# Autism support and intervention Guidance for Parents and Carers of

Guidance for Parents and Carers of Individuals within Channel/Prevent

ACT

COUNTER

### **PURPOSE OF THIS GUIDE**

#### I wrote this guide based on my experience during the autism pilot

I thought it would be useful to develop a document for Parents and Carers of autistic children/adults who have been referred to Prevent in Wales.

This booklet is intended to provide useful information, advice and guidance for parents and carers of autistic young people and adults who have been referred to Prevent. We hope it gives useful insight and provides helpful strategies that enable parents and carers to better support their loved ones.

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GWRTHDERFYSGAETH CYMRU

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# **AUTISM**

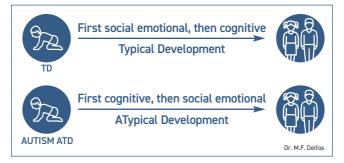
It is important to remember that while autistic people will share some common traits, the way in which these present will vary – sometimes hugely – amongst individuals, and across their daily life, and lifespan.

Put simply, every autistic person can be as different as everyone else – so whilst having a good baseline knowledge of how being can impact a person's character, functioning and life is helpful, we should always be person centred first and foremost and respect each individuals unique profile, abilities and needs.

The information in the following pages is an 'introduction to autism', but is by no means an exhaustive list – so always remember, everyone is different! A useful way to think about autism and other neurodevelopmental conditions is that the person is 'wired differently', i.e. their brain develops, works and experiences the world around them in a different way.

Some people find it helpful to think of the analogy of a Mac vs Windows computer – it has a different operating system so needs different information, and processes it differently, but with the right adjustments, it can often run the same programs...

Once you've met one person with autism, you've met one person with autism Dr Stephen Shore



Autism is a neuro-

developmental condition that affects the way a person communicates and interacts with people, and how they perceive and process their environment.

An autistic person is likely to use their cognitive development to compensate for their delay in social and emotional development. They will use their intellect to make up for a lack of instinct and intuition.

I cannot understand how what I posted was offensive.. I mean how can FACTS be racist? " 22 Autistic Adult in Prevent

WW2 has become a intense interest with my son repeatedly watching videos of Hitler, I am really worried because he has even started learning German. He has a fixation with immigration, and has learned a great deal about statistics and population tables. He has said many times we shouldn't mix races and thinks white people will be in the minority by 2050.

The Soci	o Scheme
The ME placed in the world	
In a physical sense body scheme body foundaries body functioning	In a psychological sense me Other differentiation self image sense of space sense of time social insight empathy theory-of-mind social functioning

Autism is a neuro developmental condition that affects the way development occurs. This can impact a person physically and psychologically, and can co occur with intellectual disabilities affecting cognitive development.

This can have a profound impact on an individuals understanding of who they are, and as such they may struggle to gain a sense of how they fit in the world.

At the heart of an autism diagnosis is a persons

challenge to evaluate the social situation and know instinctively how to respond and behave.

Autistic individuals may instead use logic and their cognitive abilities to try to work out how the world works and how other people are likely to behave.

As such this can lead to an increased fascination in history, politics and religion. To gain knowledge and understanding that hasn't developed in the same way as neurotypical peers.

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# **SOCIAL DIFFERENCES**

Judith Gould and Lorna Wing established the diagnostic criteria for autism in the 1970's and it is often referred to as the 'triad of impairments'



#### **Social Communication**

- Communication confined to the expression of needs only
- May not understand words or only seem to hear parts of sentences
- Use language confidently but lack comprehension
- Talks incessantly about one subject

 Ability to communicate will be linked to anxiety



- One-sided communication, difficulties with turntaking. May interrupt
- Absence of desire to communicate with others
- Difficulty with non-verbal communication

#### **Social Interaction**

- Approaches others but not be very socially skilled may appear 'odd' or inappropriate
- Finds it hard to understand games and turn taking
- Never seems to listen doesn't respond to name

#### **Social Imagination**

- Desire to maintain sameness and stick to routines – difficulty with change
- Difficulties imagining what may happen next (consequence of actions)
- Lack of symbolic play
- Runs off no sense of danger

 Difficulty making and keeping friends



- Difficulty understanding the unwritten rules of behaviour
- Being with people may be stressful
- Not knowing how to act around other people
- Doesn't pick up clues on how others are feeling



- Fascinations or obsessional behaviour about certain objects/subjects
- Keen eye for detail
- Struggles to move from one activity to the next

### Social Imagination does not refer to ones creativity but is specifically related to 3 theories:

- Theory of Mind (Baron Cohen)
- Executive Functioning
- Central Coherence (Uta Frith)

It is essentially the ability to instinctively imagine what others may be thinking and feeling, and how the world works, as well as predicting likely consequences of their actions.

# **SENSORY NEEDS**

Autistic people often have differences in the way they receive, process and respond to sensory information.

They may be looking for more sensory input (sensory seeking), or avoiding sensory input (sensory avoiding), or a combination of both – and this can fluctuate.

Being sensory sensitive can mean that sounds can be painfully loud, smells can be overpowering, or lights might be very enthralling – and there are many more ways sensory differences can impact autistic people on an individual basis.

In addition to differences in touch, taste, sight, smell and sound, autistic people can have differences in their balance and special awareness – meaning they might find some physical tasks difficult, appear clumsy and so on.

INTEROCEPTION

Autistic people often have differences in their interoceptive system – which helps us identify bodily sensations like pain, hunger, thirst etc and to separate these feelings from our emotions.

(GUSTATO)

### UNDERSTANDING INTENSE INTERESTS

Autistic people are much more likely to have 'intense' interests as repetitive behaviour forms part of the diagnostic criteria.

These are more than just a 'hobby'. Central Coherence challenges can mean autistic people have a tendency to 'Hyper focus' on an interest or subject and find it harder to place things in context

These interests can seem extreme and consuming, they can stimulate an autistic individual bringing excitement and a marked change in behaviour.

### When does an interest become unhealthy?

- When it starts restricting other opportunities, causing distress or impacting on learning?
- It increases levels stress and anxiety
- Is unlawful or social inappropriate

Try not to confront or challenge the autistic persons

perspective, create an alternative narratives that challenge indirectly through external sources.

Provide clear, non judgemental information about why an interest is unhealthy

- Explore the underlying function of the interest (lots enjoy case show casing knowledge and cognitive abilities such as knowing dates and statistics)
- Think about alternative activities that could redirect, replace or reduce the unhealthy interest
- Importance of developing clear boundaries collaboratively
- Even when an interest is unhealthy it might be an important coping mechanism – so never simply stop – always replace.

# **EXECUTIVE FUNCTION**

Executive functioning describes the cognitive processes that enable us to think, plan, organise and prioritise.

Most Autistic individuals struggles with a degree of executive dysfunction.

This can lead to challenges in not being able to imagine what is going to happen, when its going to happen, who will be there and how will I know when it's finished.



Struggles with executive functioning can cause issue higher anxiety and stress and a difficulty understanding and foreseeing consequences.

> I cannot hold one piece of information in my mind while I manipulate the next step in the sequence Temple Grandin

# focus

## **CENTRAL COHERENCE**

First described by Uta Frith in 1989 who theorised that Autistic individuals have 'weak central coherence'

Central coherence is sometimes described as the ability to 'see the big picture' – Autistic people are often far better at focusing on the details but can find it really difficult to form these into a cohesive whole and put them into context.

It can bring unique skills, talents and knowledge.

An ability to stay focussed for long periods and an ability to spot anomalies.

My son says he has a hatred of Muslims, yet talks happily to a teacher at school who is a Muslim. When asked he replied -Yeah but I know him and he's alright.

# **EMOTIONAL REGULATION**

66 Autistic people often have trouble managing or even identifying their emotion, this can sometimes result in extreme, unpredictable or unwise inappropriate behaviour

Mood Instability Impulsivity

Emotional Dysregulation



### MASKING/CAMOUFLAGING & FUNCTIONING

Some autistic people 'mask' or 'camouflage' their autistic traits. This can mean their difficulties and support needs may be less visible.

It can mean that an autistic person engages so fully in masking as a survival mechanism, that they begin to lose their sense of self, and can make them feel intensely lonely and exhausted.

There is emerging evidence that engaging in masking can

cause mental health issues for autistic people.

It is important to create spaces where autistic people feel accepted and safe to be who they are. Whilst developing coping mechanisms is important, supressing their autistic nature is harmful and should not be encouraged.

# DIAGNOSIS

A person without a confirmed diagnosis of autism needs to be referred to the diagnostic pathway - pathways can vary between different local authorities.

### Children & young adults

Children and young people will need to be referred to the Neuro Developmental Team or NDT lead by the health board. Referrals to this team generally come via education or social services.

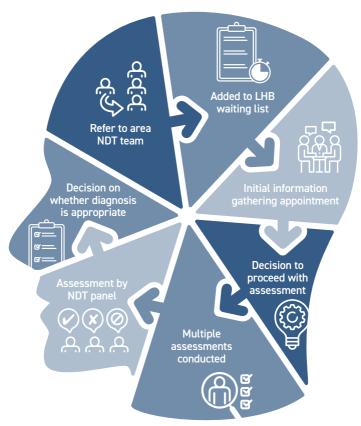
- An Educational Psychology Assessment
- A report from the teacher responsible for co-ordinating additional learning needs (ALNco)
- Any other agency that works with the child that can add evidence. (GP, social worker)
- A parental questionnaire that provides; information regarding the child's early developmental history, variations in communication, physical development, social interaction and play.
- An ADOS (autism diagnostic observation schedule) to be completed by a trained diagnostician

Once gathered it is sent to an NDT panel who confirm a diagnosis of autism, or confirm that the individual does not meet the criteria.

Sometimes when there is not enough evidence they are referred to as having "ASD traits" or as a "Broader Phenotype" This however is now considered bad practice.

# **DIAGNOSTIC PATHWAY:**

#### Children & young adults





### DIAGNOSIS: Adults

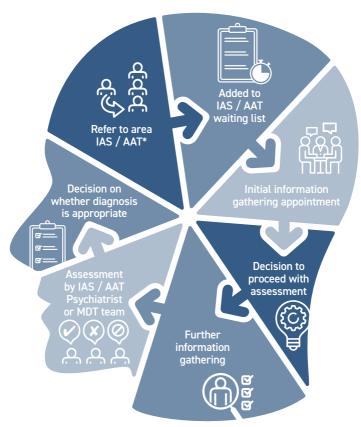
Adults without a co-occurring intellectual disability or mental illness can self refer or refer via the GP to the Integrated Autism Service or Integrated Autism Society (IAS) / Adult Autism Team (AAT) which is the responsibility of the health board.

The adult is interviewed and an ADOS completed. The IAS / AAT then provides them with post diagnostic support.

For adults that are more complex, you might find a

multi disciplinary approach via psychiatrists and neurologists may confirm an autism diagnosis.

### DIAGNOSTIC PATHWAY: Adults





### WHAT HAPPENS NEXT? Post Diagnosis

Regard should be given to the profile a person presents with in determining the support that is provided. We would expect that their support needs generally would include plans that include:

- Communication and speech and language sometimes provided by a Speech and Language Therapist or SALT
- Behaviour plans the most common would be an Individual Education Plan (IEP) or Statement of Educational Needs
- A sensory plan or physical therapy plan provided by an Occupational Therapist (OT)
- An eating plan provided by a Nutritionist
- ✓ For adults a Person Centred Profile, Positive Behaviour Support (PBS) Plan or Health Plan

### **KEY VULNERABILITIES:** For autistic individuals

Social and emotional understanding develops differently in Autistic people, leading to key differences in communication, socialisation and interaction. This means there may be vulnerabilities including:

- Difficulty understanding the motivations of others, therefore becoming vulnerable to being groomed
- Finding it difficult to understand and/or accept another person's perspective
- Difficulty understanding other people's thoughts, feelings and beliefs
- Difficulty understanding the consequences of their actions, or cause and effect
- Not developing a strong sense of self leading them to camouflage or mask their social difficulties
- Social isolation and loneliness

- Communication difficulties such as a literal understanding and processing delay
- High anxiety leading to confusion, paranoia and hypervigilance
- Not understanding the social rules leading to anti-social behaviour
- Intense hyper-focus on objects or topics which can lead to obsessive behaviour on a subject of interest
- Not being able to distinguish fantasy from reality
- Difficulty managing their emotions leading to outbursts and aggression

#### This is not an exhaustive list and everyone is different!

# MARGINALISATIO

Autistic people can experience barriers in everyday life, that can compound any difficulties they experience, and lead to them experiencing disadvantage and marginalisation.

Autistic people often face barriers in:

- Education
- Healthcare
- Accessing the community
- Employment
- Healthcare
- Housing
- Staying safe
- Finances

These challenges can lead to an autistic person feeling alone, left behind and undervalued – which can overlap with some of the vulnerability factors faced in PREVENT

Supporting autistic people to feel like valued members of society, able to access opportunities in education and employment, to stay safe and well is vital in maintaining overall health and wellbeing, and increase feelings of inclusion.

# WHAT CAN I EXPECT FROM PREVENT?

Channel is organised by your Local Authority, who then works with mainstream services such as education, employment, housing and police.

#### IDENTIFY

ACCESS

#### SUPPORT

Identify the individual at risk of being drawn into extremism. Assess the nature and extent of the of the individual at risk. The most appropriate support plan will be put in place to suit the individual's concerns.

#### Who makes the referrals?

Referrals can be made by a number of people such as youth offending teams, social services, police, education and local communities. When someone is referred, they are not criminalised at any stage or will not get a criminal record unless they commit a criminal offence. Participation in Channel is

voluntary. It requires consent from the individual or their parent/ guardian if they are a child.

#### Support

Once an individual has been reviewed, support will be tailored to their specific needs and concerns. This may include mentoring, anger management, life skills and education, constructive leisure activities such as sport.

The overall aim of the programme is early intervention and diverting people away from the risk they may face.

### SUPPORTING FAMILY MEMBERS

### Taking a Low Arousal approach

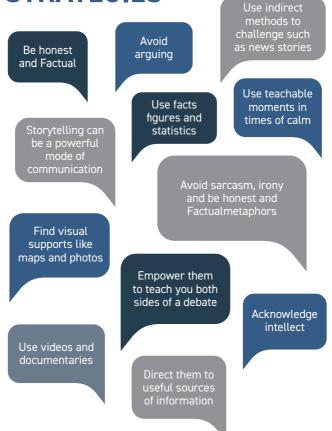
Low arousal is a nonconfrontational approach that takes into account:

- Use a persons name when starting the conversation
- Take your time and allow for processing delay
- Don't use sarcasm or irony to avoid misunderstandings
- Be aware and observant in regards to a person's level of arousal, agitation and distress
- Be passive in nature (regards to body language and personal space)
- Mindful of tone and volume of your verbal discourse

- Thinks about the environment and seeks to actively illuminate negative impact
- Be positive about the person and confident in yourself

It it beneficial to take a nonconfrontational collaborate approach. Deescalating high levels of stress and minimising impact. This should include giving time and space, being patient about the level of communication and interaction from the individual.

### COMMUNICATION STRATEGIES



# **STRUCTURE & ROUTINE**

SSS

For many autistic people, structure and routine play an important role in navigating an often uncertain world.

Autistic Adults often need help to know:

- What is going to happen
- When its going to happen
- Who is going to be there
- Where is it happening
- How and How long for?
- How will they know when its finished?

We can support autistic people by helping them build healthy routines, implementing visual aids, and offering plenty of preparation and planning in everyday life.



# **SOCIAL SKILLS**

### Challenges

- Monopolising the conversation
- Making irrelevant or inappropriate comments
- Only accepting their own opinion
- Unable to read social situation and know how to respond
- The unwritten rules of behaviour
- Trouble telling or retelling stories
- Reading non verbal cues
- Over focussing on words and not seeing the bigger picture
- Being judgemental of others rather than curious
- 1. I think you think. Knowing people have their own thoughts feelings and beliefs
- 2. Explore different perspectives
- **3.** Looking for clues about how someone else maybe thinking and feeling
- 4. Use social stories and comic strip conversations
- 5. Films and TV interactions can also help build knowledge
- 6. Understanding characters motivations, personality
- 7. How they express themselves

### **Developing Self Awareness**

Takes time and maturity but can be supported. You can seek to provide positive and constructive feedback to understanding their strengths, aspiration, challenges.

Expand circles of friendship and encourage broader interests

Identity awareness could be promoted by learning about their autistic identity and connecting to other neurodivergent individuals with similar outlooks and common interests.

- Understanding the giving and receiving of relationships
- Learning to build trust and confidence
- Social Stories to talk about social situations
- Practicing social skills
- Knowing what to do when they feel socially awkward
- Making plans and having a back up plan

### Understanding 'secret' rules

Understanding 'secret' rules can be complex. Explaining them over time can be an important support tool for autistic people. When coming across idioms and metaphors it can be helpful to explain their meaning in literal terms. Practicing these skills at home could be key but need to be carefully thought about so that the autistic isn't' confused around mixed messages or concerns then about their own integrity.

### 'Social Rules' Challenges

- Idioms and metaphors
- Dress code
- Body language
- Manners
- Social hierarchy

- Environmental cues
- When honesty isn't the best policy
- Banter and Teasing

# SENSORY NEEDS

There are many ways we can support an autistic person to fulfil their sensory needs including:

- Sensory aids stress balls, wrist bands
- Encouraging safe stimming it has a function
- Physical activities e.g walking, trampolining
- Relaxation techniques such as deep pressure massage
- Activities to help organise the mind such as tangles toys
- Grounding and Mindfulness
- Avoiding different textiles in clothing
- Avoiding strong scents
- Using Weighted blankets



# **EMOTIONAL TOOLS**

Autistic people can benefit from being supported to grow an 'emotional toolkit'

This can include:

- Exploring ways to identify and express emotions
- Developing healthy coping mechanisms
- Practicing regular safe care
- Energy management
- Crisis kits
- Plans for meltdowns/shutdowns
- Building self esteem

### UNDERSTANDING BEHAVIOUR

When supporting an autistic person, it is important to look for the function of a behaviour – is it related to gaps in skills and knowledge, anxiety, sensory overload, unexpected changes, stressful situations, exhaustion etc.

It can be useful to **'be a detective'** – reframing behaviour as a result of unmet needs and working to explore what those underlying needs may be. Doing this can help us build a pattern over time, and in doing so we can work to tackle the root causes of behaviour, ultimately leading to more successful outcomes.

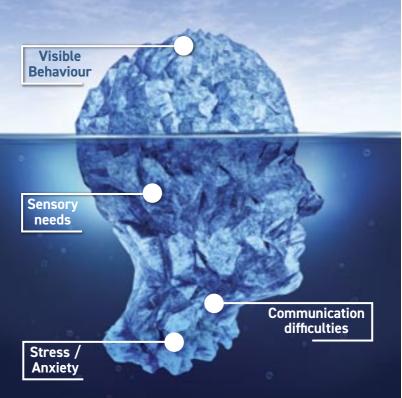
Think about the iceberg – behaviour is what you see on the surface, but there may be many causes that are not immediately visible contributing to this.



If we deal only with the outward, visible behaviours, the need will remain unmet and it is likely another behaviour will emerge as a result.



**Understanding Behaviour Tool** 



Visible behaviour is often just the 'tip of the iceberg' - it is vital to uncover and resolve the underlying functions of behaviour

### **BEHAVIOUR PLANS**

The Behaviour plan will seek to proactively support the person and 75% of the strategies included in the plan should be PROACTIVE... helping a person develop skills and strategies to enable them to live independently. These should include:

- Learning social skills, (taking turns, starting conversations, asking for help)
- Forming healthy and positive relationships
- Problem solving and making choices
- Mental health and wellbeing toolkits

- Communication Passports
- Sensory profile
- Emotional regulation.

The other 25% of strategies are ACTIVE (observing elevated stress and knowing how to positively support someone to lower their levels of arousal) and REACTIVE (managing meltdowns and loss of control).

#### Longer term consistent approaches work best.

Consequences and punishment are known to not be as effective or appropriate in managing the behaviour of an autistic person.

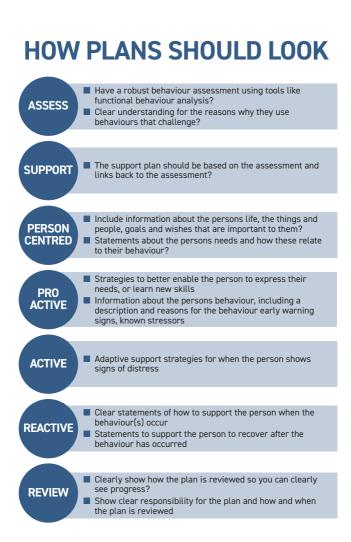
Police interventions such as arresting/detaining an autistic person are not appropriate strategies to support an autistic person to engage more successfully in the community.

### **BEHAVIOUR PLANS** What should they include?

- A person centred plan
- ✓ A health care plan that is specific for each person
- ✓ A one-page profile
- A support plan
- Use of communication passports
- A plan of what is going to happen each day
- Communication aids

#### Remember

There may be some goals that are private to the person and written information about their progress may be kept confidentially



### STAYING SAFE ONLINE Pros and Cons to the online world

The online world can open doors for autistic individuals and they can be encouraged to meet others and share interests using online groups.

There will however need to be adequate Education and Supervision and establishing boundaries and time limiting online activities.

#### Vulnerabilities can include:

✗ Bullying can be 24/7

 Ver stimulating, causing aggressive behaviour

However online spaces can provide an important access to niche communities

- Online socialisation can build confidence and social skills
- Online Gaming can be a way to create links with others with the same interests and provide a topic of conversation

× Grooming

Education should be given around types of healthy and unhealthy online activities

- Online behaviour etiquette
- Communication Strategies and using "Appropriate" language
- When to ask for help or report something as unsafe
- How to FACT Check information online
- What platforms are appropriate and what should be off limits

#### Supervision should be centred around

- Time spent online being appropriate including times of day. Screens tend to stimulate the mind so late night gaming could prove problematic.
- Parental controls and checks there are also apps that can be bought to help view online technology at a distance.

### **USEFUL WEBSITES**



autism.org.uk



autismwestmidlands.org.uk



pdasociety.org.uk

nice.org.uk

autism west midlands

National Institute for Health and Care Excellence

autismwestmidlands.org.uk

G The Autism

theautismdirectory.com

asdinfowales.co.uk

cerebra.org.uk



AwtistiaethCymru org AutismWales.org

ldw.org.uk

### or visit us at **autsideeducation.co.uk**

### **GLOSSARY:** Abbreviations

Abbreviation	Description
AAT	Adult Autism Team
ABA	Applied Behaviour Analysis
ADOS	Autism Diagnostic Observation Schedule
ALN	Additional Learning Needs
ALNCO	Additional Learning Needs Coordinator
ASC	Autism Spectrum Condition
ASD	Autism Spectrum Disorder
CAMHS	Children and Adult mental health services
DISCO	Diagnostic Interview for social and communication disorders
DIR (FLOORTIME)	Developmental Individual Relationship model
IAS	Integrated Autism Service
IEP	Individual Education plan
LEA	Local Education Authority
MDT	Multi Disciplinary Team
NDT	Neuro Development Team
ОТ	Occupational Therapy(ist)
PBS	Positive behaviour Support
SALT	Speech & Language Therapy(ist)
SEN	Special Educational Needs
SENCO	Special Education Needs Coordinator

### **GLOSSARY:** Key Terms

Abbreviation	Description
Autistic Traits	Identifying as having characteristics that resemble communication, social interaction or sensory/other challenges
Broader Autistic Phenotype	Someone who is considered close to the autism spectrum
Central Coherence	The tendency of the brain to focus on small details. A struggle to see the bigger picture and be able to put things into context
Executive Functioning	Affects the way our brain is able to plan, organise and prioritise tasks and activities
Expressive/ Receptive Language	Communication can differ in terms of expressive and receptive language. A person maybe highly articulate but have processing delay and may struggle with comprehension
Interoception	The ability to know what is happening inside our bodies. Registering hunger, thirst, heat and pain
Occupational Therapy	Autistic people often have sensory differences needing occupational therapy to identify them and support the central nervous system and our brain to better receive and process messages that come from our senses. This is called sensory integration
Proprioception	The ability of our bodies to receive messages so we know where we are in space
Processing Time	The length of time taken for our brain to receive and comprehend verbal communication

# **KEY AGENCIES/SERVICES**

Abbreviation	Description
ASD Info Wales	All wales team that collaborates across sectors to co-produce information relating to autism
CAMHS	Mental Health Service to assess and support people with mental illness
Community Mental Health Teams	Teams that support people with mental health needs in the community
IAS / AAT	Team that provides diagnostic support for adults and post diagnostic support, as well as some support for parents/carers
NDT	Team that diagnoses autism and other conditions in children
Inclusion	Service that supports children to be able to access learning at school
National Autistic Society	UK's largest autism charity that provides services for autistic adults and has a network of parent support branches
Autism Directory	Charity that provides an online directory of relevant services, support etc, a helpline, employment support and other services for autistic individuals and families
Autism Connexions	Adult and Employment support service (Cardiff only)
Learning Disability Wales	Service that provides advice and guidance and employment support
All Wales People First	Advocacy Service led by people with Intellectual disabilities and autism








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