



# Top tips for diagnosing, supporting and meeting the needs of people on the autistic spectrum.

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# Useful Resources

- Autism NI – [www.autismni.org](http://www.autismni.org)
- Action for Children – [www.actionforchildren.org.uk](http://www.actionforchildren.org.uk)
- Autism Initiatives – [www.autisminitiatives.org](http://www.autisminitiatives.org)
- Barnardos – [www.barnardos.org.uk/northernireland.htm](http://www.barnardos.org.uk/northernireland.htm)
- Carers NI – [www.carersuk.org/northernireland](http://www.carersuk.org/northernireland)
- Cedar Foundation – [www.cedar-foundation.org](http://www.cedar-foundation.org)
- Children and Adolescent Mental Health services - [www.camh.org.uk](http://www.camh.org.uk)
- Children in Northern Ireland (CINI) – [www.ci-ni.org.uk](http://www.ci-ni.org.uk)
- Department of Education – [www.deni.gov.uk](http://www.deni.gov.uk)
- Department of Health and Social Services – [www.dhsspsni.gov.uk/ni](http://www.dhsspsni.gov.uk/ni)
- Disability Action – [www.disabilityaction.org](http://www.disabilityaction.org)
- Local Autism co-ordinator – contact local Health and Social Care Trust
- Mencap – [www.mencap.org.uk/northern-ireland](http://www.mencap.org.uk/northern-ireland)
- Middletown Centre for Autism – [www.middletownautism.com](http://www.middletownautism.com)
- National Autistic Society – [www.autism.org.uk](http://www.autism.org.uk)
- NI Commissioner for Children and Young people – [www.niccy.org](http://www.niccy.org)
- PEAT – [www.peatni.org](http://www.peatni.org)

# Introduction

**Autism is a lifelong neurodevelopmental disorder affecting about 1:100 of the population. Most adults remain undiagnosed. It can have a profound effect across all age groups on individuals, their families and work place/ employability.**

New guidelines issued in June 2012 by NICE ([www.nice.org.uk/CG142](http://www.nice.org.uk/CG142)) aims to improve services and care offered to those affected and Primary care has a vital role to play in this respect. Implementation of the NICE guidelines is an important start in helping this group of individuals who so often have poor social, health and employment outcomes.

The disorder affects individuals in a unique way specific to that person but underlying it are the same three core impairments. (triad of impairment).

- 1) Difficulties in social interaction.
- 2) Difficulties in social communication.
- 3) Rigid and repetitive behaviours with resistance to change and / or restricted interests.

There may be hyper- or hyposensitivity to sound, light, touch or pain etc.

There are often significant co-morbidities associated with a diagnosis of autism such as:

- 1) depression
- 2) anxiety
- 3) obsessive compulsive disorder
- 4) attention deficit +- hyperactivity
- 5) learning disability
- 6) epilepsy
- 7) addiction
- 8) eating disorders

The term Aspergers syndrome is often used to refer to someone with autism who is not significantly intellectually disabled.

# Top tips for considering autism

- Lifelong difficulties making/keeping social relationships.
- Persistent gaffes or upsetting of people.
- Naivety/vulnerability out of keeping with age.
- Rigidity/routine or rituals which when broken cause marked upset.
- Inability to hold down steady employment or education.
- Crisis at a time of change out of keeping with what one might normally expect.
- Individuals with multiple pathologies/attendances/referrals to secondary care....”heart sink” patients.
- Eating disorders.
- People who cause chaos and upset, and appear unaware / insouciant of the results of their behaviour.
- Egocentricity with little regard/empathy/sympathy for others feelings out of keeping with what would be expected.
- Individuals who may make multiple complaints with a steadfast feeling of perceived mistreatment/inequality/ .....
- When a patient asks you to consider it!
- Those identified by the criminal justice system (victims or offenders).
- The reliable history/information from an informant (family/friend/consultant/ police etc) with persons agreement.

# Autism Radar alerts visually

- Poor eye contact also staring.
- Awkward body language.
- Clothing unusual in appropriateness for season/weather/colour combinations/may be always the same.
- Few gestures or over the top gesticulation.
- Voice-loud, monotone, too quiet, labile affected modulation.
- Responding literally to direct questions and not to comments/humour.

# Tips in considering a referral

## Consider first:

- What will a diagnosis achieve for this patient?
- Can I manage this in practice by addressing social, educational or employment issues?
- Increasing routine/ immersion in specialist interests area/time off work short term for anxiety alleviation.
- Encourage organisation both written and visual.
- Try to identify the issue which may be destabilising the situation.

## Then.....

- Patient request.
- Involvement with the criminal justice system or employment tribunals/ grievance.
- When person just not coping with world around them.
- "Unemployables" or difficulties at school/college.
- Significant impact socially/psychologically/medically on themselves and/or others.
- If social services becoming involved due to care needs.
- If impending crisis can be averted ie. Death/sickness of elderly carer.
- If medically and socially difficult to manage.
- Extreme vulnerability/naivety which puts them/others at risk.

# Why is diagnosis important?

- Autistic Spectrum Disorders 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.
- Better understanding of the self helps planning for the future.
- Families, friends, carers, employers, criminal justice system and educational establishments are helped to understand, accept and respond appropriately to individuals needs.
- Diagnosis helps individuals' access appropriate support.
- Better understanding of a person can help consultations, dynamics within the surgery, access to and engagement with medical services.
- Possibility that many undiagnosed individuals with ASD are frequent surgery/out of hours and casualty attendees as well as generating/seeking multiple referrals.
- A condition affecting 1:100 patients has to have some impact on chronic disease or long term condition treatment engagement with medical services.
- A diagnosis of suspected autism can be used in the notes as an alert.  
READ CODE 1J9.

# Top consultation skill tips

- Give consultations the same structure. You may have this set down in written form so that the patient knows what to expect and can even fill in the presenting complaint before coming in.
- Give patients time to talk, assimilate information and respond.
- Valuable information may be gleaned from family/carer/friend.
- Direct closed simple clear short questions work!
- Check on shared understanding of history, assessment and management. Don't assume "I understand" means they do.
- Where ever possible offer written evidence of the above.
- Offer patient leaflets to take away.
- Poor eye contact does not mean they are not listening to you.
- Don't expect eye contact.
- Try to keep consulting room's tidy, low arousal for any sensory issues.
- Keep sentences short direct and avoid sudden changes in voice volume.
- Don't use lots of body / hand movements when talking. Limit non-verbal communication.
- Treat the person not the disorder.
- Give advance warning of what is going to happen. If possible demonstrate.
- Empathise with their point of view. You may not understand it but we should respect it.
- Offer few and simple options.
- Use special interests if known to help communication and motivation.
- Avoid ambiguity, sarcasm, cynicism and other idioms etc. Careful with jokes! Keep Language concrete.

# Top referral letter tips

- Identify reason why referral has been done and what patient expects from referral.
- Indicate the medical, psychological, educational, and social impact of difficulties.
- Document name and nature of any informant. And try to recommend they attend the out patient appointment.
- Document any involvement with the criminal justice system as well as employment tribunals, litigation etc.
- Inform patient of the assessment procedure and what to expect. An awareness of the diagnostic procedure and support/care after available locally is paramount as unmet expectations can generate complaints.
- Identification of concurrent medical conditions and extent of engagement with healthcare system.
- Identification of any carers and any issues pertaining to them which may affect the patients care/support. (illness etc).
- Include any pertinent paediatric/educational psychology reports.
- Attach any written report from the patient/carers of their ideas/issues which lead them to suspect autism.



# Support in Northern Ireland (NI)



Autism NI is Northern Ireland's own independent Autism charity. It provides the following services:

- **Advice Line:** Autism NI provides an Advice Line Service for post diagnosis support. Advice Line advisers provide comprehensive information on Autism and signpost families, carers and those with Autism to local community and statutory services. Contact **028 9040 1729 option 1**.
- **Training:** Autism NI was commissioned by the DHSSPS in 2002 to provide quality training in Autism. Since then Autism NI has provided training for Health and Social Care Boards and Education Boards in Northern Ireland and the Republic of Ireland. We provide a range of training for parents and extended family in coping strategies, communication, sexual health and growing up. Contact **028 9040 1729 option 2** for further information.
- **Family Support:** Autism NI facilitates a growing network of support groups throughout Northern Ireland which currently serves over 23 locations. Groups organise Autism friendly activities in their local area and invite speakers to their monthly meetings from voluntary and statutory settings to inform parents on a variety of topics relating to Autism. Contact **028 9040 1729 option 1** for further information.
- **Lobbying:** Autism NI led the campaign for the Autism Act (NI) 2011 which now provides recognition for Autism within the Disability Discrimination Act definition of disability and has led to a cross departmental government strategy on Autism. To find out more about our journey, please contact **028 9040 1729 option 4**.
- **Contact details:** Autism NI, Donard House, Knockbracken Healthcare Pk, Saintfield Road, Belfast, BT8 8BH.  
Tel: 028 9040 1729. Web: [www.autismni.org](http://www.autismni.org). Charity no XR22944.

# Diagnosis referral process in NI

## Process of Child Diagnosis

### Referral criteria as follows:

- If a child is encountering difficulties, refer him/her to a paediatrician for assessment
- Assessment may be at an outpatient appointment at a hospital or a child development clinic, care centre, or by a professional in the field of education or health
- Complete an Autism Service Team referral form to start the process of referral

## Process of Adult Diagnosis

### Referral criteria as follows:

- Before referral, you must get valid and informed consent from the individual
- On receiving referral the individual must be 18 years or over
- All referrals should specify there is a concern about Autism with examples and evidence, using the diagnostic criteria
- It is appropriate to make a referral to a specialist diagnostic assessment if an adult has significant difficulty in daily functioning
- Referrals should be completed on the Standardised Referral Form (found in the Health and Social Care Autism Pathway appendix 4). This should be sent to the specific referral pathway in the relevant Health and Social Care Trust, which will be one of the following:
  - Learning Disability Service (where there is a suspected or known diagnosis of learning disability)
  - Mental Health Service Single Point of Access (whether the adult has a mental health condition or not)
  - A psychiatrist or clinical psychologist

For more information, please visit: [www.hscboard.hscni.net/asdnetwork](http://www.hscboard.hscni.net/asdnetwork)

# Practical practice tips/ideas

- Consider in house staff autism awareness training.
- Read code using same code to aid any research/audit.
- Use suspicion of autism code 1J9.
- Place alert on patients notes to identify ASD.
- Information leaflet to patients detailing how to make appts, obtain medication and other services offered in written /electronic form.
- Ability to book appointments online.
- Ability to book first thing/last appt of day.
- Give higher priority order than would be normal in triage clinics/urgent appointments as may have unusual response to pain/illness or very high pain threshold.
- Touch screen booking in for appts.
- Quiet corner in waiting room.
- Offer ability to wait in car and be called in for appointment.
- If appropriate person available try to get someone with ASD to attend your PPG. (Patient Participation Group) or offer electronic route for feedback/comments rather than face to face or group attendance.

## My notes and contacts