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Llywodraeth Cymru
Welsh Government

Welsh Government
Consultation Document

Supporting Guidance Document

Code of Practice on the Delivery of Autism Services Supporting Guidance Document

Date of issue: 21 September 2020
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	**Large print, Braille and alternative language, easy read versions of this document are available on request.**
For any queries please contact	Autism Policy Team Partnership and Integration Division Social Services and Integration Directorate Welsh Government Cathays Park Cardiff CF10 3NQ E-mail: Autism.CodeofPracticeConsultation@gov.wales

General Data Protection Regulation (GDPR)

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.

You should also be aware of our responsibilities under Freedom of Information legislation If your details are published as part of the consultation response then these published reports will be retained indefinitely. Any of your data held otherwise by Welsh Government will be kept for no more than three years.

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Data Protection Officer:
Welsh Government
Cathays Park
CARDIFF
CF10 3NQ
E-mail:
Data.ProtectionOfficer@gov.wales

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/

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About this Guidance

This guidance is issued by the Welsh Ministers to assist in the interpretation of the Code of Practice on the Delivery of Autism Services in Wales (the Code), prepared under section 145 of the Social Services and Well – Being (Wales) Act 2014 and sections 1 and 2 of the NHS (Wales) Act 2006. Both the Code and this guidance will apply from September 2021.

This guidance will support the implementation of Welsh Government's autism policy priorities, currently published in the Autistic Spectrum Disorder Strategic Action Plan 2016. It will provide local authorities and local health bodies with information on the level and range of 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 accompanies this Act will apply;
- where autistic individuals have health needs under the NHS (Wales) Act 2006, the relevant guidance which accompanies this Act will apply.

This guidance sets out:

- how providers of services should comply with the requirements imposed by the Code and;
- how practitioner and individuals should comply with the requirements imposed by the Code.

This guidance has been produced with the engagement of autistic people, their representatives, health and local authority stakeholders, third sector organisations and Welsh Government departments. It covers services providing health or social care and support to autistic individuals of different ages and with different aspirations and needs. It is detailed in part to ensure that autistic individuals, particularly those who are more vulnerable, receive the right care to promote their well-being and safety.

Enforcement

The Code of Practice is prepared under section 145 of the Social Services and Well – Being (Wales) Act 2014 and sections 1 and 2 of the NHS (Wales) Act 2006.

The Code of Practice gives rules and advice about the best ways of working when providing services for autistic people. It explains how to follow the:

- NHS Wales Act 2006;
- Social Services and Well Being (Wales) Act (2014) and the relevant guidance and Codes of Practice which accompanies this Act;
- Equality Act 2010.

Further details of the enforcement mechanisms to ensure successful implementation of the Code can be found in section 4 which relates to Monitoring of Services.

Background and Context

Terminology

Throughout the guidance, as in the strategy, the term “autism” is used as an umbrella term for all autistic spectrum conditions. Many autistic people also have related hidden impairments such as attention deficit hyperactivity disorder, dyspraxia, dyslexia, dyscalculia and language impairments as well as associated mental health conditions and linked impairments.

This guidance 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”.

Autistic Spectrum Disorder (ASD) Strategic Action Plan

The 2008 ASD Strategic Action Plan was updated in November 2016, and was accompanied by a delivery plan setting out the actions the Welsh Government and partners are taking to improve autism services in Wales. The progress is reported in an annual report which is published on the Welsh Government website

Children and Young People Neurodevelopmental Services

There are children and young people’s neurodevelopmental assessment and diagnosis services in each health board. There is a nationally agreed pathway, which has been agreed by all seven regions.

Improvements for neurodevelopmental services for children and young people are being progressed as part of the Together for Children and Young people Programme 2 (T4CYP2). This programme is improving assessment and diagnostic services for all neurodevelopmental conditions and services are linked at local level to ensure that there is a strong relationship with the Integrated Autism Service (IAS). We are seeking ways to achieve closer join up between this service and the IAS in the longer term.

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 autistic learners, 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, NHS Trusts 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.

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. These duties are re-enforced through the SSWBW Act and NHS Act.

United Nations Principles and Conventions and Covenants

This Code 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

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[1]. 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's

1 National Autistic Society 'Gender and Autism. https://www.autism.org.uk/about/what-is/gender.aspx accessed 29 October 2018

presentation of autism may be more subtle making it more difficult to diagnose. 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 to sustain social relationships but in reality experience exhaustion when trying to adapt their own behaviour to mirror that of others and what is seen as more acceptable. Additionally, there are significant life milestones where women may require more individual support such as, during puberty and pregnancy.

Gender Identity

There is increasing literature linking autism with gender identity/dysphoria, with a higher incidence of autistic people reporting a psychological identify 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 Group2 to provide advice. The Welsh Gender Team is be based in St David's Hospital in Cardiff3.

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*)[4] 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 autistic people are perceived and supported and adapt their practice to recognise these differences.

Welsh Language Services

Local health boards, NHS trusts and local authorities should make sure Welsh language services are built into planning and delivery and that Welsh language services are offered to autistic Welsh speakers without them having to request it. The Welsh Government has established a Strategic Framework for Welsh Language Services in

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2 http://www.genderidentity.wales.nhs.uk/all-wales-gender-identity-group
3 http://www.cardiffandvaleuhb.wales.nhs.uk/wgs
4 The National Autistic Society (2014) Diverse perspectives: The challenges for families affected by autism from Black, Asian and Minority Ethnic communities (2014)

Health, Social Services and Social Care (*More than just words*)5. Practitioners need to acknowledge that children may have Welsh as a first language and this will impact on assessment outcomes undertaken through the medium of English.

Complaints

This Code of Practice sets out the Welsh Government's expectations about the planning and delivery of autism services by local authorities and health bodies in Wales. There may be occasions where individuals may disagree with decisions made about the range of services available in their local areas.

When disagreements arise, individuals should first raise their concerns directly with the local authority or health body at a local level, if agreements cannot be reached quickly, there will be formal complaints procedures in each organisation. Each authority are required to publish information about their complaints process, this should be available on each organisation's website.

Enforcement of the Code

At a national level, where the Welsh Government has serious concerns about an organisation's ability to meet the requirements in the Code, there are built in mechanisms within the SSWBW Act for intervention and enforcement. 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.

5 Welsh Government (2016) Strategic Framework for Welsh Language Services in Health, Social Services and Social Care (*More than just words)*
http://wales.gov.uk/topics/health/publications/health/guidance/words/?lang=en

SECTION 1: Arrangements for Autism Assessment and Diagnosis

This section describes the arrangements for:

1.1 Identification
1.2 Referral to Autism Assessment Services
1.3 Assessment and Diagnosis pathways for Autism
1.4 Autism assessment and diagnosis services
1.5 Autism assessment and diagnosis process
1.6 Support following an autism diagnosis

Section 1.1 Identification

Autism Spectrum Condition (ASC) is a developmental disability that affects the way people communicate, behave, or interact with others. Some people may have very noticeable characteristics others may not. The common thread is differences in social skills, communication, and behavior compared with people who are not on the spectrum. In females the presentation can be very subtle which makes it harder to spot the signs as females can become competent at camouflaging symptoms and masking it from friends, family and especially health professionals.

A diagnosis can be an important step in ensuring that support takes account of how a person's autism affects them and their family, as well as their participation in learning, employment or other activities. Some people with suspected autism may not need further support. However, this does not mean that they should not have access to a diagnosis. For some people, simply having a diagnosis of autism confirmed can be incredibly important, and can help them avoid needing more intensive support at a later stage for example, if they hit a crisis point.

All staff working directly with children, young people or adults should undertake awareness training. Understanding possible identification signs can help in facilitating referrals for diagnosis. Adults, parents / carers who have significant concerns which meet the signs can also make referrals. Signs can include but are not restricted to:

Young children

- Delays in reaching developmental milestones
- Saying the same word repetitively
- Not responding to their name
- Not mimicking expressions and gestures
- Repetitive behaviour such as flapping hands or rocking.

Older children

- Not making eye contact
- Finding it hard to make friends
- Being happy to play alone for long periods of time

- Not sharing interest or enjoyment with others
- Difficulty understanding other people's emotions
- Being upset by minor changes
- Focusing on or becoming obsessed by certain subjects, objects or activities
- Unexpected reactions to sounds, tastes, sights, touch and smells.

Research conducted by the Cardiff University has led to the creation of SIGNS – a way for frontline professionals to identify and understand the different behaviours in autistic children.

S = Social Interaction and verbal communication are impaired
I = Imagination, ideas and creativity are reduced
G = Gestures or non-verbal communication are limited
N = Narrow range of interests, routines and repetitive behaviours
S = Sensory responses are unusual
https://sites.cardiff.ac.uk/warc/signs-and-diagnosis/signs/

Adults

Indications for autism in adults:

- Difficulties making and/or maintaining social relationships
- Difficulties understanding and managing emotions
- Getting anxious about social situations
- Unusual speech, perhaps using formal language or flat intonation
- Finding it hard to make small talk and hold conversations
- Avoiding eye contact
- Reduced facial expression or gesturing
- Highly focused or all-encompassing interests or obsessions with certain topics
- Preference for routines and rules
- Noticing small details, patterns or sounds that other people do not notice
- Problems sustaining education or employment.

Case Study

a. My son was 20 months old and meeting all his developmental milestones. After a hospital admission for an unknown virus I noticed some significant changes such as loss of language, regression in physical ability and lack of eye contact when playing. I spoke with my health visitor, who undertook developmental checks, observed my son and gathered information from family. He was referred to the first point of contact in the neurodevelopmental team. He was then assessed by a multidisciplinary team – paediatrician, speech and language, occupational therapist and educational psychologist. He received an autism diagnosis at 2 years and 6 months.

Case Study

b. I often suspected I might have autistic traits but dismissed it as I was able to function well at times. However, after some difficult experiences and struggles with anxiety, especially at work, I reluctantly entered the mental health system and had a working diagnosis of bipolar disorder. But this didn't really fit and after another meltdown that I couldn't attribute to whether a "high" or a "low" and having watched some documentaries about autism that I related to strongly I decided to mention to the mental health team that I thought I might be autistic.

Initially the psychiatrist disagreed with my assessment and was reluctant to make a referral. He mentioned that my difficulties could be due to another psychiatric disorder that I though was an even worse fit than bipolar. I was very persistent and the referral to the IAS was made. After a wait, I was assessed and diagnosed as autistic at the age of 40. Then the long process of coming to terms with it and reassessing my whole life through this new lens began.

Further information and support can be found:

https://pathways.nice.org.uk/pathways/autism-spectrum-disorder
www.nice.org.uk/guidance/cg128/chapter/1-Guidance#recognising-children-and-young-people-with-possible-autism]
https://www.asdinfowales.co.uk/resource/autism_do_you_know_the_signs-a4.pdf

Section 1.2 Referral to Autism Assessment Services

An autism referral pathway is a series of actions or steps taken after identifying a person has the potential for an autism diagnosis. There are national referral pathways available which are based on NICE best practice guidelines. These are intended to ensure that the individual is seen by the right people at the right time. Referrals to assessment and diagnostic services can be made through various routes.

Child

For preschool children; referrals can be made via the Pre-school Pathway by:

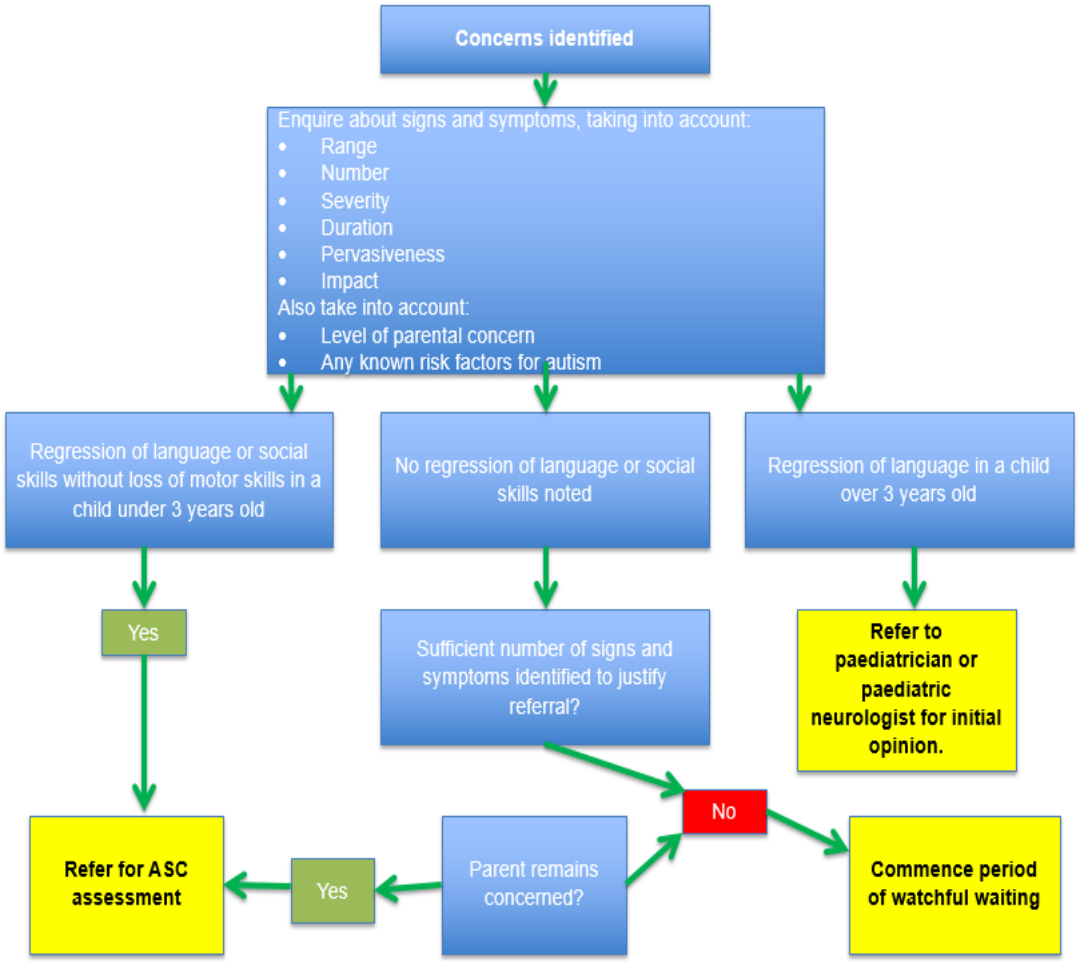
- Health Visitor,
- GP,
- Therapist, or
- Paediatrician and directed to the Community Paediatrician.

For children who are attending school (including nursery pupils) the referral should be made via the:

- School-age Assessment Pathway
- Self-referral for older children or by parents for younger children - neurodevelopmental teams state that they accept self-referrals. However they are keen to highlight that these referrals are considered on a case to case basis because collating the information is difficult for individuals and accessing some records for individuals is onerous and time consuming.

Example:

Referral process for children



Adults

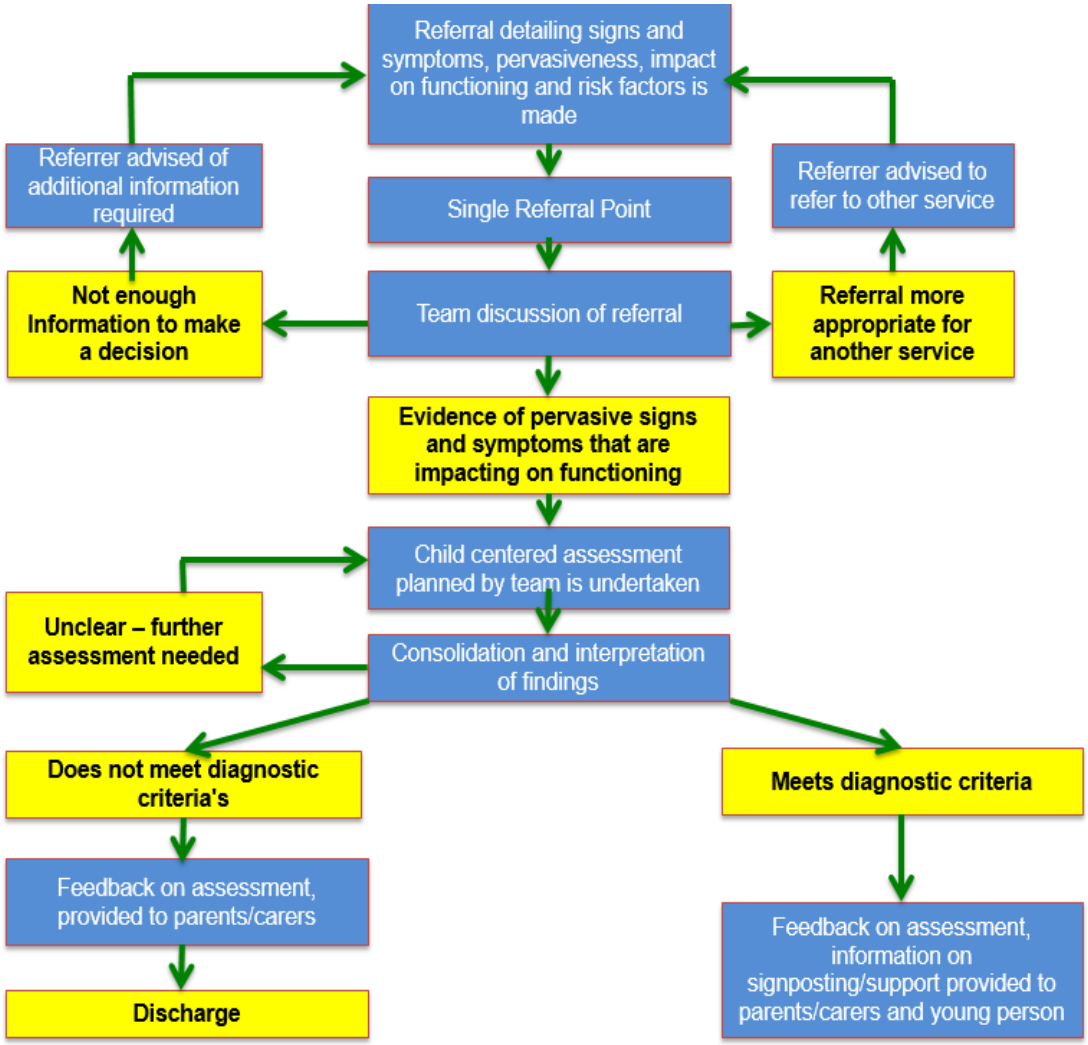
- GPs,
- medical practitioners for other conditions already been diagnoses and receiving treatment,
- social care teams,
- self-referral to Integrated Autism Service.

It is important that as much relevant information is captured in the referral to ensure informed decisions can be made in a timely manner. Decisions to accept for assessment are based on the provision of clear relevant information.

Example:

Child Referral Pathway

Parental / guardians consent must be obtained prior to referrals being made.



Referrals for **children** should include information on:

- schools or playgroups attending
- any current medication / diagnosed medical conditions /investigations
- method of communication – verbal, non-verbal

- any agencies already involved - flying start
- any health risk associated to the family
- areas of difficulty;
    - achieving milestones
    - feeding / swallowing
    - attention / listening
    - interaction /play
    - understanding / using spoken language / speech sounds
    - sitting unaided / upset when moved
    - respiratory complications / reoccurring chest infections
    - equipment needed
    - sensory difficulties – food intolerance, taste and textures, noise, touch, movement
    - motor skills – handwriting, cutlery
    - gross motor skills – hopping, skipping, crawling, balancing, jumping
    - perceptual skills – spatial body awareness, knowing left and right, up and down, back and front
    - activities of daily living – independent dressing, undressing, eating, toileting
    - any assessments.

Young adults

Young adults may need a combination of adult/child approaches which may be facilitated by the IAS. This is agreed locally in each region between the IAS and neurodevelopmental services.

Adults

- social interaction and verbal communication – use/understanding of language, lack of interest in social interaction, difficulty with social communication, relationships, friendships, awareness/response to others' feelings
- imagination, ideas and creativity – lack of pretend play as a child, solitary imaginary activities, lack of generating or sharing of creative ideas, inability to see consequences of actions, expectations, intention of others
- gestures and non-verbal communication - infrequent use of pointing to objects, gestures that lack spontaneity or appropriateness, particularly gestures expressing emotion, facial expression, tone of voice, eye contact, body language, proximity
- narrow range of interests, routines and repetitive behaviours – arranging objects in patterns, repetitive motor behaviours (hand flapping, spinning), repetitive routines/rituals, over-focused interests
- sensory responses – sensitivity or avoidance of particular sensations (sight sounds, touch, smell or taste) unusual seeking out of sensory sensations, reduced sensory reaction to pain or temperature
- problems with employment, relationships,
- history of neurodevelopmental, mental health
- known to other services – social care
- family history of ASC.

Example:

In some areas young people over the age of 16 or parents can complete the referral and send it in. Support is offered to the young person and the parent in this position, by phone or email. They are encouraged to get support from others that know them well because the neurodevelopment team will need information that they may not have already, e.g. school reports, GP, professional recommendation. Young people would also be encouraged to involve their parents in the process, if they hadn't already discussed this with them.

Self referral to the adult **IAS** service should include;

- information from any professionals already involved
- information from any services already involved
- what would a diagnosis mean to the individual
- development history
- social interaction – relationships, managing emotions, understanding others' emotions, understanding social norms
- communication – unusual speech, repetitive speech, unusual eye contact, difficulty understanding (taking things literally)
- repetitive / restricted behaviour – highly focused on interests, resistance to change, inflexible thinking, repetitive behaviour or rituals, adherence to rules
- sensory difficulties – textures, foods, tastes, smells, noise, temperature regulation, distressed with sensory stimuli
- employment difficulties – sustaining jobs
- any familial risks to autism.

Further information and support can be found:

http://www.1000livesplus.wales.nhs.uk/sitesplus/documents/1011/t4cyp+nd+pathway+pdf+final.pdf
https://pathways.nice.org.uk/pathways/autism-spectrum-disorder
https://www.autism.org.uk/about/strategy/2010-strategy/diagnostic-pathways.aspx
https://asdinfowales.co.uk/managing-referrals
http://www.rcgp.org.uk/clinical-and research/toolkits/asd-toolkit.aspx
www.ASDinfoWales.co.uk/recognise-ASD-adult

Section 1.3 Assessment and Diagnosis pathways for Autism
When a referral has been made and the individual accepted for assessment the individual must be made aware of the process and journey for assessment. NICE guidelines set out clear expectations on how local services should be configured and pathways developed. https://pathways.nice.org.uk/ Each region in Wales should have a designated lead role **(see s.4.6 and 4.7)** to ensure that national and local pathways are maintained and developed in partnership with autistic people, their families or carers, to maintain consistent standards and to promote further improvement. This will ensure that a child, young person's or adult's autism needs and those of their family/carers are central to the pathway. **Role of the Local Authority Autism Lead Officer** The first autism strategic action plan published in 2008 created a local authority infrastructure, supported by Welsh Government funding which is now included in local authorities overall annual revenue support grant. This infrastructure has supported the delivery of local action identified within the Strategic Action Plan. Each of the 22 Welsh local authority areas has in place an autism Local Action Plan which is developed, implemented and reviewed by a local stakeholder group. In addition each local authority has in place an ASD Lead Officer. The ASD Lead Officer's role is central to the delivery of autism services at a local level by bringing together professionals to work collaboratively in local authority areas as well as providing a local point of contact for both autistic individuals and families/carers seeking support. The ASD Lead Officers work through a network which meets regularly throughout the year promoting collaboration and sharing good practice between services. The network is supported by the National Autism Team NICE suggest that no patient should have to wait longer than **three months** between a referral for diagnosis and first appointment. Welsh Government, although adhering to the standards of NICE guidance have currently set the waiting time policy at **26 weeks** for children. There is currently no waiting time policy for adults in Wales. Timescales for childrens neurodevelopment referrals are monitored by Welsh Government via the NHS Wales Informatics Service (NWIS). Outcomes from referrals for adult assessments are being monitored by Welsh Government via the Integrated Autism Service (IAS). **Private diagnosis** Private assessments will be accepted as long as it is agreed by the accepting NHS neurodevelopmental team that NICE guidelines/All Wales standards have been met and that the assessment is of a high enough quality. **Section 1.4** describes the assessment and diagnosis process in more detail.

Further information and support can be found:

https://pathways.nice.org.uk/pathways/autism-spectrum-disorder
asdinfowales.co.uk

Section 1.4 Autism assessment and diagnosis services

In order to receive a diagnosis of autism, individuals need to be assessed by a multi-disciplinary team of practitioners with specialist training in assessing for autism. NICE guidance is clear that there should be integrated teams with age appropriate expertise in every area and that a partnership board or local planning group should oversee the work of the team.

Example:

Children and young people

The core staff of the autism team for children and young people should include:

- paediatricians and/or child and adolescent psychiatrists
- speech and language therapists
- clinical and/or educational psychologists.

The autism team should either include or have regular access to:

- paediatricians or paediatric neurologists
- child and adolescent psychiatrists
- clinical and educational psychologists
- occupational therapists
- other professionals who may assist with the assessment, for example specialist health visitors or nurses, specialist teachers or social workers.

Adults

A local adult autism team should include:

- clinical psychologists
- primary care services
- nurses
- occupational therapists
- psychiatrists
- social workers
- speech and language therapists

support staff (for example, to support access to housing, educational and employment services, financial advice, and personal and community safety skills).

It is important that all assessments are holistic and look at **needs** rather than **diagnosis**. This means looking at an individual in the context of health **and** social care to evaluate the physical, emotional, mental health, spiritual, environmental, social, sexual, financial, and cultural needs. This reinforces the expectation that teams are multidisciplinary and multiagency.

Child

If the referral describes regression in language in a child over 3 **or** regression in motor skills at any age, the referral should be seen by a paediatrician or paediatric neurologist for an initial opinion. They can then refer back to the autism team if necessary.

If the referral describes regression in language in a child under 3, an autism assessment should be undertaken.

If neither of above apply, then take into account the following when deciding whether to assess for ASC:

- the severity and duration of the signs and/or symptoms
- the extent to which the signs and/or symptoms are present across different settings (for example, home and school)
- the impact of the signs and/or symptoms on the child or young person and on their family or carer
- the level of parental or carer concern, and if appropriate the concerns of the child or young person
- factors associated with an increased prevalence of autism
- the likelihood of an alternative diagnosis.

If there is insufficient information to make a decision, seek further information from the referrer or other healthcare professionals.

If the referral is accepted, and if the parents/carers consent, also seek additional information from school/college as well as any other involved health or social care professionals. This should include results from any vision or hearing assessments.

Consider carrying out home or school observations of the child, or alternatively obtaining video recordings of home or school.

Adults

For a diagnosis of autism to be made a person needs to have significant difficulties in:

- social interaction & communication **and** restricted and repetitive behaviours, interests or activities – see table below for examples of the kinds of difficulties people may experience.
- These difficulties have to be **lifelong.** This means that they will have started in childhood.
- These difficulties need to be having an impact on **multiple** aspects of the individuals life (not just creating problems in one situation).

When a referral is accepted, a case coordinator must be appointed and the team must aim to begin diagnostic assessment as soon as possible. If the child or their family have identified support needs, do not wait for diagnosis in order to put in place support. The role of the case coordinator should be to:

- act as a single point of contact for the individual, parents or carers through whom they can communicate with the rest of the autism team
- keep individuals, parents or carers up-to-date about the likely time and sequence of assessments
- arrange the provision of information and support as directed by the autism team
- gather information relevant to the autism diagnostic assessment.

It is important that all practitioners avoid repeated information gathering and assessments by ensuring effective and efficient communication between services.

Further information and support can be found:

www.nice.org.uk/guidance/cg128/chapter/1-Guidance#recognising-children-and-young-people-with-possible-autism

Section 1.5 Autism assessment and diagnosis process

Whilst the assessment and diagnosis process is being undertaken individuals and their families/carers should be able to obtain support from:

- GP's or social prescribers attached to the GP practice offering information regarding local support groups
- referrers offering information regarding the Autism Wales website
- referrers offering information regarding the National Autistic Society services directory
- where applicable parents talking to teachers or special educational needs (SENCO) staff at the child's school
- individuals speaking to student support services at college or university (where applicable)
- individuals speaking to a manager or human resources at work
- requesting a needs assessment from the local authority to see what support they can offer during the process which may include Advocacy services.

For children health boards should offer early support for parents during this referral / assessment period and should be linked to the first 1000 days Public Health Wales programme in the context of the Wellbeing of Future Generations (Wales) Act 2015. This requires key public bodies to make decisions that take into account the impact they could have on future generations living in Wales. They must ensure that they think more about the long term, work better with people and communities and each other, look to prevent problems and take a more joined-up approach.

The assessment process

Children and young people

The following should be included in every autism diagnostic assessment for children and young people:

- Detailed questions about parents or carers' concerns and, if appropriate, the child or young person's concerns.
- Details of the child or young person's experiences of home life, education and social care.
- A developmental history, focusing on developmental and behavioural features consistent with the International Statistical Classification of Diseases and Related Health Problems (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5) criteria (consider using an autism-specific tool to gather this information).
- Assessment (by interacting with and observing the child or young person) of social and communication skills and repetitive and stereotyped behaviours, including sensory sensitivities, focusing on features consistent with the ICD-10 or DSM-5 criteria (consider using an autism-specific tool to gather this information).
- A medical history, including prenatal, perinatal and family history, and past and current health conditions.
- A physical examination.
- Consideration of the differential diagnoses (see NICE clinical guideline 128, recommendation 1.5.7).
- Systematic assessment for conditions that may coexist with autism (see NICE clinical guideline 128, recommendation 1.5.15).
- Developing a profile of the child or young person's strengths, skills, impairments and needs, including: intellectual ability and learning style, academic skills, speech, language and communication, fine and gross motor skills, adaptive behaviour (including self-help skills), mental and emotional health (including self-esteem), physical health and nutrition, sensory sensitivities, and behaviour likely to affect day-to-day functioning and social participation.
- The profile should be used to create a personalised plan, taking into account family and educational context. The assessment findings should be communicated to the parent or carer and, if appropriate, the child or young person.

Example:

Individual Profile

A profile for the child or young person, should include the following topics:

- intellectual ability and learning style
- academic skills
- speech, language and communication+
- fine and gross motor skills
- adaptive behaviour (including self-help skills)
- mental and emotional health (including self-esteem)

- physical health and nutrition
- sensory sensitivities
- behaviour likely to affect day-to-day functioning and social participation
- socialisation skills.

Adults

During a comprehensive diagnostic assessment, enquire about and assess:

- core autism signs and symptoms (difficulties in social interaction and communication, stereotypic behaviour, resistance to change or restricted interests, and also strengths) that were present in childhood and have continued into adulthood
- early developmental history, if possible
- behavioural problems
- functioning at home and in the community (for example, in education or in employment)
- past and current physical and mental health problems
- other neurodevelopmental conditions
- hyper- and hypo-sensory sensitivities.
- Carry out direct observation of core autism signs and symptoms, especially in social situations.
- Include observation of risk behaviours and safeguarding issues.

Carers Assessments

Many carers find it easier to continue in their caring role if they can get some support. Local councils can provide care and support for people who require care and their carers.

Carers assessments should be included in the assessment of an individual who has identified needs.

Section 1.6 Support following an autism diagnosis

Post diagnostic support for parents of children should be provided by neurodevelopmental health services and the IAS for adults, parents of children, carers and professionals. Local authorities, local health boards and Regional Partnership Boards need to ensure they support local initiatives and local partnerships to maintain the level of support required in their areas.

The autism team and the case coordinator should meet with the individual, family and/or carer as soon as possible after the assessment to explain the outcome of the assessment. They should supply a written report saying what they found in the assessment, and with consent send a copy to the GP. They should also send a copy to other adults involved in

the care and support of the individual, such as teacher or social worker. The team or the case co-ordinator should also:

- give information about what autism is and what it **might** mean for the individual, family or carer, now and in the future
- discuss plans for providing support for the autistic person and family
- offer information on local services
- arrange a follow up appointment. This should be within 6 weeks of the assessment ending but should be mutually agreed and led by the autistic person and their family/carer and not purely for the convenience of the service

If the outcome is the individual is **not** autistic, the team should explain how they reached this decision and discuss referral to other services that might help. Where possible childrens neurodevelopmental teams should endeavour to provide an alternative diagnosis (if it is apparent) as soon as possible. Where indicated, adults who have not received a diagnosis of autism should be referred for additional assessments. This should be without further unnecessary waiting.

If the individual, family or carer disagree with the outcome of the original assessment and the disagreement cannot be resolved through discussion with the Clinical Lead for the ND Service they can request a second opinion.
http://www.1000livesplus.wales.nhs.uk/sitesplus/documents/1011/2018-03-13%20Protocol%20for%20second%20opinion-re-%20assessment.pdf

Protocol for reassessment with children

- The ND Service Manager and/or Clinical Lead are notified and identify a named person to lead on the reassessment process
- the family must be notified in writing of the protocol for reassessment and who will conduct the reassessment and time frame
- the request is initially considered by a second opinion panel. This panel will be made up of several clinicians from across teams, but will not include anyone involved in the assessment being considered
- the ND Service Manager and Clinical Lead for the reassessment to liaise with clinician and family – this will provide the opportunity to explore what the family is concerned about in particular. It will also enable the opportunity to check that the feedback of the assessment outcome was conducted appropriately
- the panel will identify a Lead Clinician to conduct the reassessment/second opinion, who will be from a different team to the first assessment to maximise objectivity and will have support of the panel in making their decisions
- acceptance for reassessment/second opinion to be decided within 30 days of receipt of request
- panel reviews the file and any information relevant to the assessments. In some instances as Lead Clinician may be asked to view specific elements e.g. tapes of Autism Diagnostic Observation Schedule(ADOS)
- panel/Lead Clinician verifies that a sufficient assessment was conducted
- panel/Lead Clinician reviews the ADOS/ Autism Diagnostic Interview-Revised /other scoring based on information in the file

- Lead Clinician may meet with the family to clarify any information
- if there are any discrepancies in the overall conclusions, the Lead Clinician will coordinate a full reassessment
- if there are no discrepancies in the overall conclusions, then no further assessment will be offered unless the criteria for reassessment above are met
- Lead Clinician will meet with the family to explain their findings.

Information, advice and assistance

Local authorities are required to provide a bi-lingual Information, Advice and Assistance (IAA) service, to enable anyone to access relevant, clear information and advice about all of the services available in the area. Staff providing IAA services should have their autism training needs assessed and have access to training which meets these needs so they are able to assist autistic people and adapt their practice where required.

Local authority IAA services **must** include, as a minimum, the publication of information and advice on:

- how the care and support system operates with regard to autism services in the local authority area
- the types of care and support available for autistic people
- how to access the care and support that is available
- how to raise concerns about the well-being of a person who appears to have unmet care and support needs.

Local Health Boards, or NHS Trusts providing services for autistic people in the area of a local authority, **must** provide that local authority with information about the care and support it provides in the local authority's area. Other partner organisations, including third and independent sector organisations, and citizens of the local authority's area, including those in prison, youth detention and bail accommodation, will have an interest in its content and delivery and should be made aware of IAA service and have access to offering information or have equal rights to access the information.

Further information and support can be found:

www.ASDinfoWales.co.uk/practitioner-toolkit-support-and-interventions-for-adults-withasd

SECTION 2: Arrangements for Assessment and Diagnosis

This section will describe the arrangements for:

2.1 Accessing health and social care services
2.2 Advocacy
2.3 Preventative services
2.4 Eligibility and Intelligence Quotient (IQ)
2.5 Assessment for Local Authority care and support
2.6 Transition
2.7 Carer Assessment
2.8 Accessing health care
2.9 Support within secure estates
2.10 Mental health services for autistic children, young people and adults
2.11 Services for autistic people with co-occurring conditions

Section 2.1 Accessing health and social care services
NICE sets out clear expectations on how local services should be configured. Autism: recognition, referral, diagnosis and management of adults on the autism spectrum. Effective diagnostic and post diagnostic services must be developed in ways that achieve better health outcomes for autistic people. In order to avoid the duplication of assessments a local authority may carry out a number of needs assessment at the same time. In such cases, the local authority may carry out the assessment on behalf of or jointly with the health board. To help standardise and improve the care and management of autism, and to enable health and social services to support people with autism more effectively, NICE has published clinical guidelines on autism, which outlines the key actions that commissioners should take to deliver the quality improvements outlined in the NICE quality standards. • An Implementation Pack: Developing a multi-agency local autism team implementation pack – https://www.nice.org.uk/ guidance/cg128/resources/autism-developing-amultiagency-local-autism-team-implementationpack • Developing a multi-agency local autism team, to support local areas; • A series of costing tools; NICE guidelines [CG142]: Autism: recognition, referral, diagnosis and management of adults on the autism spectrum – costing tools and templates https://www.nice.org.uk/guidance/ cg142/costing • Support for Commissioning Autism: support for commissioning – http:// www.nice.org.uk/guidance/qs51/resources/qs51autism-support-for-commissioning **Organisation and delivery of care** • Pathways should be:

- negotiable, workable and understandable for adults with autism, their families, partners and carers, and professionals
- accessible and acceptable to all people in need of the services served by the pathway
- responsive to the needs of adults with autism and their families, partners and carers
- integrated so that there are no barriers to movement between different levels of the pathway
- outcome focused (including measures of quality, service user experience and harm).

- Health boards, NHS Trusts, local authorities and/or regional partnerships boards should:

  - ensure the provision of multi-agency training about signs and symptoms of autism, and training and support on the operation of any pathways
  - make sure the relevant professionals (health, social care, housing, educational and employment services and the third sector) are aware of the local autism pathways and how to access services
  - support the integrated delivery of services across all care settings
  - support the smooth transition to adult services for young people going through the pathways
  - audit and review the performance of the pathway.

- Pathways should promote access to services for all children and adults with autism, including:

  - people with coexisting physical and mental disorders (including substance misuse)
  - women
  - people with learning disabilities
  - older people
  - people from black and minority ethnic groups
  - transgender people
  - homeless people
  - people from the traveller community
  - people in the criminal justice system
  - parents with autism.

Information Advice and Assistance

The purpose of the service is to provide people with information and advice relating to care and support, including support for carers, and to provide **assistance** to them in **accessing** it.

Local Health Boards providing services within the area of the local authority are under a duty to facilitate the service by providing the local authority with information about the care and support that they provide

Where local authorities and Local Health Boards have a mutual interest in commissioning services, such as preventative autism services, they should work together to consider whether alternative not for profit business models will best meet the well-being needs of their autistic population. The Code of Practice on Part 2 of the SSWBW Act includes further advice on promoting social enterprises, co-operatives, user-led services and the third sector.

Case Study

a. Carmarthenshire County Council - Carmarthenshire Adult Autism Advice (CAAA) project

We developed a well-attended Social group for autistic young people who were not accessing other services and had become quite socially isolated. We met monthly either to go bowling, to laser zone, or the cinema, this has been running for nearly 6 years. The group has evolved over the years with some moving on and other new members joining. This group was run by our outreach workers and they used this group to increase the young people's confidence to attend other smaller offshoot groups such as a photography project, a gardening volunteering project and a healthy eating cooking course. We have worked together with the young people in the group and they have recently developed enough confidence to start to take over the group themselves. We have taken a co productive approach and held a number of meetings to plan how they would continue the group independently. The first bowling meeting was a success and they plan to continue to bowl but also to meet up to go to the cinema or some other social activities. We continue to support as and when needed but delighted that they were keen to take over!

Case Study:

b. Cam Nesa Autism project - Our support workers have supported many autistic young people on the project. For example, an autistic young person was in employment but had to leave their job due to ill health and was then not in education, employment or training.
Our service worked with the young person to build up their confidence and develop social skills by supporting the young person to be able to go out in the community, increase their independence, organisational skills and communicate with others. Our support worker supported them to attend a range of courses and achieve a first aid and cooking skills qualification. This increased their confidence and belief in themselves and they were able to add these qualifications to their CV. They have gained in confidence and developed their skills and gone on to gain a successful paid work placement provided by another project with our support worker supporting as and when needed.

Section 2.2 Advocacy

Despite the barriers individuals may be experiencing, local authorities must involve people to help them express their views, wishes and feelings, to support them to weigh up options and to make decisions about their well-being outcomes. These requirements apply irrespective of where an individual is living, including the secure estate. Effective advocacy should help promote independence in individuals and give a voice to the most vulnerable.

The Code of Practice in relation to Advocacy (Part 10 of the Act) sets out the requirements for access to advocacy services and support. In responding to the population assessment, Regional Partnership Boards will need to ensure they are able to respond to the advocacy requirements for all individuals including autistic people. The Code of Practice on Advocacy provides further advice on the key factors that impact upon individuals and their needs for specific support.

Local authorities **must** arrange for the provision of an independent professional advocate when an autistic person family/carer can only overcome any relevant barriers to participate fully in a social care assessment, care and support planning, review and safeguarding processes with assistance from an appropriate individual.

- Practitioners should be aware of what advocacy is and why it is important for autistic people to have choice and control
- The advocacy service must be trained to support autistic people
- Advocacy services must be monitored for outcomes.

Local authorities **must** consider people's needs for advocacy where a local authority exercises a specific function in relation to that person. Third sector organisations can often offer advocacy and support when an individual does not meet the critieria in statutory organisation and this should always be a consideration by practitioners when dealing with autistic people and their families/carers.

Further information and support can be found:
https://gov.wales/advocacy-services-code-practice
www.advocacymatterswales.co.uk
https://www.autism.org.uk/about/adult-life/advocacy.aspx
https://gov.wales/sites/default/files/publications/2019-05/part-10-code-of-practice-advocacy.pdf
http://peoplefirstltd.com/

Section 2.3 Preventative services

The purposes of preventative services include contributing towards preventing or delaying the development of people's needs for care and support and reducing the needs for care and support of people who have such needs. One of the other purposes is the promotion of the upbringing of children by their families, where this is consistent with the well-being of children.

Local authorities have to consider the importance of achieving these purposes when exercising their other functions. This means that it is the responsibility of the local authority **as a whole**, not just the social services department, to consider the kind of preventative services which could be provided.

In the same way, Local Health Boards (LHBs) also have to consider the importance of achieving these purposes when exercising their functions. This means that LHBs have to consider whether there are things they can provide or arrange under their existing functions which would achieve these purposes.

Both local authorities and local health boards must provide or arrange for the provision of a range and level of services. The purposes of these services are to:

(a) contribute towards preventing or delaying the development of people's needs for care and support
(b) reduce the needs for care and support of people who have such needs
(c) promote the upbringing of children by their families, where that is consistent with the well-being of the children
(d) minimise the effect on disabled people of their disabilities
(e) contribute towards preventing people from suffering abuse or neglect
(f) reducing the need for -

- proceedings for care or supervision orders under the Children Act 1989
- criminal proceedings against children
- any family or other proceedings in relation to children which might lead to them being placed in local authority care, or
- proceedings under the inherent jurisdiction of the High Court in relation to children

- encouraging children not to commit criminal offences
- avoiding the need for children to be placed in secure accommodation
- enabling people to live their lives as independently as possible.

Part 4 of SSWBW Act sets out how local authorities should go about fulfilling their responsibilities and achieve the aims of promoting wellbeing and independence and reducing dependency through preventative services both individually and in partnership with health, other local organisations, communities, and people themselves.

The local authority's responsibilities for prevention apply to all **adults**, including:

- people who do not have any current needs for care and support
- adults with needs for care and support, whether their needs are eligible and/or met by the local authority or not
- carers, including those who may be about to take on a caring role or who do not currently have any needs for support, and those with needs for support which may not be being met by the local authority or other organisation

Early intervention and prevention especially with **children** are intended to provide individualised, focussed support to reduce the need for services or avoid more intensive interventions at a later date.

Practitioners assessing the needs of autistic people their family or carers for preventative services **must** have received appropriate training and understand the core features of autism. It is important that conversations are documented to enable opportunities to take part in age-appropriate psychosocial interventions which will help address the core features of autism and reduce the need for more intensive services can be offered.

Where mainstream preventative services are being accessed such as health prevention/ promotion services, adaptations to accommodate individual autistic needs **must** be made.

Example:

Ensure the environment is quiet, times are scheduled and any changes relayed. Information on what to expect offered prior to the appointment. These adjustments should be made to routine appointments for instance:

Children

- immunization clinics
- health visitor appointments
- developmental assessments
- GP/ specialist appointment.

Adults

- cervical screeing
- breast screening
- mens health clinics.

Respite services to keep families together must be tailored to the needs of individual families i.e. overnight facilities, befriending families, direct payments.

Residential environments

Commissioners of residential care should ensure that care environments include activities that are:

- structured and purposeful for autistic people
- designed to promote integration with the local community and use of local amenities
- clearly timetabled with daily, weekly and sequential programmes that promote choice and autonomy.

Care environments should have:

- designated areas for different activities that provide visual cues about expected behaviour
- adaptations to the physical environment for people with hyper- and/or hypo-sensory sensitivities
- inside and outside spaces where the person with autism can be alone (for example, if they are over-stimulated).

Further information and support can be found:
https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance

Section 2.4 Eligibility and Intelligence Quotient (IQ)

IQ is not a good measure of functioning ability and services **must** not be based on a persons IQ. Additionally, it should not be replaced by diagnosis led assessments / services. A profile of differences, strengths and needs would be more helpful although, it does depend on the purpose (and age). IQ may be a useful tool to determine appropriateness of individual service provision, in these instances a cognitive assessment could be instrumental instead of an IQ assessment.

Part 3 s.63 of the SSWBW Act and its associated regulations introduce assessment and eligibility criteria based on a comprehensive 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; and
- assess and have regard to the person's strengths and capabilities.

For autistic **children** and their parents/carers eligibility for support should not be diagnosis based. If practitioners identify health or social care needs support should be

provided to enable and promote independent living and for the individual to reach their potential.

For autistic **adults** who are unable to access advice or support from statutory services due to eligibility exclusion, (and where the provision is not available elsewhere) the IAS will provide:

- diagnostic assessment
- post diagnostic information and support
- social learning programmes based on developing social interaction
- structured and predictable training programmes based on behavioural principles focussed on improving daily living skills
- support to access leisure activity programmes to reduce social isolation
- emotional awareness and regulation interventions, adjusted to the needs of autistic adults
- anti-victimisation interventions based on teaching decision-making and problem solving skills
- evidence based interventions for distressing behaviour based on behavioural principles
- access to National autism programmes which promote awareness and acceptance in the community, for autistic adults at a local level
- information, advice, training and support to family and carers of autistic adults.

Further information and support can be found:
http://www.nice.org.uk/guidance/cg142
www.ASDinfoWales.co.uk/practitioner-toolkit-support-and-interventions-for-adults-withasd

Section 2.5 Assessment for Local Authority care and Support
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 individuals, parents and carers. All practitioners undertaking assessments must be suitably skilled, trained and qualified in undertaking assessments. This requirement is set out in regulation 3 of the assessment regulations. Appropriate levels of qualification for undertaking these activities include: ○ **either** a registered social work or social care practitioner holding a professional qualification at level 5 or above ○ **or** a person holding a social care qualification at level 4 or above, which includes knowledge and skills undertaking person centred assessment, under the supervision of a registered social work or social care practitioner.

Additionally, to meet **suitably skilled** practitioners should have appropriate understanding and training in autism and related behaviour support.

Direct Payments

The purpose of direct payments is to give recipients control over their own life by providing an alternative to social care services provided by a local authority. A financial payment gives the autistic person flexibility to look beyond local authority service solutions for certain housing, employment, education and leisure activities as well as for personal assistance to meet their individual assessed needs. This will help increase opportunities for autistic people to be independent, have social inclusion and enhance their self-esteem. Local direct payment schemes can facilitate this by building links with health, housing, education and other agencies.

Local authorities have a duty to offer Direct Payments to all who are potentially eligible (under the regulations and the 2001 and 1989 Acts) to receive them. The eligible groups are:

- Adult disabled persons receiving community care services (that is, persons to whom section 29 of the National Assistance Act applies)
- Persons receiving carers services under section 2(1) of the Carers and Disabled Children Act 2000
- all people aged 65 or over in receipt of community care services.

The following persons receiving services under section 17 of the Children Act 1989:

- a person with parental responsibility for a disabled child
- a disabled person with parental responsibility for a child
- a disabled child aged 16 or 17

This means that local authorities can no longer choose to make direct payments available only to certain groups of disabled people nor can they make them available only for certain services.

Not all social care services are included in the direct payments legislation so wherever a person is assessed as needing social care services, the authority should check whether there is a duty to offer a direct payment in respect of that service. Legislation. https://gov.wales/sites/default/files/publications/2019-05/part-4-code-of-practice-meeting-needs.pdf

Continuing care packages

Services provided as part of the package for autistic children and young people with continuing care needs will be arranged by the local health boards, local authorities and their partners as appropriate, enabling the autistic child or young person to function optimally within their family, community, education or care setting. The key point is the autistic child or young person's needs should be at the heart of the process.

Provision of services should not be delayed by issues around who will pay for particular aspects of those services and Welsh Government expects all parties to consider the use of pooled budgets where possible.

Unmet needs

When assessing individual needs, unmet needs **must** to be recorded for service development.

For children they tend to be around;

- early intervention therapies
- speech and language
- support / knowledge /information for parents.

For adults they tend to be around;

- independent living skills and
- housing related support As well as
- employment related support and
- opportunities to socialise.

Section 2.6 Transition

Moving between different stages of life, such as school, college and work, is especially hard if you find change difficult, as many autistic people do. Therefore, there is a real need to ensure that an autistic child or young person's move between and through services is as well coordinated as possible and that the autistic individual has a say in the process.

Rather than take a strict age bound approach, the system must respond to the autistic child or young person's individual needs. A child's experience of growing older into adulthood is a process, not an event, and may span a wide age range.

Local authorities and local health boards need to ensure that a well structured, effective process is in place to meet the integrated health and social care needs of autistic children, young people and young adults, promote quality and safety, access, autonomy and efficient care for improved outcomes.

NICE guidance on transition should be used by all health services and local health boards should take into account the recommendations within the NICE guideline and associated quality standard to help young people and their carers have a better experience of transition and handover by improving the way it's planned and carried out.

For local authority practitioners the transition from child to adult constitutes a significant change in circumstances and so creates a **right** to a re-assessment of needs.
All transitions must be carefully planned in advance to make them as seamless as possible. Due to long waiting list they may change age bands by the time they get to the top of the waiting list the IAS have therefore agreed at present to accept referrals at 17 ½ years.

Further information and assistance can be found:
https://www.nice.org.uk/guidance/ng43
https://www.autism.org.uk/about/transition.aspx

Section 2.7 Carers assessment

Local authorities must ensure that there is a named individual whose function is to co-ordinate and facilitate or carry out the assessment. There must be a written record of the assessment and a copy given to the carer. If the assessment involves a meeting, it should be carried out in a convenient and private place. Assessments can be over the phone or online but this should only happen if the carer agrees. Some local authorities carry out a supported self-assessment. This involves the carer filling in a self-assessment questionnaire, and then being contacted by the local authority to discuss what has been submitted. In some areas, local organisations carry out the assessments on behalf of the local authority but arrangements should still be made through the local authority and an explanation offered to the carer regarding who will carry out the assessment. In these instances it is essential that the local authorities ensure that the 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.

Not all carers will need an assessment and this needs to be clear, especially to referrers. Carers also need to be aware of the assessment and the services available and the eligibility to access. There will be a significant impact on demand and capacity.

If the autistic person receives an assessment in their own right and for their own needs the local authority can combine the assessment of the carer so that they are linked and complementary but this should only be done with the carers permission. The assessors must not assume that the carer can and is able and willing to meet any caring needs.

Carers do not need to be providing 'regular and substantial' care to be entitled to a carer's needs assessment. Carers of all ages are able to receive a carers assessment.

The assessment should include offering information and advice, training, emotional support or a short break.

The assessment should disclose:

- what the outcomes are for the carer
- whether the carer is able and willing to continue in the caring role
- how the carer can balance caring with other aspects of day-to-day life
- whether the carer wishes to work or continue to work
- whether the carer want's to participate in education, training or leisure activities.

Sharing the caring role

The demands of modern life can mean that families often share the caring role.

All carers are entitled to a carer's needs assessment even when there are multiple carers looking after one person.

Section 2.8 Accessing health care / passport to health / reasonable adjustments

An appointment at the hospital, optician or dentist can be extremely stressful to an autistic person. They may experience sensory overload and subsequently exhibit challenging behaviour. It is important to involve parents/carers in all aspects of the patient's care as appropriate with the consent of autistic adults.

Health boards must ensure that all hospitals departments irrespective of the clinical provision, develop strategies and make reasonable adjustments. Where possible a practitioner with relevant experience of autism should be involved. 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.

Suggested strategies to adopt in primary, secondary and tertiary clinical areas:

Appointments

If possible:

- arrange an informal trip prior to actual treatment
- involve health professional at these times so that the autistic person can get to know them, their room and any equipment, a special chair or eye glasses
- allow the person to watch while a sibling or other family member is being treated
- information from the patient's carer will help to inform the approach
- it may be helpful to book a double appointment to accommodate the patient's additional needs and ensure that you are not rushed
- try to give the patient the first or last appointment of the day. Autistic people find waiting around for an appointment extremely stressful
- if possible, find a small side room the family can wait in, alternatively, they may prefer to wait outside or in the car and a member of staff should be identified to collect them when the health professional is ready
- if the appointment is likely to be delayed, the family may wish to leave the building completely and return at a later agreed time.

Health/ Communication 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
There is also an electronic mobile phone and tablet app which improves information sharing and support for children and young people with autism. 'The About Me' app

aims to put the child at the centre of clinical practice. The mobile app, currently available on the Android platform, contains key information about a person with autism including a profile of their needs and strengths, a progress tracker of the assessment process and information about support services available. It can be downloaded free of charge from the Google Play Store, search for 'About Me (autism passport)' or from:
https://play.google.com/store/apps/details?id=ua.com.doublekey.aboutme&hl=en_GB

Medical procedures and physical examinations

Practitioners should;

- always explain before starting any procedure or examination
- show a picture of what is going to happen or use a doll (if appropriate) to explain the procedure
- physical examinations may prove very stressful to an autistic patient and it is essential to warn them before touching them
- always explain what you are doing and why
- enlist the parent/carers help wherever possible, especially if the patient is non-verbal or uses an alternative communication method or aid.

Language

- use clear simple language with short sentences
- avoid using idioms, irony, metaphors and words with double meanings, for example "It's raining cats and dogs out there"
- give direct requests, for example "Please stand up." If you say, "Can you stand up?" this may result in the person staying seated or the answer "yes", as they may not understand you are asking them to do something
- check understanding – some autistic people speak clearly but do not always have clear understanding
- avoid using body language, gestures or facial expressions without verbal instructions – they may not be understood
- ask for all information – an autistic person may not volunteer vital information without being asked directly.

Response by patient

- there may not be eye contact especially if the patient is distressed – this does not mean they are not listening
- allow the patient extra time to process what's been said
- don't assume that a non-verbal patient does not understand what is being said
- autistic people find it difficult to understand another perspective but may expect others to know what they are thinking
- they may nor understand personal space – they may invade other, or may want their own.

Sensory stimuli

- some autistic people are extremely sensitive to light and can discern the flashing of fluorescent lights
- pen lights can trigger seizures in susceptible individuals. Seizures occur in 20-30% of autistic people
- the hustle and bustle of an A&E department, emergency lights and machines that emit high-pitched 'whistle' sounds can be agonising to autistic people
- at the dentist, the noise of the drill and even the feel of cold instruments in the mouth can all contribute to sensory overload. The strong taste of mouthwash or paste can also be problematic. Similarly, the equipment used by the optician, such as the heavy eye glasses, can be difficult for the patient to cope with
- where some autistic patient may withdraw (they might, for example, put their fingers in their ears, close their eyes) others 'stim' (self-stimulate). This means they make motions such as flapping hands, rocking or flicking fingers in order to stimulate sensation or to deal with stress. This kind of behaviour may also be calming to the individual, or aid balance and posture, so do not try and stop it unless absolutely essential.

Pain

- autistic people can have a very high pain threshold. Even if the person does not appear to be in pain, they may, for example, have broken a bone. They may show an unusual response to pain that could include laughter, humming, singing and removal of clothing
- agitation and behaviour may be the only clues that the child or adult is in pain
- use of pain symbols may assist.

Injections/blood tests

- use pictures or a doll to demonstrate what is going to happen, explain which part of the body you are going to inject
- autistic people can be either under or over sensitive to pain so that some may feel the pain acutely and be very distressed whereas others may not appear to react at all
- it is advisable to assume that the patient will feel the pain and use a local anaesthetic cream to numb the site of injection.

Paramedics

Sensory issues are particularly pertinent for the paramedic.

- the sound of a siren can be excruciatingly painful to autistic people, turn it off if at all possible
- some autistic people can be terrified by the restraints used to strap people to a stretcher. They may become extremely agitated. Try and explain why you are strapping or get their parent/carer to explain.

Accident and emergency

A&E is a very stressful experience for anybody, but for an autistic patient, it can be totally overwhelming. Not only is it a strange place, and often apparently chaotic, but the sensory experience of bright lights, bleeping monitors and other equipment can completely overload their system causing a 'meltdown', withdrawal, or challenging behaviour.

- Allow the parent or carer to take control, as they will know the best way to support the patient
- allow relatives/carers to stay if possible and with the consent of the patient if there is capacity. This can help reassure the patient, and will also allow the relatives/carers to give valuable information about the patient and their behaviour
- inform the triage nurse that the patient is autistic so that they can be given a higher priority than would be normal. This is to minimise the time the patient has to wait
- allow the patient and carers to use the relatives room if it is free
- try to limit the number of staff caring for the patient. Predictability will help them understand what is happening to them and to identify the roles of care providers
- allocate a key person to the patient if possible.

Section 2.9 Support within secure estates

The secure estate is defined as an establishment which accommodates children, young people or adults where there is a restriction on liberty.

The SSWBW Act sets out the local authority duties under the act for:

- adults with care and support needs in prison, approved premises and bail accommodation, including those over the age of 18 in youth detention centres;
- children with care and support needs in youth detention, prison, approved premises or bail accommodation in England and Wales.

Assessing need and undertaking assessments

- The local authority is responsible for the assessment of all adults in custody in their area, who appear to have eligible needs regardless of the area the individual ordinarily resides or they will be released to. Prison authorities should alert the local authority that an individual appears to have an eligible need.
- Assessments should be carried out following the same procedure and criteria as if they lived in the community. However, there may be some need to adapt delivery of assessment arrangements to comply with the restrictions of the estate regime. In addition, the fluctuating needs of an individual in custody may require assessments or reviews to be carried out at different times during their detention or when transferring between establishments.

- Staff undertaking the assessment should have their autism training needs assessed and have access to training which meets these needs so they are able to assist autistic people and adapt their practice where required
- Where prisoners are transferring across local authority areas, the relevant authorities should liaise closely together to ensure continuity of services where care and support plans are already in place.

In the case of children the responsibility for care and support needs rests with the local authority where the child was ordinarily resident prior to being in custody. If the child has no known ordinary residence status, responsibility for their care and support falls on the local authority where the child is detained.

Where a local authority has established that an individual has been receiving care and support before entering the secure estate they will need to re-assess how their care and support needs can be met within the secure estate setting.

If an individual refuses an assessment the requirement for the local authority to undertake an assessment does not apply, except in circumstances where the individual is deemed to not have capacity. Local Authorities should make a best interest decision under the Mental Capacity Act for assessment and input and refer to an independent Mental Capacity Advocate.

Referrals

Referrals can be made by the individual or a member of staff to social care or medical staff at the prison, this can occur at any time during the sentence.

Determining eligibility

The model of eligibility under SSWBW Act confers the eligibility on the individual need not on the person. For individuals in the secure estate the eligibility of need is the same as for those in the community. Where a person has been detained under a relevant provision of the Mental Health Act, s.117 comes into effect for their mental health needs, responsibility will remain with the originating local authority area.

Care and support planning

Care and support plans for individuals detained within the secure estate are subject to the same review process as all other plans and should be reviewed each time an individual enters custody or is released into the community. Staff involved in preparing a care and support plan should have their autism training needs assessed and have access to training which meets these needs so they are able to assist autistic people and adapt their practice where required. The SSWBW Act encourages the use of co-production to prepare care and support plans.

Charging and assessing financial resource

Individuals detained within the secure estate will be financially assessed in the same way as any other citizen.

Provision of equipment

Where specialist equipment is required it is the responsibility of the local authority where the person is detained to provide it.

Continuity of care

Individuals who are detained within the secure estate should receive continuity of care when they are transferred to another secure setting or are released into the community. The local health board (or prison health staff in private prisons), local authority and prison staff should ensure there is communication between parties to facilitate continuity of care.

People leaving prison

The social worker, health staff (where indicated) and probation officer will work together to plan for the individuals release and provide input to a resettlement plan.

Partnership and governance

Local authorities should work in partnership with all relevant agencies to deliver safe and effective care. A representative should attend the Prison Partnership Board.

Safeguarding

Safeguarding boards under the Act are in place to protect adults who have care and support needs and are experiencing or are at risk of abuse or neglect and to prevent such individuals from becoming at risk of of abuse or neglect. Children's safeguarding boards have a similar purpose to protect children who are experiencing, at risk of, abuse, neglect or other kinds of harm and to prevent children from experiencing or at risk of abuse, neglect and other kinds of harm.

Local Health Boards and the Local Authority are statutory partners on adult and children's safeguarding boards under section 134 (2) (e) and (f) of the 2014 Act. Prison Governors are not a specified board member but where there is a prison within the boundaries of the board it would be helpful to invite the governor or a representative to sit on the board. Safeguarding boards may take an interest in the safeguarding work undertaken in the prison and provide advice and assistance on how safeguarding concerns are managed.

Safeguarding Adults

In line with instructions issued by NOMS (Prison Service Instruction 16/2016), now known as HMPPS prison governors must put in place processes to ensure that prisoners receive a level of protection equivalent to that provided to adults in the community.

Safeguarding children

In 2002, the High Court ruled that duties placed on local authorities by the Children Act 1989 to provide an appropriate range of services for children in need also applied to children detained in the secure estate. The court also ruled that the Human Rights Act 1998 applied to children in custodial facilities.

Local Authorities in Wales are required to visit any child who is detained in the secure estate, this includes children who are detained in England. The visit should be used to ensure the child's welfare is adequately safeguarded and to make arrangements for future visits and contacts and that the child will be safeguarded following their release.

Transition

When a child detained within the secure estate reaches 18 they are legally regarded as an adult. Generally there is no obligation upon the home local authority after the child reaches 18 unless the same local authority would be responsible as a result of the adult being transferred into their area. However local authorities must continue to meet its duties in relation to sections 105-108 of the 2014 act in relation to care leavers during the period they are detained.

Care leavers

Where a young person is entitled to care and support services as a care leaver, their status remains unchanged whilst they are in custody. The local authority responsible for the care leaver prior to their detention will retain responsibility upon their release.

Information, advice and assistance

The local authority should work closely with HMPPS and prison staff to design and deliver an IAA service which can be appropriately accessed by individuals within the secure estate.

Memorandum Of Understanding

A memorandum of understanding must be agreed between the local authority, HMPPS, youth justice boards and the secure estate facility, setting out how care and support services will be delivered.

Advocacy

Where individuals need additional support to ensure they understand their needs, the services available to them and how to access these services, advocacy must be made available to ensure individuals can participate in the decision making process. Advocacy for people within the secure estate must be delivered in the same way as it would be for those in the community.

Complaints and appeals
People in prison will be able to make a complaint about assessment and provision. Details on how to make a complaint should be made available.

Section 2.10 Mental health services for autistic children, young people and adults
The Mental Health Measure (Wales) Act's definition of mental disorder covers the full range of ASCs including those existing alongside a learning disability or other mental health problem. It is possible, but rare, for an autistic person to meet the conditions for treatment under the Act without having any other form of mental disorder. ASC disorders are developmental difficulties and not mental illnesses in themselves. However, people with an ASC may have additional or related problems which frequently include anxiety. These may be related to communication problems or patterns of thought and behaviour that are literal in nature. It should be borne in mind that people with ASC may also have co-occurring mental disorders. Autistic people **should only** be detained in mental health facilities if there is a co-occurring mental health need. When this occurs a practitioner with relevant experience of autism should be involved where at all practicable. If this is not possible practitioners should seek assistance from specialists with appropriate expertise from neighbouring health boards but this should not be allowed to delay action that is immediately necessary **Care and treatment** Generally, this includes: • ensuring that if the assessors have only limited expertise with this patient group, they seek advice from the local specialist service who should provide details of alternatives to compulsory treatment and advice on good communication. This however should not be allowed to delay action which is considered immediately necessary • understanding that an autistic person may have additional sensory and motor difficulties, which make them behave unusually and which could be interpreted as a mental illness but is in fact a coping mechanism. • they may have sensitivity to light, sound, touch or balance, possibly resulting in a range of regulatory behaviours, including rocking, self-injury and avoidance (such as running away) • there can also be a repetitive element to behaviour where someone appears to be choosing to act in a particular way, but their behaviour may distress themselves and may be driven or made worse by anxiety and could lead to harm of self or others. Repetitive behaviour in itself **does not** constitute a mental disorder • an autistic person may show a marked difference between their intellectual and their emotional development. They may be able to discuss an action intellectually and express a desire not to do it, but not have the instinctive social empathy to keep to their intentions • therapeutic teams should try to help the person to understand their behaviour and work with them to minimise it. When the person is unable to prevent themselves from causing severe harm to themselves or others, compulsion under the Act **may** become necessary

autistic people with social and communication disorders can also become mentally ill and this mental illness may need compulsory treatment. When someone is brought to hospital under compulsion, they should be placed in a setting which can accommodate their social and communication needs as well as treat the mental disorder

- it is important that consideration is given as soon as possible to whether the person with social and communication disorders is eligible as a 'qualifying patient' to support from an independent mental health advocate.

Example:

1. Admission assessments should contain the following additional information for an autistic patient:

- mode of communication – verbal, PECS, Makaton, BSL, non-verbal
- sensory difficulties – noise, light, touch, taste, smell
- repetitive routines – personal care routine, need to pace, jump (rebound therapy), food presentation
- any relevant information from family/carer/significant other.

2. Have things in place:

- Some people with ASC take longer to process information and answer questions: you will need to leave enough time to allow them to respond. This might mean leaving extra time for consultation – especially for topics that might require a more lengthy discussion (providing accessible written information and allowing for written answers might be good practice. Find out what time works best for them. It's really important to get their input on timescales.
- Have a regular venue time and date for meeting is important as most people with ASD like and need routine. Give plenty of warning if there are changes
- Create supportive social environments that meet their sensory needs. Noise, lighting and constant change to physical space can increase anxiety for people with ASD. It's important to be mindful of sensory need and how the environment may impact that.
- Try to find and hold a social group or 1:1 meetings in a room/space with low lighting or ideally no fluorescent lighting, with a private area for quiet withdrawal. Rooms are not always easy to control but if there are fluorescent lights try not to switch all of them on. Lamps can sometimes be better than overhead lighting. To manage changes to the environment, try to inform of changes in advance.

Further information and assistance can be found:
https://www.mind.org.uk/media/3120340/autism-guide-web-version.pdf
http://www.wales.nhs.uk/sites3/documents/816/Mental%20Health%20Act%201983%20Code%20of%20Practice%20for%20Wales.pdf

Section 2.11 Services for autistic people with co-occurring conditions

Autism is often diagnosed alongside other conditions. It is important to support people with more than one condition in a way that meets all their needs, while understanding that the needs arising from autism are distinct.

Both neurodevelopmental and adult pathways currently include further investigations for diagnosis of co-occurring conditions. These referrals should not delay any support interventions that are immediately necessary.

Support can often be through advice on making environmental and emotional modifications. Self help groups, third sector organisation and charities or local activity groups can be sources of assistance.

Example:

a. the parents of an autistic child who may also be displaying symptoms of ADHD should receive information and support in behaviour management / modification techniques whilst awaiting further assessment.

b. an autistic person who is displaying symptoms of severe anxiety should be offered support to develop coping strategies whilst awaiting further assessment.

Health boards need to ensure that all health pathways are designed to ensure that autistic people have access to a practitioner with relevant experience of autism where at all practicable. If this is not possible practitioners should seek assistance from specialists with appropriate expertise from neighbouring health boards but this should not be allowed to delay action that is immediately necessary

Local Health Boards and local authorities already have partnership arrangements in place in relation to mental health services and services for people with substance misuse issues which should include adjustments for autistic people. There are also national partnership boards in place for both of these services.

The Regional Partnership Boards should therefore consider what additional or alternative arrangements may be required to integrate services to improve outcomes for autistic individuals and/or make more effective use of resources. This should also include consideration of what arrangements would be more effective at a national, rather than regional or local level.

Further information and assistance can be found:
https://www.autism.org.uk/about/what-is/related-conditions.aspx

Section 3: Arrangements for Awareness Raising and Training on Autism

This section describes the arrangements for:

3.1 Promoting Equality and Inclusion
3.2 Raising awareness of autism in the community
3.3 Workforce learning and development
3.4 Primary Care Health services
3.6 Social Care services
3.7 Educational Establishments

Section 3.1 Promoting Equality and Inclusion
Health Inequalities People with autism can experience health inequalities compared with other people, in accessing health care and services. The causes of these inequalities are complex and multiple, and we need a better understanding of the health, lifespan, health care and health inequalities of autistic people to improve equality and access to services. **Example:** A local service may not have the expertise to carry out a complex autism assessment and an individual may need to be referred to a more specialist team. If there is not a specialist autism team near their homes, and the individual has difficulty travelling long distances (because of the financial cost or other reasons), support may be needed from health or the local authority to help them access the service. Good health depends on much more than the provision of good health services. The way a society is organised; its economic prosperity; a person's early life chances; their education and employment opportunities; community support and cohesion; the food we eat; the homes in which we live and many more factors impact on health and health inequalities. Therefore, offering a holistic assessment to an autistic person is a proactive duty for local authorities and health boards. Because many autistic people might have complex health and social care issues, assessments must ensure that any underlying support needs related to a person's autism are considered to ensure that people's wellbeing is reflected in any assessment. Autistic people can find assessments perplexing. While this in part relates to the nature of autism, many carers also find assessment processes confusing, so the issue is one that services should address. People have the right to independent advocacy if they need someone to help them have their say about their care needs, though this role

might be carried out by a family member or friend. Assessments need to be carried out in a way that is appropriate for the person being assessed.

Example:

Successful assessment
Preparing in advance and flexibility towards the autistic person may help the assessment capture the right information, and the assessment must be proportionate to the complex nature of autism. If you are conducting an assessment with an autistic person:

- be clear about your role from the start
- consider sending a photograph of yourself in advance
- accept that you may need more than one or two meetings; autistic people can often only manage short conversations
- be flexible about how information is recorded; use formats that the autistic person can understand
- find out what would help the person feel in control of the meeting
- where appropriate, find out from the person's family or carers how they
- best communicate
- read about the person on their file, without fixing your views on the basis of what you learn there
- ensure that you are punctual as lateness can cause anxiety
- focus on the person's strengths and achievements.

You might also want to ask yourself:

- Does the person have special interests I could use to foster a good relationship?
- Does the person have sensory sensitivities; should I, for example, not wear perfume or aftershave?
- Are there things that might trigger anxiety for the person?
- Do I have to do the assessment face to face, or could it be done by email, for example?
- Can I send the assessment questions in advance so the person can prepare their responses?
- Does the person need extra time to answer questions?
- Have I been asking them questions while asking them to read something or fill out a form?
- Does the person want a friend, family member or advocate with them?
- Is there a time of day that would suit the person well?
- Would the person prefer to be assessed while walking, for example, so that eye contact need not be made so often?

There are also a number of issues, often connected to autism, which an assessor should consider:

- sensory issues, both in the room at the time, but also as a factor in determining need
- other specific learning difficulties or conditions, such as dyslexia or attention deficit hyperactivity disorder

- sleep issues – many people with autism have disrupted sleep patterns, which can be difficult for them and their carers
- dietary restrictions.

Consider too whether the person with autism is also a parent or carer and, if so, how their autism affects how they care for the other person.

NICE have developed a new indicator which is part of the NICE menu of indicators for General Practice to encourage practices to record the diagnosis using appropriate clinical codes and to proactively seek to understand the reasonable adjustments needed by these people in order to access services. This helps assist autistic people to access primary care services.

Examples:

A GP practice has placed a flag on the name of an autistic child to offer information to the receptionist when a parent telephones the surgery. The receptionist will know;

- which GP has best knowledge and experience of the child and is first choice if available
- to try and accommodate appointments first in the morning or first after lunch
- when surgery is running late, the child and parent can be directed to a quiet waiting area
- with the patient (or parents) permission this information can be shared with any referrals to other services

The **Orange Wallet Scheme** is a communication tool, which can be used by people who sometimes find difficulty communicating their needs to staff when using public transport. The wallet contains space for the user to insert written and/or visual prompts to show staff. Staff in public transport services across Wales are trained to recognise the wallet and know to be patient and provide appropriate help. The wallet will be recognised by staff across all Arriva Train Wales lines and by major local bus services including First Cymru, Stagecoach, Cardiff Bus, Newport Bus and Arriva Bus.

Case Study:

C was diagnosed by the Integrated Autism Service (IAS) in 2018. At the time he felt he needed time to process his diagnosis, and made further contact with the service in 2019.

He self-referred to undertake the Post Diagnostic Course (PDC) which he completed in October 2019. Following the course, C felt that he may need some support around his confidence, in particular in relation to having some issues at work that he felt he could not challenge.

In December 2019, the IAS made a visit to C to explore these issues further. They advised C to make notes of his priorities that needed to be addressed, and making consideration to what he had learned from the PDC in relation to addressing his sensory needs. C's employer initially told him he would have a lengthy wait for a full needs assessment but when C provided his list of issues and solutions to his employer, he was then assessed within a few days. C has since had a height adjustable desk, a chair with lumbar support, a change to lighting, agreed use of headphones at times if needed, and access to a break out area in times of stress. All of this has meant C now looks forward to going to work.
C also reported that since doing the PDC on which he made friends, he has a life outside of his immediate family, which has given him a greater sense of purpose and wellbeing.

Further information and support can be found:

https://www.nice.org.uk/standards-and-indicators
https://www.autism.org.uk/get-involved/media-centre/news/2017-08-01-nice.aspx
https://www.nice.org.uk/standards-and-indicators/index/QOF/Autism
https://www.autism.org.uk/professionals/employers/sign-up/adjustments.aspx
https://www.asdinfowales.co.uk/resource/04456--Orange-Wallet-Fold.pdf

Section 3.2 Raising awareness of autism in the community

There is a welcome increase in awareness of autism in the community and many more practitioners now understand the need to adapt their practice to meet the specific needs of autistic people. The ASD National 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.

Both the National Autistic Team and The National Autistic Society have Autism Friendly Awards which champions premises such as businesses and public spaces that commit to making sure that autistic visitors receive the same warm welcome as everybody else. Across Wales, businesses, venues and tourist attractions have been taking dedicated steps to make themselves more autism-friendly and help create a society that works for autistic people.

Equally, there are national and regional third sector organisations, charities and individuals who undertake similar work in raising awareness.

Examples of raising awareness:

a. Services who have tele advertising in waiting rooms could link into national campaigns and information sites.

b. Services can become Autism Aware Organisations and raise awareness through displaying signage in public places / asdinfowales.co.uk/autism-aware-certification. This accreditation will also be displayed on the asdinfowales website to raise public awareness of autism friendly organisations.

Case Study

a. The Can You See Me programme provides resources including information explaining the experience of autistic people and the adaptations which can be put in place to provide assistance. asdinfowales.co.uk/can-you-see-**me**

Case Study

b. Wrexham AFC were awarded the Autism Friendly Award, after working closely with the National Autistic Society Cymru's Wrexham branch to understand how they could make the match day experience more accessible for autistic people and families in the area.
The club have made a series of small but important changes, such as a making a quiet room available, taking food and drink orders from the seats to avoid the busy concourse and providing some sensory equipment and ear defenders. These have meant that match days have become far more inclusive and can now be enjoyed by many autistic supporters for whom watching their team might be otherwise impossible. www.autism.org.uk/autismfriendly.

DEWIS Cymru is a national well-being directory developed, owned and resourced by local government in Wales. It shares information with the third sector's directory "Infoengine" and NHS Direct Wales' directory of health services to provide a shared directory of local and national services. The creation of this shared directory is significant to autistic people as it can help the public and frontline staff to identify and connect with the right care, support or opportunity, from the right service, organisation or person, at the right time.

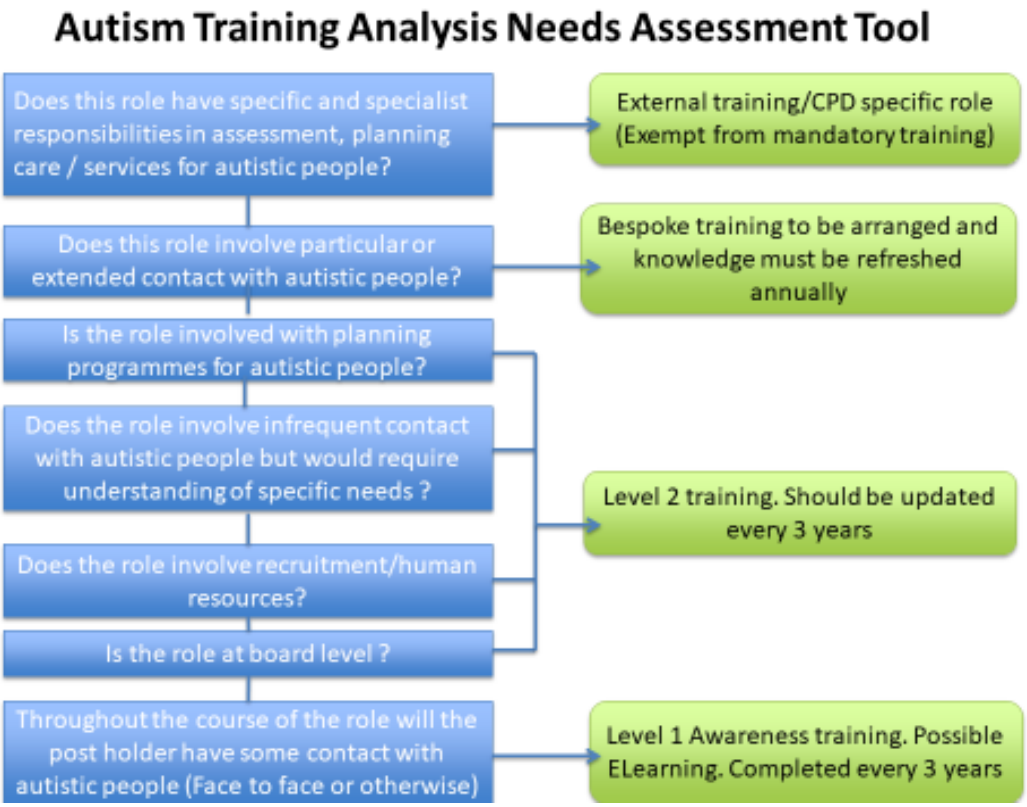
A Health and Well-being Wales app provides off-line access to all the resources within the shared directory, ensuring access to accurate and up-to-date information regardless of mobile connectivity. Providing the app to frontline staff such as community connectors, GP's, blue light services, health visitors, housing officers and hospital discharge teams, will enable them to have immediate access to local, regional and national resources. www.dewis.wales

Social prescribing

- Social prescribing, sometimes referred to as community referral, is a means of enabling GPs, nurses and other primary care professionals to refer people, including autistic people, to a range of local, non-clinical services
- In addition to supporting individuals to take greater control of their own health, social prescribing schemes may also lead to a reduction in the use of NHS services
- Social prescribing is designed to support people with a wide range of social, emotional or practical needs, and many schemes are focussed on improving mental health and physical well-being.
  Those who could benefit from social prescribing schemes include people with mild or long-term mental health problems, vulnerable groups, autistic people, people who are socially isolated, and those who frequently attend either primary or secondary health care.

Section 3.3 Workforce learning and development

Statutory bodies will be expected to undertake autism training needs analysis for their staff, tailored to their professional needs.



It will be the responsibility of managers to evaluate the different roles within their department and determine the level of training appropriate to the role. It is recommended that this should be done at the recruitment stage to determine the level of autism training that is appropriate to the role and to feed this into individual development plans.

Example:

Individual assessment tool:

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 plans

There must be minimum training standards for all staff in organisations. This training should include foundation training around understanding autism, behaviour management and communication. More detailed training, specific to specialisms must be offered to practitioners working directly with autistic people.

At present training in autism is not mandatory in Wales. Health colleagues in England have already agreed to mandate. As of March 2020 Wales have yet to decide.

However, equality training includes reasonable adjustments for people with identified needs and this includes autistic people.

Teacher Training

The Additional Learning Needs (ALN) Act will support training for teachers in neurodevelopmental conditions and although not specifically for autism there are developments in ITT training regarding the wellbeing of learners. As many autistic children do not meet the ALN threshold but still have emotional and psychological needs which impact their school experience the **Whole School Approach** embraces individual tailored support. Positive relationships between school staff and pupils are at the heart of ensuring a whole-school approach to emotional and mental well-being. However this is only possible if staff have the confidence and time to actively listen to

children and young people and respond appropriately even to challenging or concerning topics and behaviour. Staff need appropriate training for this and the space to put it into practice.

Teachers should be given opportunities and time to access training on children and young people's well-being. Some teachers may also wish to develop a greater knowledge and professional understanding of more specific issues such as autism and should have access to a range of resources and additional training to do so. Such professional learning opportunities will also support the implementation and adherence to the new national curriculum.

Understanding and having a knowledge of the emotional and mental well-being of learners as well as a need to recognise individual learner needs is a core part of the new programmes in Initial Teacher Education (ITE). To support this and as part of our commitment to support a consistent whole-school approach across Wales, the Welsh Government is working with partners to develop training modules on child development, emotional and mental well-being, neurodevelopment and pedagogy, and others that would be available to teachers from Initial Teacher Training, through Newly Qualified Teachers and as part of continuous professional development.

However, rather than limiting emotional and mental well-being training to teachers, it is important that appropriate training resources are available for all school-based staff who work directly with children and young people. They should be given time to allow them to support learners and staff, working as part of multidisciplinary teams to provide consultation, liaison and advice where appropriate. Joint training, to foster a greater understanding of the different roles members of staff have and to build relationships should also be considered.

Schools should ensure staff have access to refresher training, which could be run by well-being co-ordinators on a train-the-trainer basis.

Work Based Learning (WBL) guides

There are two guides that were co-produced with Autism Leads across Wales, the National Training Federation for Wales and ACT Training and autistic people. One new guide is designed to help work-based training providers to support autistic people. The other is aimed at the autistic learner to assist them in successfully completing their work-based learning journey.

The resource pack form part of the Working with Autism scheme. The pack contains useful advice, information, hints and tips for training providers to help create autism friendly environments for learners in the workplace, ranging from sensory and communication considerations, to task management and supporting learners with their work.

The learner pack contains information and advice on how to choose the right WBL placement. Then once on placement there are advice sheets on how to organise their workload and time, how to manage unstructured periods and where to get the advice and help they need. Both guides follow the learner's journey through the WBL process. Asdinfowales.co.uk/Professional/Work Based Learning.

Examples:

Best Practice would suggest the following should undertake training in autism;

- Teachers – the new curriculum inset days – linked to whole school approach, equality training
- Those doing care and support assessments
- General Practitioners – they should be the gateway into services. As a minimum they should know how the pathway works **in their area**
- Primary mental health - children and adults
- Substance misuse teams
- Learning Disability Teams
- Frontline Staff
- Consortia
- Local authorities – e.g. armed forces and domestic abuse training has been rolled out to all staff
- Nurses
- Dentist
- Paramedics
- Leisure service personnel.

Section 3.4 Primary Care Health services

Our agreed approach to health and well-being is the Primary Care Model for Wales, which supports the vision in *A Healthier Wales.*

Core to this model is integrated working where GPs, nurses, pharmacists, dentists, optometrists, dentists, physiotherapists, occupational therapists, social workers and people working in the voluntary sector work together in the local community to plan and provide people with a range of ways to access seamless care and support so they receive the right care at the right time from the right source at or close to home.

In line with legislation information about individuals should be shared between agencies to ensure services are joined-up and provided in a seamless and timely way across the community. Modern technology, local facilities and services should be used to help people lead healthy lives and to support those who need care.

Two of the four objectives of the Regional Partnership Boards are to ensure the partnership bodies work effectively together to:

- provide sufficient resources for the partnership arrangements, in accordance with their powers under section 167 of the SSWBW Act
- promote the establishment of pooled funds where appropriate.

Regional Partnership Boards **must** also ensure that all partners work effectively together to improve outcomes for autistic people in their region. They **must** ensure that services and resources are used in the most effective and efficient way to enable this.

Regional Partnership Boards **must** prioritise the integration of services which include autistic people and their family/carers in relation to:

- older people with complex needs and long term conditions
- people with learning disabilities
- children with complex needs
- carers, including young carers
- integrated Family Support Services.

There must be an integrated approach to the development of services, care and support, which focuses on opportunities for prevention and early intervention.

Children and young people;

- providing early help and support to prevent the emergence of more challenging needs
- providing support to families to prevent the need for children to become looked after
- where a child is looked after, providing models of care and support which deescalate need and promote positive outcomes, and
- promoting approaches which prevent children ending up in custody.

In the first instance, Regional Partnership Boards need to consolidate the development of Integrated Family Support Services and also to develop an integrated approach to delivering services for children with complex needs. This includes supporting effective, integrated transition arrangements from childrens' to adults' services.

Section 3.6 Social Care Services
Regulation 3 of the Care and Support (Assessment) (Wales) Regulations 2015 (SI 2015/1503 (W. 111), which requires LAs to: A local authority must ensure that any person carrying out an assessment— (a) has the skills, knowledge and competence to carry out the assessment in question, and (b) has received training in the carrying out of assessments. When carrying out an assessment, a local authority must consider whether the nature of the person's needs calls for the involvement of a person who has specialist skills, knowledge or expertise. If the local authority decides that such involvement is called for, it must either consult with a person who it considers will be able to provide those skills or that knowledge or expertise or arrange for the assessment to be carried out by a person with the required specialist skills, knowledge or expertise.

Section 3.7 Educational Establishments
The possibility that a child has autism and additional learning needs might be “brought to the attention of” the school by the child themselves, by a parent or other family member, or by an external body or professional, such as the local authority. If the school is aware of that possibility, then the duty to decide applies (subject to the exceptions in the Act). (Guidance on the definition of ALN and identifying when a child may have ALN is set out in Chapter 7 of the ALN Act) The new Additional Learning Needs guidance states; (proposed) The school **must** notify the child and the child’s parents that it is required to decide whether the child has ALN. The notification **must** contain: • the name and contact details of the designated co-ordinator; • information about how to access the responsible local authority’s arrangements for providing people with information and advice about ALN and the ALN system. This could be done by providing a local authority leaflet about the ALN system or the address of the local authority’s relevant web pages and drawing attention to how to get further information and advice • it **should** also provide an indication of the likely timescales for the process Where it is brought to the attention of a school by a child or a child’s parent that the child may have ALN but it has previously decided the issue is satisfied that the child’s needs have not changed materially since that decision and there is no new information which materially affects that decision it **should** communicate this to the child and the child’s parents and **should** provide them with information and advice about ALN and the ALN system (including rights of appeal) if it has not previously or recently done so. • Consideration **should** be given as to whether the child has any engagement with or support from other agencies and involve them as appropriate in the process of deciding whether the child has ALN and in preparing any IDP. (Further guidance on the role of different agencies and professionals is provided in Chapter 7 of the ALN Act). • As described in Chapter 3 (ALN Act) there is a general duty to involve children and their parents in decisions that relate to any ALN they might have and the preparation of IDP’s. Furthermore, putting the child at the heart of the process that identifies their ALN and determines their ALP is a fundamental objective of the ALN system. To fulfil this duty and objective, the designated co-ordinator **should** normally arrange a meeting or meetings, as appropriate, with the child and the child’s parents to discuss and decide the child’s needs and if required, prepare an IDP for them. (Further guidance on these meetings are in Chapter 18 of the ALN Act). • The school **must** consider whether ALP should be provided to the child in Welsh and if it decides that a particular ALP should be provided in Welsh, the body **must** specify in the plan that it should be provided in Welsh.

Access to education for disabled children including autistic children means considering

- the curriculum and how it is taught;
- the accessibility of school buildings and their surroundings, school activities including school trips and transport; and
- information and activities provided by schools and how easy it is for disabled pupils and/or their disabled parents to understand.

The updated School Accessibility guidance helps schools and local authorities identify and address the barriers which can prevent disabled children including autistic children and young people having equal access to education, and ensure they have the same opportunities as their peers to develop and achieve their potential. There are duties which are a statutory requirement of Schedule 10 of the Equality Act 2010.

- **At least every three years,** each local authority must prepare, implement, review and update **a written accessibility strategy** which identifies how strategic actions will improve accessibility to education for disabled pupils against each of the three planning duties.
- **At least every three years,** the responsible body for a school must prepare, implement, review and update **a written accessibility plan** which identifies how specific improvements will improve accessibility to education against the three planning duties for existing and prospective disabled pupils.

Children with an ASC present with a variety of strengths, difficulties and sometimes behaviour issues. For these children the cause of behavioural difficulties usually relates to the core symptoms of autism not being appreciated, and suitable support and adaptions not being put into place.

By adapting your practice, a child with an ASC will feel safer, less anxious and have an increased understanding of what is expected of them. This in turn will mean that the child is more likely to have increased attainment, improved engagement and is less likely to display challenging behaviour.

All children with an ASC have impairments in social communication, social interaction, social imagination and a preference for routines. Many have sensory issues and a restricted pattern of behaviours. It is important to remember that the way in which this affects a child varies, and strengths or weaknesses in one area are not necessarily accompanied by strengths or weaknesses in other areas.
For example, children with higher functioning ASD may also have good or above average use of language. Having a complex vocabulary does not mean that the child will understand the same level of vocabulary, nor that the child will understand the vocabulary that he or she is using.

We shouldn't forget the many positive attributes of children with an ASC. Having an ASC often means that children are skilled at paying attention to detail, follow clear rules and are honest. These abilities can be used to encourage engagement, and enable them to make their own, unique contribution within the setting.
Due to the issues children with an ASC experience, many have difficulties in accessing the curriculum especially where play based and will need differentiation in teaching styles and approaches.

The Learning with Autism programme has been developed to equip early years settings with enhanced understanding of ASC and how to meet the needs of children with the condition.
https://www.asdinfowales.co.uk/resource/A-Guide-for-Early-Years-Settings_Eng.pdf

Not all autistic children will have additional learning needs. However, there maybe other identified needs to consider to facilitate a conducive learning environment.

Wales has created 'Our National Mission' for education, in which objective 3 (Strong and inclusive schools committed to excellence, equity and well-being) recognises that "all learners must be supported to be emotionally and physically ready to learn in a safe and supportive environment". The new curriculum will be introduced from 2022, placing health and wellbeing at its heart. It will ensure mental health is given equal priority to physical health, and that the wellbeing of pupils is treated of equal importance to their academic attainment.

The whole school approach involves everyone within the school – students, staff and external agency representatives – placing the wellbeing of students, teachers and all those involved in the effective functioning of the school at the heart of all they do. It is an ethos which values inclusion, where everybody works together, contributing their individual skills and resources to the collective good. Fostering a shared understanding of what constitutes a supporting environment where young people are encouraged to fulfil their personal and academic potential, supported by teachers who operate in a culture which values their and others' wellbeing.
Adopting these values will help support autistic children with the emotional and psychological barriers that some face when managing their school life.

The updated Part 9 statutory guidance for the SSWBW Act states that Regional Partnership Boards have a key role to play in relation to bringing together partners to determine where the integrated provision of services, care and support will be most beneficial to children, young people and adults, including autistic people. Regional Partnership Boards will need to ensure that all partners work effectively together to improve outcomes. Regional Partnership Boards will also play a vital role in the oversight and governance of partnership arrangements. The terms of reference of the Regional Partnership Board should make clear whether members of the board have delegated decision-making from their respective bodies, or organisations, where appropriate. Membership of the board **will now** include;

- at least one senior local authority officer who has responsibility for education in one of the areas covered by the regional partnership board.

Further information and support can be found at:

https://www.asdinfowales.co.uk/learning-with-autism
https://gov.wales/sites/default/files/publications/2018-03/education-in-wales-our-national-mission.pdf

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

This section describes the arrangements for:

4.1 Population assessments
4.3 Autism data collection
4.4 Monitoring and service improvement for autism
4.5 Compliance with the Code
4.6 Autism stakeholder involvement
4.7 Regional autism champion role

Section 4.1 Population assessments
Regional Partnerships boards **must** ensure they collect local information on the needs of their local autistic population to inform the population needs assessment and to monitor the delivery of the annual plan as they relate to the needs of autistic people and family/carers. This will be facilitated through the Autism Champion **(see flowchart 4.7).** Health boards and local authorities **must** collect information at a local level to support the development of population needs assessment in relation to autism. This will be facilitated through the ASD Leads **(see flowchart 4.6)** At present population assessments cover eight core themes, including learning disability/autism 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). By September 2020 this will be amended to make **autism a standalone** theme, and questions will relate specifically to autism provision. In preparation for this RPB's should consider developing the structures in **4.6** and **4.7** of this guidance.

Section 4.3 Autism data collection
The Welsh Government currently collects high level data on autism as part of wider data collections. This includes: • SSWBW Act – People receiving Care and Support • Neurodevelopmental 26 week waiting time standard – children (planned for adults) • Schools – Pupil Level Annual School Census • Wales Children Receiving Care and Support Census • Outcomes based and throughput data from IAS • NHS Planning Framework • Health Integrated Medium Term Plans • SAIL Databank (Swansea University) is an invaluable resource for its richness and breadth of routinely collected data currently available for data linkage research. The vast array of datasets ranges from GP records, hospital data and emergency services, through to mental health, social services, education and national survey data

- WCCIS – Welsh Community Care Information System. The Code will inform the fields that would need to be set in the system to collate evidence on Autism
- Welsh Government workforce data will be used to inform demand and capacity.

Section 4.4 Monitoring and service improvement for autism
Welsh Government are currently undertaking a demand and capacity review of service provision throughout Wales. This will include both children and adult services. It will be followed by an in depth review of UK wide and further service provision, offering models of best practice which will include outcomes for autistic people. Further guidance on monitoring and service provision will be aligned to the recommendations made in the report. Service Outcomes will be measured utilising an accredited tool. The IAS are currently using the Outcome Star tool to measure individual outcomes. The demand and capacity review will discuss monitoring of service provision in greater depth. The nature and pace of the local service improvement plans will reflect local health and social care needs and the nature of existing services.

Section 4.5 Compliance with the Code
Enforcement of the Code Breach of the Code may amount, in a local authority's case, to failure to perform a function properly under the Social Services and Well– Being (Wales) Act 2014. In a Local Health Board case, this may amount to a breach of a direction under the NHS (Wales) Act 2006. In both of these cases, such a breach will open the way to intervention by Welsh Ministers. However, the code itself will not create any new remedies for enforcement. Welsh Government will be made aware of a failure to perform through: • local authority and health boards complaints / concerns • current mandatory reporting to WG and • engagement with autistic people and their representatives. **Breach of the Social Services and Wellbeing (Wales) Act 2014** • When a local authority is not following the duties and requirements set out within the Code, and therefore is not following the Social Services and Wellbeing (Wales) Act 2014 • The Code specifies duties and requirements forlocal authorities. The first are those that **must** be complied with by local authorities and, the second are guidelines that a local authority should HAVE REGARD to (**should** follow). • Section 150 of SSWB Act 2014 sets out the **grounds** for intervention. These are as follows: ➢ **Ground 1** - the local authority has failed, or is likely to fail, to comply with a duty that is a social services function;

- **Ground 2** - the local authority has acted, or is proposing to act, unreasonably in the exercise of a social services function;
- **Ground 3** - the local authority is failing, or is likely to fail, to perform a social services function to an adequate standard.

The first ground only materialises in the event that a DUTY that is a social services function of the local authority is not performed or is likely to not be performed. The code of practice does not set out functions of local authorities, but it sets out **the way** in which the functions should be exercised. Therefore it would be difficult to argue that Ground 1 would be met in respect of any breach of the code.

However, the second and third grounds for intervention may arise in the event that either a duty (something that the local authority MUST do) is not followed, or in the event that a Local Authority fails to have proper regard to a requirement of the code (something they SHOULD do). In either scenario it may be possible to argue that the local authority has either acted unreasonably (ground 2) of failed to perform a function to an adequate standard (ground 3).

In the event that Welsh Ministers are satisfied that one or more of these grounds exist in relation to a local authority, the Welsh Minsters may issue a **warning notice** under section 151. There are specific matters laid out in that section that must be specified in the warning notice. These are as follows:

(a) the grounds for intervention;
(b) the reasons why they are satisfied that the grounds exist;
(c) the action they require the local authority to take in order to deal with the grounds for intervention;
(d) the period within which the action is to be taken by the local authority ("the compliance period");
(e) the action they are minded to take if the local authority fails to take the required action.

Following the issuing of a warning notice, should the Welsh Ministers be satisfied that the local authority have failed to comply or secure compliance with the notice within the period specified, the Welsh Ministers have a power of **intervention** under section 152(2).

The Welsh Ministers also have the power to '**intervene**' under section 152(3) if 1 of the grounds 1 – 3 above exist, and the Welsh Ministers have reasons to believe that:

(a) there is a related risk to the health or safety of any person that calls for urgent intervention under this Part, or
(b) the local authority is unlikely to be able to comply, or secure compliance, with a warning notice.

In the event that intervention is justified (either 152(2) or (3) above apply), there are then a number of steps that the Welsh Ministers may take:

- Under section 153 the Welsh Ministers may direct a local authority obtain advisory services to assist them.

- Under Section 154 the Welsh Ministers may direct that a local authority functions are performed by other persons on behalf of the Authority.
- Under section 155 the Welsh Ministers may direct that a local authorities functions are performed by the Welsh Ministers. A local authority MUST comply with a direction in accordance with section 159.

If the Welsh Ministers exercise their power of direction they must lay a copy of the direction before the Assembly and report to the Assembly on the steps taken by the local authority to comply with the direction. Any direction is enforceable by applying to the High Court for an order. Defiance of the order would be treated as contempt of court.

Breach of the NHS (Wales) Act 2006

- When a local health board is not following the duties and requirements set out within the Code, and therefore is not following the NHS Act 2006 or s. 169 of the Social Services and Wellbeing (Wales) Act 2014.

- The Code specifies duties and requirements for local health boards and Trusts. The first are those that **must** be complied with by local health board and Trusts, the second are guidelines that a local health board and Trust should HAVE REGARD to (**should** follow).

In order to place a **requirement** upon local health board's one option would be to use the power under s.12(3) of the NHS (Wales) Act 2006. This allows Welsh Ministers to give directions to a local health board about its exercise of any function.

A direction can be made setting out how the local health board should undertake its functions. In the event that the local health board did not comply with the direction then s.28 of the Act sets out the steps the Welsh Ministers may take in determining the local health board to be in default.

Direction under s.12 of the Act must be '*by regulations or an instrument in writing'.* An 'instrument in writing' includes a letter, a Welsh health circular or an SI style direction.

The power to issue directions to LHB's is under s.12(3) of the NHS (Wales) Act 2006.

https://gov.wales/docs/legislation/inforcenonsi/nationalhealth/120213direct5eng.pdf
Whatever form the direction takes it must be sufficiently clear so that the Local Health Board knows exactly what would be required of them.

In addition local health boards and local authorities must have regard to statutory guidance issued under s.169 of SSWB(W) Act 2014 relating to partnership agreements.

Section 4.6 Autism stakeholder involvement
Regional partnership boards, local authorities, health boards and NHS trusts must ensure autistic people and their parents and carers have the opportunity to be involved in the development and monitoring of autism services.

Organisation and delivery of care

Autism strategy groups should be responsible for developing, managing and evaluating national and local care pathways. The group should appoint a lead professional responsible for the local autism care pathway. The aims of the strategy group should include:

- developing clear policy and protocols for the operation of the pathway
- ensuring the provision of multi-agency training about signs and symptoms of autism, and training and support on the operation of the pathway
- making sure the relevant professionals (health, social care, housing, educational and employment services and the third sector) are aware of the local autism pathway and how to access services
- supporting the integrated delivery of services across all care settings
- supporting the smooth transition to adult services for young people going through the pathway
- auditing and reviewing the performance of the pathway.

https://www.nice.org.uk/guidance/cg142/resources/autism-spectrum-disorder-in-adults-diagnosis-and-management-pdf-35109567475909

There are already established engagement groups that are making excellent contributions to many different areas of autism provision. Standards to measure efficacy of engagement are;

1. We will identify and involve the people and organisations that are affected by the focus of the engagement.
2. We will identify and overcome any barriers to participation.
3. There is a clear purpose for the engagement, which is based on a shared understanding of community needs and ambitions.
4. We will work effectively together to achieve the aims of the engagement
5. We will communicate clearly and regularly with the people, organisations and communities affected by the engagement.
6. We will assess the impact of the engagement and use what we have learned to improve our future community engagement.

The development of a regional steering group co-ordinated by the ASD local authority leads and overseen by the Autism champion would ensure autistic people and service providers have a voice which can influence the direction of autism services within a region. This group would bring together the views of smaller engagement groups already established. Scrutiny should be through brief quarterly reports from the ASD lead. Membership should include – ASD leads, IAS representation, autism specific health representatives, DECLO's, third sector and autistic people/families and carers.

Example:

Quarterly Reports should include at least brief updates on:

- population and service data both health and local authority
- relevant information from professionals, third sector working with this group
- outcomes from consultation with autistic people, their carers and families
- identified gaps in service provision
- identified gaps in knowledge

Section 4.7 Regional autism champion role

The role of the Autism Champion will sit within the governance structure of the Regional Partnership Board to ensure that there is effective scrutiny of autism services in the region.

Examples*:*

In one region, the RPB Carer's representative has been nominated by the Board to be the Autism Champion. The individual happens to have a particular knowledge and experience of autism as a parent, as well as knowledge of local autism services in the county in which they live.

Another region has nominated the chair of the RPB as Autism Champion, who is also Chair of the Health Board and has family experience of autism. In this way, the RPB membership numbers remain the same and someone is nominated from within the Board to be Autism Champion.

Regional Partnership Board Autism Champion Role Profile

Being an Autism Champion means being an advocate for awareness raising around the issues faced by autistic individuals and parents and carers of autistic adults and children. It means being interested and willing to learn more about issues facing autistic individuals.

What are the expectations of the role?

- To encourage colleagues on the Regional Partnership Board to raise awareness of ASD and the issues people face.
- To assist with awareness raising of the breadth of issues highlighted in the Autism Strategic Action Plan including growing, learning, living and working with Autism.
- To be the key contact on the Regional Partnership Board for autism and to know who to contact for more information.
- To be an advocate of service provision in your region.

What might you be asked to do?

- Positively promote your role and be a point of contact on the Regional Partnership Board in relation to autism.
- Provide feedback on the progress of services and developments in relation to autism from key RPB partners.
- Help to implement specific awareness raising initiatives at a regional level.

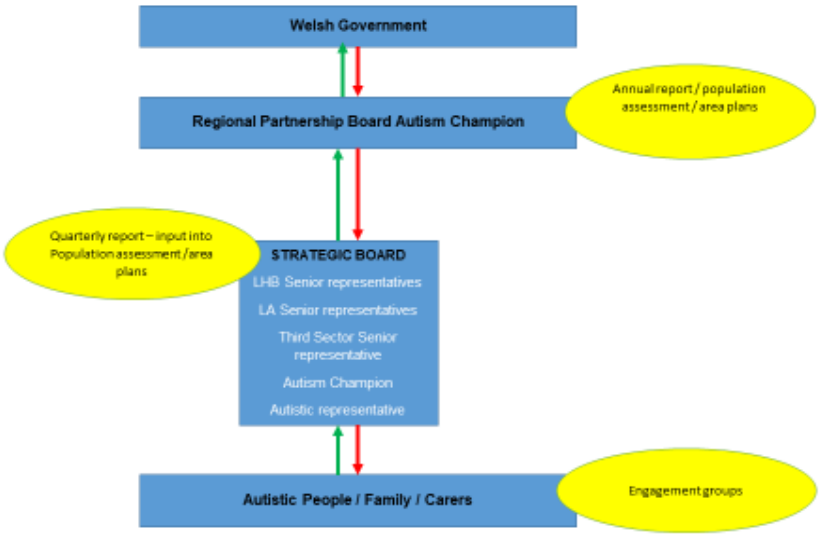
- Liaise with Autism Leads in the Local Authorities and other partner agencies as required.

Requirements

- No specialist knowledge of issues in relation to Autism Spectrum Disorders is assumed but some experience and knowledge of ASD would be beneficial.
- The role will require one hour per week, though however much you wish to volunteer will assist local ASD Leads and the regional services in raising awareness of ASC.

Example:

The Autism Champion will provide information collated from the strategic board quarterly reports on the progress of services and developments in relation to autism which will inform the area plan and population assessments.



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: • 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— (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: • 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

	in the local community to help meet their health and wellbeing needs. 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.
Quality and Impact	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.
Reciprocal Social and Communication skills	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
Referrers	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.
Regional Partnership Boards	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

	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