

Autism

A guide for GP's and
Professionals in
Worcestershire

"Content adapted from "Adults with Autism A Guide for GPs in Birmingham" by Jess Cook, with permission from Dr Elisabeth Hurley and Sarah Francis with material from Leicestershire County Council's "Top Tips for diagnosing, supporting and meeting the needs of people on the autistic spectrum" by Dr Y Delargy-Aziz"

Find out more online:
www.worcestershire.gov.uk

What is Autism?

Autism and Asperger's can be grouped under the term Autism Spectrum Conditions (ASC). For the purposes of this guide the term autism or ASC will encompass both autism and Asperger's.

Autism is a life-long neuro developmental condition affecting around 1.1% of the population. It is a spectrum condition meaning that it affects people differently and to varying degrees. Autism is broadly defined as affecting three main areas. These areas are:

- **Social Understanding** – Difficulty in understanding social behaviour and emotional expressions.
- **Social Communication** – Difficulty with understanding and using communication and language
- **Special Interests and differences in information processing**

Also, people with autism often have issues with sensory processing. They can either be over or under sensitive to any of the senses (sight, smell, touch, hearing, taste, balance and self-awareness).

It is important to remember that autism is not defined as a learning disability or a mental health condition/difficulty. However, autism can be associated with depression and anxiety. Other common co-occurring conditions may include Attention Deficit Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder, Epilepsy, Learning Disabilities, Learning Difficulties, addiction or Eating Disorders.

Early identification, needs assessment and appropriate support have been shown to greatly improve the quality of life of people with autism.

What might lead you to suspect that a person has an ASC?

It is important to remember that everyone with ASC is unique. However, the following may alert to the need for autism screening.

- High motivation and knowledge in special interests
- Rigidity of thinking
- Good attention to detail but unable to see the bigger picture
- Difficulty with planning and time management
- Unusual eye contact
- Stilted speech with repetitive use of phrases
- Out of context body language
- Unusual voice tone and volume
- Inability to pick up on and understand conversational cues.
- Difficulty understanding non-verbal cues, such as facial expressions, body language or eye contact
- An apparent lack of empathy with other people, resulting in them appearing rude, tactless or selfish.
- Clothing is unusual or inappropriate for the season or context of the actual weather
- A dependence on predictable, repetitive activities to provide reassurance
- Naivety or behaviour that is out of sync with their age
- Literal interpretation of language
- The reliable history/information from a family member or third party, such as a social worker raises the possibility of autism.

Worcestershire's Autism Partnership Steering Group has commissioned an Autism Pathway, which can be found on page 8 and 9.

How may autism affect a person's life?

- They might find contact with other people, especially strangers, distressing.
- They may cause offence without being aware and appear egocentric or rude.
- Forming and keeping friendships or other close relationships might be more difficult for them throughout their life.
- They may become extremely anxious if routines are broken.
- They may have been referred numerous times to a wide range of services.
- They might experience crisis at times of change, out of keeping with what one might normally expect.
- They might become angry or anxious if their expectations are not met or understood.
- They may display naivety or vulnerability out of keeping with their age.
- They may be unable to hold down steady employment or education.
- They may be identified by the criminal justice system as either victims or offenders.
- They may be vulnerable to abuse.

So...

- Their anxiety about speaking to unfamiliar people in an unfamiliar place might prevent them from speaking to a doctor even when they really need to.
- They could misinterpret your questions or instructions and as a result receive inadequate medical treatment.
- You could misinterpret their answers or explanations with the same result.
- If you unintentionally do not meet their expectation they might become angry or anxious and complain.

From a treatment perspective...

- Sensory sensitivity can affect pain perception. Therefore, if someone with a high pain threshold is complaining of pain, it may be more serious than it appears.
- Sometimes the location of pain can be problematic, so be clear when working with someone with ASC and physical problems.
- Some people on the spectrum may not have the same sense of when they need to go to the toilet, particularly if they are preoccupied with something else.

"You are a gatekeeper to assessment and support that could change their life."

Autism in Women and Girls

Ratio of diagnosed men to women is 4:1. This ratio probably misrepresents the true picture and is due to misdiagnosis, diagnostic overshadowing and male bias in current understanding of autism.

- Women are less likely to display the classic autism signs as they may work harder to fit in socially by modelling their behaviour on others.
- There may be a higher rate of mental health conditions in women due to the effort of compensating for the symptoms.
- Special interests will vary between men and women. Women may have more social special interests like soaps and celebrities so attention should be given to the intensity of the interest.

- Women are often diagnosed with a number of other conditions before a diagnosis of autism is made. It is therefore important to consider the above when considering referral for diagnosis and support for girls and women.

Further information is available on the final page of this pack.



How to have an autism-friendly conversation

Although it is general good practice to communicate with your patient in a way which is best for them, people with autism will benefit significantly during consultation if their GP:-

- Explains verbally and/or in writing what is going to happen next at each point during the consultation so that the person has clear expectations throughout. Consider demonstrating by using the actual items (such as a syringe or blood pressure device) or use pictures if appropriate.
- Asks direct and closed questions.
- Waits longer than usual for a response to questions rather than repeating yourself or rephrasing your question if they don't answer immediately.
- Offers additional appointments and support. It can take people on the autism spectrum longer to process the information required to make a decision, so they may need follow up appointments and additional support to help make a decision.
- Remembers that no eye contact does not mean that they are not listening.
- Speaks in short sentences and avoid sudden changes in voice volume.
- Keeps Language as literal as possible.
- Keeps facial expressions and gestures to a minimum.
- Consults family or friends with the permission of the person if you think further information would be useful.

Check on shared understanding of history, assessment and management. Don't assume that saying "I understand" means that they do.

Why is recognition important?

ASC's are a recognised disability and diagnosis can open pathways making life easier for the patient.

Diagnosis helps individuals make sense of the world around them, their history and difficulties.

Families, friends, carers, employers, the criminal justice system and educational establishments are helped to understand, accept and respond appropriately to the individual's needs.

Diagnosis helps individuals' access appropriate support.

Better understanding of a person can help consultation, dynamics within the surgery, access to and engagement with medical services.

There is a possibility that many undiagnosed individuals with ASC are frequent surgery/out of hours and casualty attendees as well as generating/ seeking multiple referrals.

Although it is not known what causes ASC, it is a condition that affects every 1 in 100 patients which has to have some impact on chronic disease or long term conditions, treatment and engagements with medical services.

61% of people surveyed about their diagnosis by the National Autistic Society in 2012 said they were relieved to receive their diagnosis and 58% said it led to getting new or more support.¹

Self-referrals will often simply want to know whether or not they have ASC (after identification one often hears the phrase "it is a relief to know what it is") to better understand themselves, explain past behaviour and enable them to develop coping strategies.²

¹ Bancroft, K., A. Batten, S. Lambert and T. Madders. (2012) The way we are: autism in 2012. The National Autistic Society.

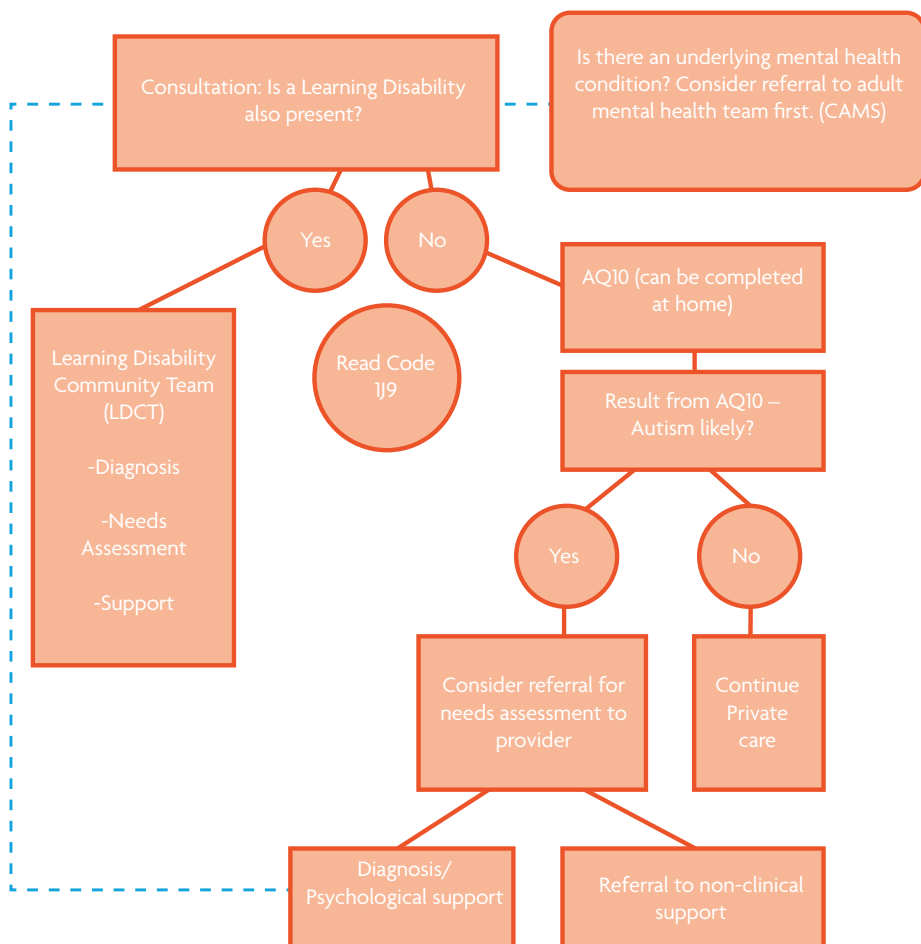
² Beardon L and N. Chown (2013) West Midlands Adult Autism Identification Pathways: Principles and Practise. Sheffield Hallam University.

What next for adults (18 and over)?

If during a consultation you suspect a patient may have undiagnosed autism, consider asking the person to fill in the AQ10 to give an indication, but only if they don't have a Learning Disability or there are signs of an underlying mental health condition. It may be worth checking their previous medical history and childhood documentation.

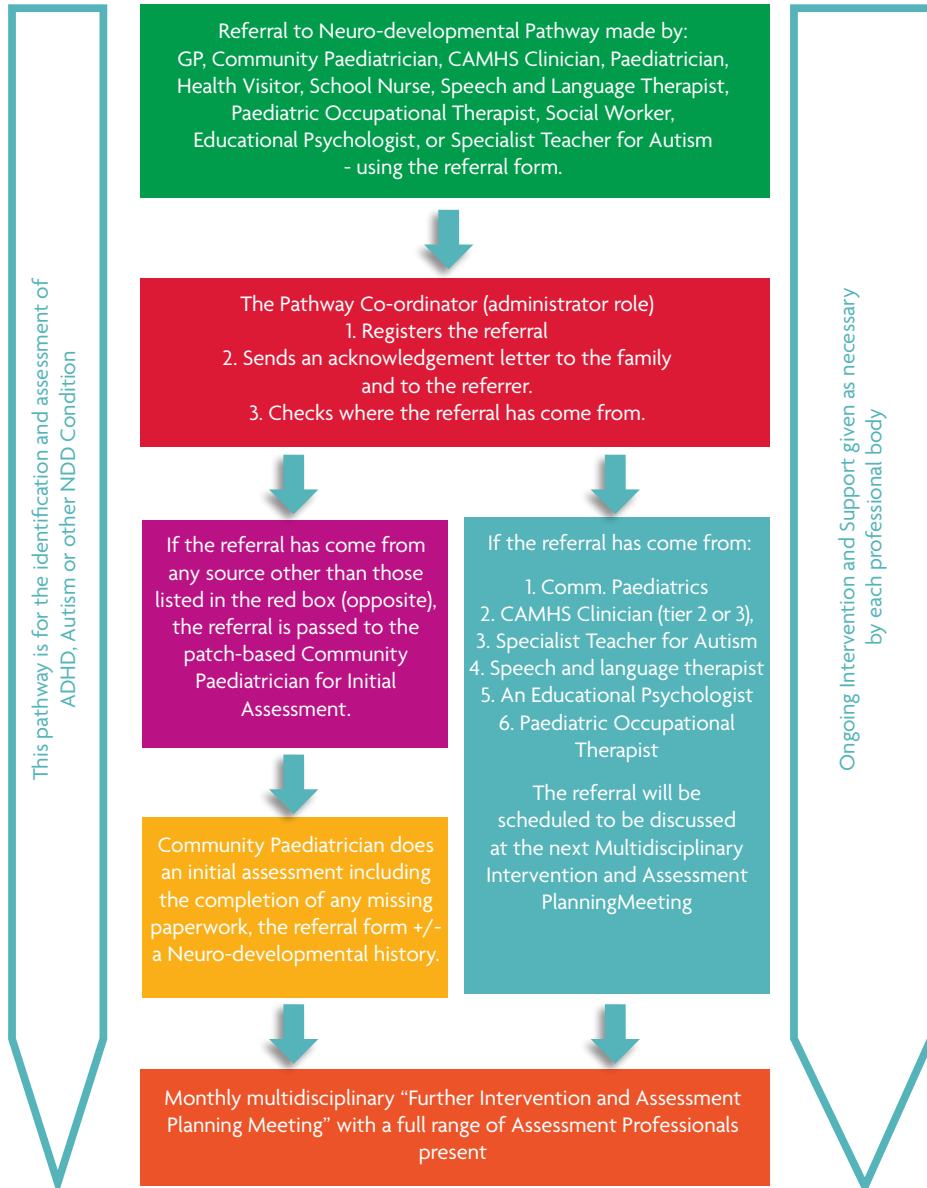
If the patient also has a learning disability, refer to the Community Learning Disability Team.

If they do NOT have a Learning Disability and do not have an underlying mental health conditions, refer to Autism Service.



What next for Children (under 18)?

Neuro- developmental Pathway for school aged Intervention and assessment



Practical Practise Tips and Ideas

The following things could cause a person to feel anxious, agitated and distressed when visiting the doctors:

- Calling to book an appointment and having to speak to a stranger.
- Appointments consistently being at a time of day that is not suitable for them.
- Travelling to the surgery, especially if they have not been before.
- The lighting or noises in the waiting area.
- If the doctor or nurse does not keep to their appointment time.
- If they have an appointment at a busy time when lots of people will be in the waiting area.
- Seeing a different doctor or nurse every time they visit.

So, here are some suggestions to help people with autism feel less anxious about coming to see the doctor:

- All in house staff should receive autism awareness training.
- Place information online and in writing about visiting the surgery and what to expect, the services available, and step-by-step guides to common processes, such as collecting medication from the chemist.
- Having some pre-bookable appointments may be necessary.
- Appointments can be booked online or by email as well as by phone.
- People with autism known to the surgery can choose a time for their appointment rather than by allocated times.
- Quiet area of the waiting room or the option to wait outside or in their car and be called in.
- Give higher priority than would be normal in triage clinics/urgent appointments, as people with autism may have unusual responses to pain/illness or very high pain thresholds.

More information about Autism and Local Services

National Institute for Health and Care Excellence (NICE) clinical guidelines on recognition, referral, diagnosis and management:

- NICE clinical guidelines for adults
<http://www.nice.org.uk/guidance/cg142/resources>
- NICE clinical guidelines for Children
<http://www.nice.org.uk/guidance/cg128/resources>
- The National Autistic Society is a national charity for people with autism. Visit www.autism.org.uk or the national directory of autism services at www.autism.org.uk/directory
- Autism West Midlands is a regional autism charity providing information about autism and a wide range of services across the West Midlands. Visit www.autismwestmidlands.org.uk
- Police/emergency services autism alert cards available online www.autismwestmidlands.org.uk/attention
- ASPIE is a social self-help and motivation group for adults with Asperger's syndrome. <http://www.aspieeverywhere.org.uk/> email: Admin@wits-endweb.co.uk Tel: 01905 27825
- Rainbow is a non-profit organisation dedicated to improving the lives of those with Autistic Spectrum Condition,

including Asperger's Syndrome, and those with ADHD. <http://www.rainbowautism.org/> email: mailto:information.rainbow@sky.com Tel: 01684 312760

- Worcester Snoezelen: is a multisensory leisure therapy centre specifically for people of all ages who have disabilities. <http://www.worcestersnoezelen.org.uk/> Email enquiries@worcestersnoezelen.org.uk Tel: 01905 748229
- Ourway Self Advocacy – runs self advocacy groups for adults with learning disabilities. office@ourway.org.uk or telephone 01562 820262
- Onside Advocacy: Provide a range of services and support individuals to overcome disadvantage and be treated fairly. <http://www.onside-advocacy.org.uk> Email info@onside-advocacy.org.uk Tel: 01905 27525
- Free online autism awareness training developed by Autism Connect is available online at <https://autism-connect.org.uk/>
- Autism Education Trust: licensed trainers of the AET programmes in early years and post 16. Visit the website at <http://www.autismeducationtrust.org.uk> or contact Karen Broderick, Principle Teacher on 01905 765830.

More information about Autism and Local Services

For more information about the research and issues surrounding girls and women with autism, please explore the links below

- http://www.autismwestmidlands.org.uk/upload/pdf_files/1403677773_Autism&Women.pdf
An introduction to the research around Women and Girls with Autism produced by Autism West Midlands
- <http://network.autism.org.uk/good-practice/case-studies/cbt-based-groups-women-autistic-spectrum>
An overview of CBT based groups for Women on the Autistic Spectrum written by Clinical Psychologists.
- <http://www.autism.org.uk/about-autism/introduction/gender-and-autism/preparing-girls-for-adulthood.aspx>
Further information on the behaviour profile of girls and women produced by The National Autistic Society

- <http://www.amaze.org.au/girls-and-women-on-the-autism-spectrum/>
A scientific article on Girls and Women on the Autism Spectrum that details many of the current issues around female diagnosis of autism.

- <http://www.rightrelevance.com/search/articles/hero?article=cb92e31155ca0e0b0e72d5e97f7a4779c55c8478&query=asperger%20syndrome&taccount=aspergerrr>
An article written for the Guardian newspaper regarding the under diagnosis of women.

Find out more online:
www.worcestershire.gov.uk

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