii. the development of multidisciplinary services to undertake the assessment and diagnosis of autism for children, young people and adults
- iii. these services provide an holistic assessment or referral for other co-occurring neurodevelopmental conditions if indicated.

5. Autism assessment and diagnostic process

Services offering autism assessments to children, young people and adults must;

- i. commence the assessment in accordance with nationally agreed waiting time standards
- ii. have all available information ready for consideration during the assessment process to offer a holistic view of the individual
- iii. ensure practitioners listen to and take into account the views of young people, adults, families and/or carers
- iv. ensure the collection of additional information should not impede the progress of the autism assessment process
- v. have an established point of contact identified to answer queries from the autistic person, family or carer
- vi. ensure outcomes from the assessment are conveyed face to face to the individual and family or carer (where appropriate) by a practitioner involved in the assessment and diagnosis process. This process will also apply where an autism diagnosis is not made
- vii. support a continued person centred approach, and a profile of the individuals strengths, difficulties and needs should be documented and made available as required
- viii. ensure where autistic people have co-occurring mental health and or learning disabilities, pathways are be in place to enable access to services, which can meet their additional support needs
- ix. ensure family or carers (where appropriate) must be offered a referral for a needs assessment for support services.

6. Support following an autism diagnosis

For children, young people and adults with a diagnosis of autism, a follow-up appointment with an appropriate member of the service must be offered within 6 weeks. Post diagnosis consideration should be given to the following;

- i. specific interventions which are proportionate to identified need, evidence-based to achieve identifiable outcomes in a stated timescale and not solely driven by diagnosis
- ii. provision of information and guidance on the core features of the diagnosis. This may include written information, one to one sessions or workshops. If no diagnosis is given, other relevant information and support must be made available
- iii. information on seeking a second opinion must be provided if requested

- iv. the offer of signposting to relevant support and further information to autistic people and family or carers.

Draft Duties: Arrangements for Autism Assessment and Diagnosis

Local Authorities Must

- Ensure that autistic people are aware of the right to access a needs assessment and a carer's assessment for a carer. The process of obtaining these should align with the diagnosis.
- Ensure there is information and signposting to access assessment services.

Local Health Boards and NHS Trusts Must

- Provide access to services which can diagnose autistic spectrum condition 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 and secondary care are notified of assessment referral pathways for children, young people and adults.
- Comply with current national waiting time standards for assessment and diagnosis.
- Ensure the collection of information on waiting times for assessment for children, young people and adults comply with current national waiting time standards for autism assessment and diagnosis.
- 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 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 with Local Health Boards and NHS Trusts Must

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

This section will describe the arrangements for:

- accessing health and social care services
- establishing pathways to access mental health services
- support for those with co-occurring conditions
- how services must accommodate the needs of autistic people who access their services
- how local authorities, local health boards and NHS trusts must consider the specific needs of autistic people in the design and delivery of support.

1. Accessing health and social care services

Where appropriate, services must inform individuals where they can access further care and support. All services, particularly first contact teams, such as the Information Advice and Assistance service must know how to refer autistic people to specialist organisations to assist them in accessing support. Information must be suitable for the intended audience so that;

- i. people are able to understand how to get help and advice
- ii. information is available in alternative formats
- iii. people are signposted to access assessment for health, social care and support services in a joined up way which is based on their needs.

2. Advocacy

An autistic individual their family/carer must feel that they are an equal partner in their relationship with practitioners. It is open to any autistic individual to invite someone of their choice to support them to participate fully and express their views wishes and feelings during appointments with practitioners;

- i. this support can be provided by someone's friends, family or wider support network
- ii. local authorities must arrange for the provision of an independent professional advocate when an eligible autistic person family/carer requires support to participate fully in an assessment, care and support planning, review or safeguarding processes.

3. Preventative services

Local authorities are required to provide preventative services. Practitioners referring or providing preventative services must understand autism and its impact on individuals. Preventative services can include:

Children

- i. providing advice to family or carers
- ii. promoting and facilitating involvement in local community groups and/or recreational activities
- iii. engagement with a range of health and social care practitioners.

Adults

- i. encouraging involvement in the local community, daily living and healthy lifestyles
- ii. facilitating access to mainstream preventative services and or adaptations to accommodate their needs
- iii. supporting involvement with housing and employment services
- iv. engagement with a range of health and social care practitioners.

4. Eligibility and Intelligence Quotient (IQ)

Eligibility for social care support must be based on an analysis of five inter-related elements to ensure that the local authority considers the person's circumstances in the round. Practitioners assessing an autistic individual's eligibility for social care services must have sufficient knowledge and skills to understand the impact of autism on the ability to achieve these five inter related elements.

This requires the local authority to:

- i. assess and have regard to the autistic person's circumstances
- ii. have regard to their personal outcomes
- iii. assess and have regard to any barriers to achieving those outcomes
- iv. assess and have regard to any risks to the autistic person or to other persons if those outcomes are not achieved
- v. assess and have regard to the autistic person's strengths and capabilities.

IQ should not be a factor in the assessment of an individual's need for care and support. However, reference to intellectual abilities can be made when;

- i. agreeing the care and support an individual receives
- ii. an autistic individual may benefit from specialist services tailored to meet their needs.

5. Assessment for Local Authority Care and Support

Any autistic individual or family/carer with a care and support need 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.

- i. The assessment must start when a person accesses the information, advice and assistance service or first point of contact. However, access to an assessment should not be restricted to being accessible through this service alone

- ii. the assessment must build a better understanding of the autistic person, identify the most appropriate approach to addressing their particular circumstance, and establish a plan for how they will achieve their personal outcomes
- iii. the assessment must be undertaken between the practitioner, the autistic person and their family/carer where appropriate
- iv. more comprehensive assessments may sometimes involve several stages or discussions to establish a full understanding of the autistic person's needs and the outcomes they wish to achieve. These assessments may also involve seeking the views of other practitioners with an expertise in autism
- v. the need for a more specialist assessment to be undertaken must not prevent or delay appropriate services being provided
- vi. the autistic person and their family/carer, should be kept informed of the progress of the assessment and expected timescales for completion of the assessment process
- vii. the local authority may combine an autistic person's needs assessment with the needs assessment of his or her family/carer if it would be beneficial to do so and the autistic person gives consent
- viii. practitioners must be proactive in their approach and the autistic individual should be asked which language or communication form they would prefer at the beginning of the process
- ix. practitioners must document any unmet need and this information used to inform future service planning.

Local authorities must prepare and maintain a care and support plan or a support plan for an autistic person whose needs it is required to meet. Care and support plans must cover the following;

- i. the personal outcomes which have been identified in relation to the autistic person to whom the plan relates
- ii. the actions to be taken by the local authority and other persons to help the autistic person achieve those outcomes
- iii. the needs that will be met through the delivery of care and support
- iv. how progress towards achieving those outcomes will be monitored and measured
- v. the date of the next review of the care and support plan
- vi. details of how and when a plan must be revised in the event of any change of circumstances
- vii. a plan must not be closed without a review.

The circumstances where eligible assessed needs may be met by direct payments are:

- i. local authorities must provide appropriate, accessible information and support to enable autistic people, or their representatives, to decide whether they wish to receive direct payments
- ii. local authorities must ensure the administration of the direct payment scheme is responsive to solutions and outcomes for autistic people

- iii. local authorities must be innovative and creative when working in partnership with recipients or their representatives to explore ways a direct payment can be used to secure the personal outcomes
- iv. autistic individuals must not be refused a direct payment purely because they are unable to manage the payment, or apprehensive about managing one
- v. local authorities, in partnership with the autistic person, must explore all options for supporting the individual to manage a direct payment
- vi. where areas of difficulty are identified, local authorities must ensure the correct level of support to overcome such barriers is available
- vii. local authorities must review the arrangements for the making of direct payments and how they are being used at regular intervals.

6. *Transition*

Transitions must be carefully planned in advance to make them as seamless as possible. All transitions constitute a significant change in an autistic individual's circumstances and creates a right to a re-assessment of needs.

- i. Practitioners involved in the care and support of autistic individuals need to prepare them for subtle transition changes which may impact on their day to day life
- ii. 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
- iii. autistic individuals themselves can also request a review and reassessment, when personal outcomes have changed
- iv. for guidance regarding children and young people experiencing transition during their education, particularly when they leave school for further education or other services, the Additional Learning Needs and Education Tribunal (Wales) Act 2018 will take precedence when it comes into force.

7. *Carer Assessments*

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 to parents and carers. A carer's assessment must conclude with one of the following outcomes:

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

- vii. needs can only be met through a care and support plan, or a support plan.

8. *Accessing health care*

Autistic people have an equal right to the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. Local health boards and NHS trusts must strive to ensure that no autistic individual is deprived of their right of access to such health care services. Cognitive and communication differences can complicate identification and management of illnesses unrelated to autism. The practitioner's role is to prevent and treat while providing support and reasonable adjustments for an autistic individual's needs. Wider implementation of the health passport will enable services to recognise and act on individual needs.

Primary health care

Local health boards must ensure that primary care practitioners develop strategies and make reasonable adjustments for successful physical examinations, tests and procedures:

- i. all primary care services should identify autistic people within their patient population
- ii. where possible, extra time should be allocated for appointments
- iii. personal profiles should be developed to assist individual practitioners in delivering services
- iv. where possible consistency in staff and routine should be encouraged
- v. all staff should receive training in autism and associated behavior, communication and sensory processing issues (appropriate to their interaction).

Secondary and tertiary health care

Local health boards and NHS trusts must ensure that all hospitals, irrespective of the clinical provision, develop strategies and make reasonable adjustments which aim to achieve successful physical examinations, tests and procedures:

- i. admission assessments must include specific requirements to assist safe care provision whilst the autistic patient is in hospital
- ii. safeguarding provisions should be considered and adopted if necessary
- iii. where possible and if the situation requires, where the autistic patient has capacity/sufficient understanding and has given consent, provision for family or carer to remain with the autistic patient should be considered
- iv. call handlers/receptionists need to be trained specifically to deal with calls/queries from autistic people
- v. staff should receive training in autism and associated behavior, communication and sensory processing issues (appropriate to their interaction).

9. *Support within Secure Estates*

Local health boards, local authorities working together with prisons and youth detention accommodations must ensure:

- i. they develop strategies and make reasonable adjustments for the safe custody of autistic people
- ii. all staff receive training in autism and associated behavior, communication and sensory processing issues (appropriate to their interaction).

10. *Mental health services for autistic children, young people and adults.*

If required, autistic children, young people and adults will have full access to multidisciplinary mental health services, regardless of their intellectual ability or any co-occurring diagnosis:

- i. 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, irrespective of their autism diagnosis
- ii. reasonable adjustments must be made for autistic people when providing mental health services
- iii. a practitioner with relevant experience of autism should be involved where at all practicable. If this is not possible they should seek assistance from specialists with appropriate expertise, but this should not be allowed to delay action that is immediately necessary
- iv. steps must be taken to ensure autistic people with co-occurring conditions can access information and advice, including access to additional support such as Independent Mental Health Advocates (IMHAs) or, if applicable, Independent Mental Capacity Assessors (IMCAs)
- v. specific or additional training must be made available for staff who are likely to work with autistic people and associated co-occurring conditions.

11. *Services for autistic people with co-occurring conditions*

Autistic children, young people and adults with co-occurring conditions must be able to access support services from whichever team best meets the needs of the individual.

Children

- i. mainstream educational establishments must have support services in line with existing general education legislation
- ii. children who have identified health and/or eligible social care needs will receive support from the appropriate service

Adults

- i. adults who have identified health and/or eligible social care needs will receive support from the appropriate service
- ii. adults who have identified health and/or eligible social care needs will receive support from the appropriate service
- iii. adults who wish to live independently must receive appropriate support and interventions to maintain a safe environment
- iv. adults who may or may not have co-occurring conditions and require respite care must be offered placements in services which meet their individual needs.

Draft Duties: Arrangements for Accessing Health and Social Care Services

Local Authorities Must

- 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.
- 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.

Local Health Boards and NHS Trusts Must

- Make arrangements to ensure that health services are aware of the autism services available in their local areas and have clear pathways for referral.
- Must ensure that staff receive appropriate training in autism and associated behaviour and sensory needs at a level appropriate to their involvement.
- Ensure IQ is not considered as part of the eligibility criteria.

Local Authorities with Local Health Boards and NHS Trusts Must

- Ensure that autistic people are aware of the right to access a needs assessment. This should be offered at the diagnosis stage.
- Ensure that awaiting a diagnosis is not a reason to be refused support and other services.
- Ensure that carers of autistic people are aware of the right to access a needs assessment. The process of obtaining one should align with the diagnosis process and be offered at the diagnosis stage and a referral made if needed.
- Encourage innovation in the development of autism services.
- Ensure that reasonable adjustments are in place for autistic people to ensure they are able to access services in the same way as everyone else.
- Ensure that where the need for specialist service provisions are identified, where possible these are made available.
- Ensure that health and social care support for autistic people detained in the secure estate is provided by trained practitioners.

SECTION 3: Arrangements for Awareness Raising and Training in Autism

This section describes the arrangements for:

- local health boards, NHS trusts and local authorities to promote inclusion of autistic people in mainstream services, by ensuring that information is made available to the wider community to promote understanding of autism and how being autistic can have a different impact on each individual
- ensuring that staff working in both specialist and mainstream services have access to the appropriate level of autism understanding, knowledge and skills to provide effective services and support for autistic people, their families and/or carers.

1. Promoting Equality and Inclusion

The Equality Act 2010 places a legal duty on service providers and those providing goods and facilities to make reasonable adjustments for autistic people so they are not at a disadvantage compared to people without autism. Providers are required to make reasonable adjustments for autistic people on a case-by-case basis the duty is also anticipatory:

- i. providers need to think about what sort of reasonable adjustments can be made and how they are to be provided before they are needed, a point especially relevant in a health setting where adjustments may need to be implemented quickly and according to a specific, individual need
- ii. local authorities and local health boards (including commissioned service providers) must ensure autism training includes the skills to implement reasonable adjustments.

Good communication between service providers, autistic people and their families and/or carers (if appropriate), is essential.

- i. Treatment, care and support, and the information given about it, must be both age-appropriate, language and culturally appropriate
- ii. information must be accessible to autistic people with additional needs such as physical, sensory or learning disabilities, and to people who do not fully understand or express English/Welsh (on request)
- iii. autistic people, their families and/or carers (if appropriate), must have access to an interpreter (appropriately trained) or communication advocate if needed.

2. Raising awareness of autism in the community

To create a society inclusive of autistic people, there needs to be an understanding of the autism condition across the community. Local authorities as providers/commissioners of publicly available facilities, along with health and third

sector providers should adapt their services to meet the needs of autistic people. This can be achieved by:

- i. supporting autistic people and their family or carers to have opportunities to be involved in community activities and share experiences
- ii. providing general awareness information about the impact of autism
- iii. providing information to autistic people their families or carers about their rights
- iv. providing information about local opportunities tailored for autistic people
- v. providing information about local training available which can support autistic people and their family or carers
- vi. providing information to help autistic people and their family or carers to prepare for the future
- vii. providing the contact details of the Information, Advice and Assistance service.

3. Workforce learning and development

All individuals working for local authorities, local health boards and NHS trusts, particularly those in public facing roles, can make a positive difference to the health and wellbeing outcomes of autistic people. It is essential that all understand how they can adapt their own roles and practice to improve services and support for autistic people. This needs to start with recognition of the value of information and training to raise awareness, to change attitudes and beliefs about autism and to improve practice.

Local authorities, local health boards and NHS trusts must ensure that those working in health and social care must have specific autism awareness training. For individuals where this is needed to fulfil their role responsibilities and for those who wish to develop their knowledge of autism, there should be access to different levels of specialist learning and development.

Local health boards, NHS trusts and local authorities, as part of their workforce planning, should undertake an autism learning and development needs assessment for **all of their staff** (including volunteers) and make arrangements to ensure that suitable learning and development opportunities are provided on a regular basis. Learning and development provision must be:

- i. high quality evidence based
- ii. where required, it must meet professional standards
- iii. undertaken as part of induction and as part of continuing workforce development for refreshing skills and knowledge
- iv. repeated every two years or to reflect change in a role
- v. appropriate to the role of the staff and the level of engagement with autistic people
- vi. in line with regulatory and inspection requirements for health and social care.

All individuals **directly working with** autistic people should have an appropriate level of knowledge and skills to enable them to respond appropriately to the needs of an autistic person so that they can perform their roles effectively. Autistic people must also have confidence that they will receive high quality, evidence based advice, care and support.

- i. The priority must be all individuals who have a role in the provision of care, each practitioner will need different levels of training, to meet the requirements of their role
- ii. learning and development must aim to develop the practical skills of the workforce and ensure reasonable adjustments are made to improve the way autistic people, of all ages, are supported
- iii. learning and development must provide an understanding of the ways in which autism affects each individual differently
- iv. provision should be made for documenting learning and development undertaken and standards attained to allow portability between different organisations.

All practitioners involved in **working with, assessing, caring for and treating** autistic people should have sufficient and appropriate training and competencies to deliver the actions and interventions indicated by their practice. This will include:

- i. clinicians – psychiatrists, paediatricians, psychologists (clinical and educational)
- ii. medical, nursing and allied health professionals
- iii. social workers
- iv. teaching workforce
- v. therapists – occupational speech and language, physio
- vi. pharmacists
- vii. podiatrist
- viii. dentists
- ix. general practitioners
- x. emergency service – fire, ambulance (including call handlers)
- xi. first point of contact.

4. Primary Care Services

All primary care practitioners at some point may provide care for autistic people. It is important that local health boards ensure:

- i. their staff receive appropriate learning and development to meet the needs of an autistic person
- ii. their contractual arrangements with independent providers includes assurances regarding adequate learning and development of the providers themselves and the individuals they, in turn, employ
- iii. individuals will understand the legal obligation to make reasonable adjustment to facilitate appropriate care
- iv. provision must be made locally to maintain a current list of community support services that professionals and the Information Advice and Assistance Services can signpost autistic people for further assistance.

5. *Secondary and tertiary health services*

Local health boards and NHS trusts must ensure that secondary and tertiary health services are accessible to autistic people and they must not be denied services or support because they are autistic. Every effort must be made to offer support to help autistic people understand their treatment while in hospital. Local health boards and NHS trusts must:

- i. ensure all individual practitioners (including volunteers) receive awareness learning and development opportunities in line with their role
- ii. ensure individual practitioners (including volunteers) in specialist areas such as mental health, maternity services, accident and emergency units receive autism learning and development opportunities
- iii. ensure estates department personnel receive learning and development to promote an understanding of environmental adjustments for autistic people
- iv. ensure individual practitioners (including volunteers) understand the legal obligation to make reasonable adjustments to facilitate the delivery of appropriate care, support and advice
- v. ensure that learning and development is evidence based and updated regularly to ensure practice is current
- vi. encourage the use of the health passport. .

6. *Social Care Services*

Social care and social work practitioners will often provide care for autistic people. It is important that local authorities provide learning and development opportunities to ensure staff are able to meet the needs of an autistic person and where possible can offer clear pathways for additional advice and signposting for individuals to other services which can provide tailored support for autistic people to access services:

- i. local authorities must ensure that community practitioners receive learning and development in autism at a level appropriate to their role
- ii. local authorities must ensure their contractual arrangements with independent providers includes assurances regarding adequate learning and development of the providers themselves and the individuals they, in turn, employ
- iii. this learning and development must be evidence based and regularly updated to ensure practice is current
- iv. individuals must understand the legal obligation to make reasonable adjustment to facilitate appropriate care, advice and support
- v. provision must be made locally through the Information Advice and Assistance to maintain a current list of community services that practitioners can signpost autistic people for further assistance.

7. Educational Establishments

When it comes into force regulations made under section 60 of the Additional Learning Needs and Education Tribunal (Wales) Act 2018 may:

- i. require governing bodies of maintained schools and further education institution's in Wales to ensure that Additional Learning Needs Co-ordinators (ALNCos) have prescribed qualifications or prescribed experience (or both)
- ii. confer functions on ALNCos in relation to provision for pupils or students (as the case may be) with additional learning needs.

Draft Duties: Arrangements for Awareness Raising and Training in Autism

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.
- Where services are commissioned local authorities must ensure autism services are provided by appropriately trained and skilled staff.

Local Health Boards and NHS Trusts 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 condition with an individual has the knowledge, skills and competence required, to undertake the assessment and provide a diagnosis.
- Ensure that primary and secondary healthcare practitioners are aware of the autism services available in their local areas and have clear pathways for referral.

Local Authorities, Local Health Boards and NHS Trusts 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 workforce planning, assess the autism training needs of all their staff who are working in health and social care and identify the level of training required according to their job roles and responsibilities.
- Make arrangements to ensure a range of autism awareness information, resources and training is made publicly available.
- Make arrangements to ensure that all staff can access the training identified to meet their autism knowledge and awareness training needs.

- Ensure that health and local authority staff are aware of the Information, Advice and Assistance service and how to refer autistic people to the service
- 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 autistic people and their parents and carers are involved in the development and delivery of autism training. This may include consultation on training materials or involvement in delivery of training.

SECTION 4: Arrangements for Planning and Monitoring Services and Stakeholder Engagement

This section describes the arrangements for:

- local health boards and local authorities to undertake a joint population assessment of care and support needs
- regional partnership boards must ensure the local authorities, local health boards and their partnership board partners work together effectively to respond to the population assessments and implement the area plans.

1. Population assessments

Local authorities and local health boards must jointly undertake a regional population assessment every five years. This will include the extent to which there are autistic people who need advice, care or support and carers of autistic people who need support in their region. This assessment must be undertaken in partnership and must identify:

- i. the extent to which autism needs are not being met
- ii. the range and level of autism services required to meet identified needs
- iii. the range and level of autism services required to deliver the preventative services required
- iv. how autism services will be delivered taking into consideration population, culture and language with specific reference to the Welsh language.

The population assessment must evidence:

- i. citizen engagement from autistic people, autism groups and organisations
- ii. autism as a stand alone theme within the assessment
- iii. that the population assessment reports are published once per local government electoral cycle (five years).

2. Area plans

Regional partnership boards should ensure the local authorities, local health boards and their partnership board partners work together effectively to respond to the population assessments and implement the area plans.

- i. Regional partnership boards will review the area plans annually, this will include autism provision
- ii. the review will include actions and outcomes on autism service provision
- iii. the annual review will include an annual report, setting out regional progress on achieving the annual plan, this must align with the Welsh Government autism strategy.

3. Autism data collection

Regional partnerships boards should oversee local data on autism which informs the population needs assessment and assists in monitoring delivery of the area annual plan as they relate to the needs of autistic people and family or carers. Local health boards and local authorities must collect information on autism services at a local level to support the population needs assessment. This will include compliance with any Welsh Government data collection requirements which are in place:

- i. regional partnership boards should ensure compliance with national data collection and reporting requirements
- ii. local health boards and local authorities must ensure compliance with national data collection and reporting requirements.

4. Monitoring and service improvement for autism

Regional partnership boards, local health boards and local authorities must collect information on the extent to which individual outcomes are improved and the quality of services provided for autistic people and their family or carers. Regional partnership boards should:

- i. identify a board member to lead on autism monitoring and service improvement
- ii. discuss autism services at least annually to ensure area plans are being achieved
- iii. have operational steering groups which include and represent autistic people and can inform service improvement which meet quarterly
- iv. have strategic autism steering groups; members must be of sufficient seniority to inform service development
- v. ensure that autism pathways are reviewed and audited annually and confirm they remain fit for purpose
- vi. ensure changes to autism pathways must be promptly communicated to practitioners
- vii. ensure that service improvements align with the Welsh Government autism strategic action plan.

5. Autism stakeholder involvement

It is essential that autism services are planned, delivered and monitored in collaboration and are co-produced with autistic people, carers and their representatives. This should ensure that services receive regular feedback on their quality and effectiveness and can identify where there may be gaps in support which need to be addressed.

- i. Regional partnership boards, local authorities and local health boards must ensure autistic people and their parents and carers have the opportunity to be involved in the development and monitoring of autism services

- ii. autistic people their families and/or carers must be included in the membership of regional partnership board autism groups.

6. *Regional autism champion role*

It is important the needs of autistic people and family or carers are reflected in population assessments, areas plans and the development of future services. This must be supported by establishing a regional autism champion role. The autism champion should:

- i. attend regional partnership board meetings and report on the development of autism services in the region
- ii. have a role within the governance structure of the regional partnership board to ensure that there is effective scrutiny of autism services
- iii. ensure that stakeholders can take an active role in service development and delivery
- iv. be involved in the annual review of the area plan and must report to the board at least annually
- v. work alongside local authority and health ASD leads.

Draft Duties: Arrangements for Planning and Monitoring Services and Stakeholder Engagement

Local Health boards with Local Authorities must jointly

- Ensure an autism champion role is appointed in each regional partnership board area and is included in the governance structure of the board.
- Ensure a board member at a sufficiently senior level is identified to represent the needs of autistic people.
- 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.
- Develop strategic and operational teams which include autistic people to inform service development.

Local health boards and local authorities must

- Ensure compliance with Welsh Government data collection and monitoring requirements.

Glossary of Terms

Term	Meaning
Assessment	A meeting or meetings with a health or social care professional in which they ask questions about a person's mental and physical health, their family background and everyday life, to establish what the condition or problem is, how severe it is and what care or support would suit them best.
Assessment Pathways	A multidisciplinary tool which details the different tasks or interventions to be taken by professionals involved in patient care to optimise outcomes and support. This will ensure that the person's neurodevelopmental needs and those of their family/carers are met.
Autistic Spectrum Condition	This is a definition developed and lifted from many different sources. It is an example for consultation and comments are welcome. Feedback during the initial engagement and technical groups indicated that some words in the WHO definition were negative and autistic people and their families/carers felt strongly that autism isn't a disorder but a condition.
Available information for assessment	Educational reports, psychological reports, GP reports, parent /carer observations, the individual's perspective.
Care and Support Plans	A care and support plan is a written document which sets out what has been discussed with you during your assessment and what is going to happen as a result.
Carer's assessment	A carer is defined in the Social Services and Wellbeing (Wales) Act 2014 as a person who provides or intends to provide care for an adult or a disabled child. A carer's needs assessment is a legal entitlement and is available for all carers who, regardless of their age, care for someone who is disabled, ill or elderly. The assessment is carried out by the carer's Local Authority. The Local Authority will assess the carer's needs to see what support or services may be needed to help carry out their caring role.

Children and Adult Services	The age at which a child is treated like an adult differs depending on which legislation is being considered. For the purpose of the Code transition from child to adult will be at 18 years.
Co-production	A way of working whereby practitioners and people work together as equal partners to plan and deliver care and support.
Eligibility	Being allowed to do or receive something because you satisfy certain conditions.
Health passport	Is designed to help autistic patients to communicate their needs to doctors, nurses and other healthcare professionals. When attending for a health appointment or when admitted to hospital for treatment arrangements should be made for the passport to be brought with the patient and given to the practitioner responsible for the patients care. The passport should be kept with the patients notes at all times. https://www.autism.org.uk/about/health/hospital-passport.aspx
Information and Support	Please see Support below. This can be physical information such as leaflets, books and publications as well as virtual sources such as signposting to websites.
Lifespan services	Cradle to grave health and care services.
Local Health Boards	Local Health Boards are responsible within their area for planning, funding and delivering of: <ul style="list-style-type: none"> • Primary care services - GPs, pharmacies, dentists and optometrists • Hospital services for inpatients and outpatients • Community services, including those provided through community health centres and mental health services.
Multidisciplinary	A range of health and social workers who are members of different disciplines jointly providing specific services to an individual.
NICE (The National Institute for Health and Care Excellence)	NICE produce evidence-based recommendations developed by independent committees, including professionals and lay

	members, and consulted on by stakeholders.
Pathway	A pathway is a tool used across health and social care in order to map out health, care and support journeys, where the different steps an individual can expect to pass through are defined and sequenced.
Personal outcomes	In relation to an adult, means the outcomes that the adult wishes to achieve in day to day life; In relation to a child, means— <ul style="list-style-type: none"> (i) the outcomes that the child wishes to achieve; or (ii) the outcomes that any persons with parental responsibility wish to achieve in relation to the child.
Personal Profiles	The aim of a personal profile is to give the most detailed current picture of an individual's strengths and weaknesses. From this information reasonable adjustments can be made to facilitate improved service experiences for the individual.
Practitioners	Individuals supporting autistic people.
Preventative services	These are services which may be provided under the Social Services and Wellbeing (Wales) Act 2014 which will, for example, meet the following purposes: <ul style="list-style-type: none"> • Contribute towards preventing or delaying the development of people's needs for care and support; • Reduce the needs for care and support of people who have such needs; • Promote the upbringing of children by their families, where that is consistent with the well-being of children; • Minimise the effect on disabled people of their disabilities; • Contribute towards preventing people from suffering abuse or neglect.
Primary Care Services	These include GPs along with pharmacy, dentistry, and optometry. They also co-ordinate access for people to the wide range of services

	<p>in the local community to help meet their health and wellbeing needs.</p> <p>These community services include community and district nurses, midwives, health visitors, mental health teams, health promotion teams, physiotherapists, occupational therapists, podiatrists, phlebotomists, paramedics, social services, other local authority staff and all those people working and volunteering in voluntary organisations which support people in our communities.</p>
Quality and Impact	<p>Children and Adult services must expect performance to be monitored. The quality and impact of the services received should be recorded using a nationally recognised series of parameters to record this.</p>
Reciprocal Social and Communication skills	<p>The struggle with mutual (reciprocal) social interactions and conversations. Difficulties including dominating a conversation and speaking at length about one's interests or responding to questions with short, specific answers without elaborating. The person may have difficulty asking relevant questions to gain information about others and exhibit difficulty with attending to, recognizing, and interpreting the social intentions and emotional states of others</p>
Referrers	<p>Anyone with the ability to refer an individual for assessment, such as GP's, Paediatricians, Health Visitors, Social workers, school nurses teachers, nursery / pre-school staff, emergency personnel and in some instances parents / carers or self-referral.</p>
Regional Partnership Boards	<p>The SSWBW Act established seven Regional Partnership Boards. These boards bring together health, local authorities, 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. Co-production is a key principle in the SSWBW Act and Regional Partnership Boards are required to</p>

	work with people to develop and deliver integrated services.
Secure Estate	The secure estate includes prisons, approved premises, bail accommodation and youth detention accommodation.
Secondary health care	Health care provided by hospitals. Testing, diagnostics and treatment usually overseen by a specialist.
Service provider	The local authority or NHS body which is responsible for providing care and / or support to an individual.
Signs and Symptoms	Are a combination of delay in expected features of development and the presence of unusual features, and are intended to alert professionals to the possibility of autism in a child, young person or adult about whom concerns have been raised. They are not intended to be used alone, but to help professionals recognise a pattern of impairments in reciprocal social and communication skills, together with unusual restricted and repetitive behaviours.
Single Point of Access	The service offers a first point of contact with the care and support system. Through signposting and referring, Information Advice and Assistance workers are able to provide individuals with choices about the support and services available in their locality, giving them an opportunity to talk through the options and be advised on what is most likely to meet their particular care and support needs, as well as discussing what resources the individual themselves have available to secure this support. The service is open to everyone, whatever their circumstances.
Support	Autistic people vary greatly in their support needs. Adults awaiting an autism diagnosis will be able to get advice and support from Adult Autism Services without needing to be referred by someone else. Section 2 of the Code of Practice provide details on Care and Support.
Tertiary health care	Specialist health care including NHS Trusts.

Transition	Often there will be a movement from children to adult or from secure to community services depending on the age and situation of the individual. These services must work alongside each other and the pathways must be aligned as much as possible.
The 2014 Act	The Social Services and Well-being (Wales) Act 2014.
The 2006 Act	The National Health Service (Wales) Act 2006
The 2010 Act	The Equality Act 2010