



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

www.cymru.gov.uk

Autistic Spectrum Disorders

A Guide for People Working With Older Adults

December 2010



75% wedi'i ailgylchu
recycled

ISBN 978 0 7504 5972 3

© Crown copyright 2011

WAG10-11196

F1141011

Contents

Page

What are Autistic Spectrum Disorders?	4
Why are so few older adults with ASD known to services?	6
It's Like Rainman isn't it?	7
Impact of ASD for services to older persons	8
Hints for making your service and practice more autism-friendly	9
Helpful Links and Further Reading	13
Authors	14

What are Autism Spectrum Disorders?

Autistic Spectrum Disorder (ASD) is the group term for Autism, Asperger Syndrome and related disorders. The short-hand term 'Autism' is most commonly used. ASD is genetically transmitted and is common - it affects about one per cent of the population. Many people have heard the terms 'Autism' and 'Asperger syndrome' but assume that it is a childhood condition and not something that affects older adults. This is wrong - ASD is a lifelong condition. However, for reasons that will be explained below, very few older adults with ASD have ever been correctly diagnosed as having it. This is almost certainly resulting in many older people with ASD getting inappropriate or no treatment because their needs have not been correctly identified.

This publication is intended to help rectify this problem. In it, you will learn the basic features of ASD, its prevalence, and how you can shape your service and practice if you find you have someone with Autism in your service.

Features of ASD

A succinct summary was provided by the work of Wing and Gould¹, who argued that at the heart of ASD is a collection of problems collectively called the triad of impairment:

- Impairment of social and emotional skills, such as poor ability at forming friendships or even working relationships; and having great difficulty with dealing with 'free time' socially.
- Impairment of linguistic and communication skills, such as taking everything said literally (and thus e.g. being immune to sarcasm); having very unusual eye movements whilst conversing with someone else; having atypical facial and hand gestures; having pronounced problems in dealing with and remembering verbal information.

1 Wing, L. and Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of Autism & Developmental Disorders*, 9, pp. 11-29

- Impairment of flexibility of thought, such as profound problems imagining how others feel (and generally lacking empathy, though without being cold-hearted); having a very constricted range of interests; having extreme difficulty in dealing with changes in routine.

Diagnosis

There is no single test that identifies ASD. Diagnosis is normally made by a multi-agency team that judges if the features displayed match those set out in one of the commonly-used diagnostic manuals and this is matched with a very full developmental history of the individual. The diagnostic process is led by a suitably-trained professional (typically a psychiatrist or clinical psychologist).

Cause

It is now well established that ASD has a genetic cause. Generally, if one person in a family has it, it is highly likely that there will be at least one genetic relative who also either has the condition or some symptoms of it. It is not the result of 'faulty' parenting, poor upbringing, or similar.

Prevalence

ASD is a very common condition and is estimated that up to 1% of the population have ASD. To take an everyday example, every time you walk into a busy supermarket there are probably two or more people in there with ASD (and most probably undiagnosed). On a rather larger scale, we can predict that in Wales alone, there are circa 17-25,000 people with ASD, of whom approximately 4,000 will be aged 60 years or older, and most of the latter group remain undiagnosed². Approximately a third of these people will be aged 60 years or older. However, whereas nearly all people with ASD aged 20 or younger are known to health authorities, only a small of older adults (i.e. over 40yrs of age) with ASD are known to statutory services.

² Stuart-Hamilton, I., Griffith, G., Totsika, V., Nash, S., Hastings, R.P., Felce, D & Kerr, M. (2009) The circumstances and support needs of older people with Autism. Report for the Welsh Assembly Government. Cardiff: Welsh Assembly.

Why are so few older adults with ASD identified?

The reason why so few older adults with ASD have been identified is simple. ASD has only become a common diagnosis in the last few years. Prior to this, people with ASD were of course known, but they were classified as having different conditions. In some instances, this led to utterly incorrect treatments, in others, people's symptoms were seen as being 'eccentricities' not requiring treatment. In recent years, health authorities have become attuned to identifying ASD in children, but adults have been largely ignored. So whilst the diagnosis of ASD has skyrocketed in children and teenagers, older adults with ASD have barely registered. This has led to the occasional misguided report in the news media of an 'epidemic' of ASD, which is incorrect.

Associated problems

A lot of people with ASD have learning difficulties and a low IQ. However, ASD is not confined to them. People can have an IQ in the typical range or indeed have a very high IQ and also have ASD. It is also known that adolescents and young adults with ASD have a higher than average probability of having depression and anxiety, and have much poorer employment prospects than the mainstream population.

NB: a high proportion of people with intellectual disabilities also have ASD³. Therefore, in dealing with someone with intellectual disabilities, it is important that an especial watch is kept for symptoms of ASD that could easily be discounted as simply further manifestations of intellectual disabilities.

How can adults have missed receiving a diagnosis?

The difference is generally one of degree. People with Autism typically have far more severe symptoms than people with Asperger Syndrome. This means that Autism nearly always presents itself with very glaring deficits in all three of the triad of impairments. In the most profound of cases, people with Autism have extremely restricted forms of communication. In the case of Asperger syndrome, the symptoms can be far subtler, as they are generally less pronounced. For example, at first sight, someone with Asperger syndrome can appear to be a bit socially inept and gauche, but nothing might strike you as being out of the ordinary. Likewise, in many people with Asperger syndrome, the constricted range of interests might manifest itself as an obscure collecting hobby that is unusual but not socially marginalized.

How are older people with ASD different from children with ASD?

The simple and honest answer is that we do not know. Because so few older people with ASD have been identified, no really detailed work has been done with them. What research is available indicates that ASD is just as prevalent in older people as it is in younger age groups⁴, and that the associated psychiatric problems such as much higher rates of depression and anxiety are present in older people with ASD⁵. People who are aware of their condition generally report extreme frustration at lack of close relationships and people dismissing their problems as being simply due to intellectual failure or a blinkered view of the world⁴.

I've seen Rainman - it's like that, isn't it?

Every few years a film or documentary featuring a person with ASD comes along, and the public imagination is grabbed, because the central character has, in addition to typical symptoms, an unusual gift. Two notable examples being

4 Brugha, T., McManus, S., Meltzer, H., Purdon, S., Scott, F., Baron-Cohen, S., Wheelwright, S., Smith, J. & Bankart, J. (2009). Development and testing of methods for identifying cases of Autism Spectrum Disorder among adults in the Adult Psychiatric Morbidity Survey 2007. The NHS Information Centre.

5 Stuart-Hamilton et al. (ibid).

Dustin Hoffman's performance in 'Rainman' and more recently Sigourney Weaver's portrayal of a woman with ASD in Cardiff Director, Marc Evan's, film 'Snowflake'. These savants, as the Americans like to call such individuals, do genuinely exist, but they are very untypical of the condition. Therefore, in considering if a person has ASD, don't have the idea that they will have the ability to tell which day of the week an historical date fell on, or that they will have an all-consuming interest in timetables. Only a very small proportion of people with ASD have this ability.

Impact of ASD in Services to Older People

How do I recognise individuals with autism within my service?

Individuals with ASD become old just the same as most of us and therefore you might occasionally find such individuals living in your services for older persons. From the information given above you can see that ASD comes in a wide range of 'flavours'. Looking at the list of symptoms on paper, it can appear 'obvious' but dealing with the situation in everyday life is radically different. The following symptoms have been reported in various books, advocacy group websites and similar, as being typical specific behaviours found in children with ASD. The available evidence indicates that the following should apply to older people with ASD as well:

- An insistence on sameness and resistance to change. This should go beyond the stereotype of an older person who is 'stuck in their ways'.
- Unusual eye contact in conversation. Generally, this will consist of no or far too little eye contact, but might also include uncomfortably long eye contact.
- Uneven motor skills - can appear average or unremarkable at some skills, but very clumsy in others.
- Speech can appear over-enunciated or have unusual tonal qualities (often described as 'sing song').

- An extreme avoidance or very unusual dislike of social occasions, particularly where there is a degree of unstructured freedom about things (e.g. in a party situation where individuals are free to wander about and make conversation). Note that this goes beyond what might be considered 'normal shyness'.
- A tendency to take things literally. This particularly applies to colloquial sayings (e.g. the compliment of 'I could wrap you up and take you home with me' led one accountant with ASD to hide herself in the lavatories, convinced her line manager wanted to kidnap her). Note that older people with ASD might have rote learnt what many phrases mean, so this might not be as obvious as with younger adults.
- A tendency to get on far better with any group other than their immediate peers.
- An unusual tendency to want to be alone that goes beyond simply being shy and retiring.
- Very poor social skills, particularly in response to overt but relatively basic friendly greetings. This might be contrasted with far greater levels of communication in a highly structured situation, where e.g. there is a set of questions to be answered and there is a clear purpose to the meeting.
- Generally, people with ASD tend to thrive in the situations most people hate (boring, repetitive tasks, meetings with a high level of formality and structure) but will avoid the situations most people seek to let their hair down after such situations (e.g. a party or social gathering).

Hints for making your service and practice become more autism-friendly

The first thing to remember is that people with ASD in the main have similar likes and dislikes as the rest of the population; the difficulty arises when these likes or dislikes are taken to such a level that then inhibits an individual's capacity to function comfortably in everyday life and may impact upon other's responses to them. The following are a few suggestions:

Residential Homes

The building and environment

The guiding principle here is low arousal. Nearly everyone prefers to live in peace and quiet in big rooms without clutter. However, this is a pressing need for many people with ASD. Noise in particular can be distressing. As tranquil an environment as possible is desirable in most cases. For example:

- **Keep things the same.** People with ASD may get very distressed if their surroundings are changed. Well-intentioned spring cleaning, changing of furniture layouts, etc, can cause very great distress (and lead carers to think the person is being irrationally ungrateful). If changes have to be made, talk about things, and arrange a mutually agreeable plan.
- **Shared living areas.** People with ASD can find it very difficult and often unpleasant to interact with other people (and some one who tries to 'get them out of their shell' will probably make things worse). Giving people with ASD the opportunity to have a quiet area of their own, or easily to leave a room with other people in it if things get too noisy, is strongly advised.
- **Colour schemes.** Neutral/restful colours and soft surfaces are generally preferred (though obviously there are practical limitations to how far this can be done).
- **Echoes and other noises.** People with ASD can be unusually sensitive to echoes, clangs, rattling noises and similar. These should be minimized where possible. Little things that might not strike you as annoying or important, but which are easily fixed (e.g. a squeaking hinge) should be dealt with as a matter of routine.
- **Shiny and bright items.** Shiny surfaces and over-bright rooms can cause problems for some people with ASD. Obviously there are safety and practical needs to be considered (not least that most older people have poor vision in low light), but where possible, try to avoid too garish an environment.

- **Keep things robust.** Some people with ASD can be a bit heavy-handed. Items in everyday use might have to be a little more robust than usual.

Routines within the environment

- **Punctuality.** Some people with ASD will be distressed unless key events happen like clockwork at the same time every day. If this can be accommodated, then all well and good. If it cannot, then negotiate with the individual about a pattern that is mutually convenient (e.g. such and such an event will happen between particular times rather than exactly at a specific time).
- **Routine.** If a person with ASD decides they have a specific chair that they always must sit in, they must always wear a particular item of clothing, etc, then as far as possible accommodate them, within the limitations of pragmatics and health and safety. However, once again, negotiate to see if a more acceptable practice can be agreed (e.g. will always wear something from an agreed range of choices, can always have one of a set of chairs, etc).
- **Educating other people.** There is little point in observing the needs of a person with ASD if other people (e.g. other clients in a retirement home) are unaware and, for example, constantly trying to get a person to join in with social activities. How you approach this issue will depend very heavily on the specific circumstances, but a way should be found to ensure that other people are aware of these needs.
- **Bonuses.** A lot of (though it must be stressed, not all) people with ASD love repetitive tasks. If you can find something that is repetitive but the person likes doing and can do it competently and safely, then use it!

Private homes

Much of what has been said about residential homes applies here. However, it is likely that the person with ASD has already shaped their home to the way they want it. The issue here might be to negotiate for a safer environment (e.g. replacing a much loved but frayed stair carpet and similar). This has to be done on an individual basis. There is also an issue of social skills.

A person with ASD in their own home might have reached a stage of requiring external assistance. But that will mean dealing with other people. Offering social skills training might therefore be a high priority. It is also imperative that people sent to the person's home are aware of the person's specific needs, and training for key personnel is advisable.

Helpful Links and Further Reading

Links within Wales:

- In April 2008, the Welsh Assembly Government published the world's first government action plan for autism and this strategy has led to a local ASD lead being appointed within every local authority area in Wales. You can find out who your local ASD lead is by contacting your local social services dept or by contacting the Welsh Local Government Association (tel 02920 468600). The WLGA is the home for three ASD regional support officers who will also be able to give you the information you require. Make sure you receive by email regular copies of the WLGA ASD Strategic Action Plan newsletter, which updates autism progress and practice throughout Wales, simply give you email address to the WLGA ASD Regional Support officers. ASDinfo@wlga.co.uk
- As a result of the WAG ASD Strategic Action Plan there are a number of other awareness-raising materials being published for Teachers, GP surgeries; Clergy and so on.
- All-Wales Autism Resource : a bi-lingual information resource for ASD in Wales and each autumn runs the world on-line autism conference featuring many of the world's leading educators, clinicians, and researchers.
www.awares.org

Links outside of Wales

- The National Autistic Society website contains very useful guidance and advice.
www.nas.org.uk
- Adam Feinstein, who is a both parent of a young man with autism and is employed in Wales by Autism Cymru, is the author of “A History of Autism, Conversations with the Pioneers” published by Blackwells/Wiley. This includes the most accurate history to date of autism, the way is currently viewed throughout the world and the approaches being used by governments and those working with people with autism. This book is viewed as a modern ‘classic’ in the disabilities field.

The authors of this Welsh Assembly Government publication are:

Professor Ian Stuart Hamilton, University of Glamorgan

Dr Gareth Morgan, Welsh Assembly Government

Yvonne Apsitis, United Kingdom, Home Care Association