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Autistic Spectrum Disorders

Primary Healthcare Settings

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What are Autism Spectrum Disorders?

Autism spectrum disorders (ASD) are diagnosed when a child or adult has impairments in social interaction and social communication together with impaired social imagination and a narrow repetitive pattern of activities and interests. The term 'autism spectrum disorder' is a broad term that refers to the subgroups known as Pervasive Developmental Disorders (PDD). These subgroups include Childhood Autism, Asperger syndrome, and other autism spectrum disorders, all of which are defined by the World Health Organisation's International Classification of Mental and Behavioural Disorders. Research evidence indicates that 1 in 100 individuals has an autistic spectrum disorder (ASD) in the UK.

Impact of ASD in Primary Healthcare Settings

Therefore, a number of children and adults with ASD coming to primary health care settings will already have a diagnosis of ASD. Diagnosis involves a comprehensive assessment by an experienced team of clinicians that usually includes a detailed interview with the parent, specific psychological and language assessments and clinical observations. Referral for assessment and diagnosis enables the individual to access the most suitable support and advice and evidence shows that suitable support and early intervention provide the best outcomes for individuals with ASD.

Although population estimates show that Autistic Spectrum Disorders are relatively common, they are under-diagnosed in the current population, especially in adulthood. In addition, some individuals may have particular signs of ASD without necessarily having the full syndrome of ASD that would result in a diagnosis. It is therefore important to recognise the signs of the disorder as many people you come into contact with may not be aware that this is why they are experiencing difficulties.

It is also important to be aware that ASD is commonly found together with other medical conditions, both physical and mental. The identification and treatment of additional health conditions should be given special consideration as their effect on the individual may be exacerbated by the ASD. The following conditions are frequently found and when they co-occur with ASD they may present special difficulties: sleep difficulties, gastro-intestinal problems, glue-ear, epilepsy, anxiety, depression, dyspraxia, dyslexia, obsessive compulsive disorder, catatonia, attention deficits and hyperactivity.

The purpose of the information given below is to give advice about how the primary health care setting can be adapted to help the child or adult who has an ASD.

Accessing Health Care

People with an ASD, whether diagnosed or not, often experience difficulties in accessing health care services. Many healthcare services require a patient to seek an appointment, and to be able to visit a healthcare service and explain their difficulties to an unfamiliar person. An individual with ASD will lack the skills needed to be able to do some or all of these, and will therefore need the support of access healthcare services. Many of the difficulties an individual with ASD will experience can be eased or eradicated with a little preparation, like highlighted; comments on the patient's notes, indicating that the person in question has ASD. From reception staff to healthcare practitioners, all healthcare staff play an important role in being able to support the individual in their attempts to access services.

Appointments

Due to the difficulties individuals with ASD have with social communication they may find making an appointment difficult. Complicated appointment systems may be hard for the individual

to understand and they may not be able to communicate how urgent their need for an appointment is with you.

Individuals with ASD may find it difficult to be in a health centre / clinic when there are lots of people present where possible. Making an appointment for a quieter time of day may help. As the person may need more time to be able to express their need to the healthcare practitioner, and the practitioner may take longer to elicit relevant information, it may be beneficial to offer a longer appointment for the individual with ASD so that their healthcare needs can be recognised and addressed.

Individuals with ASD often find it difficult to cope with unpredictable situations. Appointments can cause distress if they are not kept to time. It might then be better for the patient and the healthcare practitioner to try and make appointments at times that will more likely be kept e.g. at the beginning of a session. Inevitably there will be delays. You can help the individual with ASD to cope with these by informing them of delays in advance, and offering an idea of how long the appointment will be delayed for, if possible.

If the surgery sends an appointment letter to the individual with ASD, make sure the reason for the appointment is clearly stated along with the time and venue, as an individual with ASD can become confused.

Some helpful ways to adapt your practice:

- Ensure staff responsible for making appointments are aware of the difficulties an individual with ASD may experience and how to address these.
- Allow extra time for appointments with an individual with ASD.
- Make appointments that are more likely to start on time, such as at the beginning of a clinic.
- If appointments are delayed, keep the individual informed of the delay.

- Ensure the individual is clear about what time, place and with whom the appointment has been made. Follow up in writing if possible.
- If sending appointment letters, ensure information is clear and contains details of the reason for the appointment, if known.

Waiting areas

Some people with ASD will find the waiting room environment difficult to cope with. Hypersensitivities may mean that lighting, noise or even décor can cause problems. If the waiting area is busy with lots of people coughing, children crying etc the individual with ASD may not be able to tolerate the noise. People going back and forth can represent lots of changes in the environment that may be distressing. Children with an ASD may have challenging behaviours that their parents find embarrassing to deal with in public places, especially if they are worried about the appointment.

Some helpful ways to adapt your practice:

- Allow the individual to sit in a quiet area, away from others, if there is one.
- Dim lights, remove any other sensory distractions where possible.
- Keep to appointment times, where possible, to minimise waiting times.
- Allow a parent / carer to stay with the individual.

Communication

Individuals with ASD experience impaired social communication and social interaction, and this can cause problems when eliciting and imparting information. Being aware of these difficulties and adapting your own communication style will ensure that accurate information is gained from, and given to, the individual with ASD.

Lengthy questions and explanations can cause confusion for the individual with ASD. Individuals with ASD will often have a very literal understanding of language. Idioms, metaphors and similes may be very confusing or create misunderstandings. Don't be misled by the individual using metaphors, it does not necessarily mean they will understand yours, especially if they are not familiar with them.

Individuals with ASD often have an unusual eye contact. Some describe feeling uncomfortable with maintaining eye contact. Just because the individual is not maintaining eye contact does not mean that they are not paying attention to you.

Sometimes people with ASD do not realise that you are addressing them from interpreting social cues such as eye contact and body language. If the individual has sensory problems, it may be difficult for them to focus on what you are saying.

We often use analogies to explain things in simpler terms. It is difficult for an individual with ASD to link this with the original problem you are trying to explain.

The person with ASD may need time to process and understand what you are saying. Pausing frequently and allowing time for a response can help. Do not rely on your tone of voice, facial expression or eye contact to convey a message as the individual with ASD may not be able to interpret this. Interpreting the individual with ASD's body language, facial expression or tone of voice may also create inaccurate assumptions.

Using generalised questions may produce misleading answers, e.g. "How are you feeling?" May get a learned response of "very well, thank you", but asking "are you experiencing pain?" may prompt a "yes".

Asking lots of specific questions may elicit more accurate information. People with an ASD often do not offer any more information than they are asked for. For example, if asked "can

you get dressed?” an individual may answer “yes”, but may not offer additional information such as “but only if my carer puts all my clothes out in the correct order for me”. Asking “can you get dressed without help?” would produce a more accurate answer.

If you have the individual’s consent to do so, gaining information from parents and carers can be very helpful.

When giving information, it is useful to use pictures and provide written explanations. Always check that the individual has understood the information you have given them.

Some helpful ways to adapt your practice:

- Ensure that you have the person’s attention, minimise environmental distractions and address the individual by name from the start.
- Be clear and concise, keep lengthy explanations / questions to a minimum.
- Do not use idioms or metaphors.
- Avoid using analogies to explain things.
- Do not raise your voice or speak too quietly.
- Ask specific questions, rather than relying on generalised questions.
- Avoid questions involving emotions.
- Check the individual has understood.
- Use pictures to assist explanations.
- Provide written information following your appointment.

Examinations / Hypersensitivities

A physical examination can be difficult for anyone, even more so for the individual with ASD. If the individual is very anxious about visiting the service, they may need time to explore and become used to the environment, people and equipment. A number of appointments, visiting and exploring before gradually building up to the examination may help.

Hypersensitivities may mean that even the slightest touch is not well tolerated. Noise can also present a problem; consider the noise of electronic machines to rattling of instruments.

Temperatures of equipment may cause distress as well. It is well worth being prepared by finding out about the individual's sensitivities beforehand. We appreciate this may be difficult to do in every case, but the more the practitioner knows about the patient with ASD, the easier the consultation may very well be, for both parties.

Individuals with ASD may have difficulty in predicting behaviours of others. Whilst certain behaviours such as putting on examining gloves may indicate that an examination is going to start to people without ASD, those with ASD may not see this as a cue. You may need to verbally prepare for the start of an examination.

Most individuals with ASD prefer predictability to being met with the unknown, as do many other people in society. Explaining exactly what will happen during the physiological intervention, including what the individual will feel and experience as well as how long the procedure will take can help to reduce anxiety.

Parents and carers are experienced in dealing with the individual, enlisting their help or advice may be of great benefit.

Fears and phobias are more common in individuals with ASD. If the individual has a specific phobia they may need specialist support to help with desensitisation.

Some helpful ways to adapt your practice:

- Be patient, the individual may need a number of visits before being ready to engage.
- Seek information about sensory problems before the appointment.
- Adjust the environment to meet the needs of the individual where possible.
- Discuss the examination / procedure with the individual before

starting. Explain what will happen, what the individual will experience and how long it will take.

- Continue to explain what is happening during the physical intervention.
- Use verbal prompts, don't rely on the individual interpreting your behaviour / body language.
- Enlist the help and advice of family / carers where appropriate.
- Seek specialist support for specific phobias.

Treatment / follow up

It is important to explain the follow up plan with the individual with ASD in a clear and concise manner. If the individual is expected to undertake treatment at home, it is important that they are clear about what they will need to do. Providing literature that the individual can read at home or enlist the help of a carer to explain again can be helpful.

When explaining a treatment plan impairments in communication may cause problems, 'take a tablet' does not mean the same as 'swallow a tablet' when interpreted literally. Ask the individual to repeat back to ensure that they have understood.

If there will be a follow up appointment, think about the information that you will need in terms of assessing the response to treatment. You may need to ask the individual to keep a diary of pain etc. Do not rely on the individual being able to recall this information when they return. Clearly explain the date and time of the follow up appointment and the purpose of the appointment.

If there is no planned follow up, give a clear detailed explanation as to exactly when the individual should seek help, (it is not sufficient to say "if things get worse").

Some helpful ways to adapt your practice:

- Be clear about the individual's follow up treatment
- For treatment to be followed at home, provide written information
- Ensure you use clear, literal language.
- Ask the person to repeat the plan back to you to ensure they have understood.
- Arrange follow up appointments if needed.
- Prepare the individual for the information you will need to measure response to treatment.
- If no further appointments are needed, offer advice about when they should seek further help (more information than simply "if things get worse" is needed).

Referral to Other Services

Referring an individual to another service may be very daunting to that individual. They may not understand the need for this, and will need clear explanations about what to expect.

For an individual with ASD, having to visit another service with different professionals can cause lots of problems. If the professional / service is prepared they are more likely to be able to adapt to fit the needs of the individual with ASD. Ensuring that your referral contains information about the individual's ASD and highlights any associated difficulties will ensure that the individual is able to access the service.

Some helpful ways to adapt your practice:

- Explain the reason for referral to another service.
- Explain what will happen, where the service is, how they will be informed of an appointment with them, provide them with a map.
- Ensure you inform the other service provider of the individual's ASD, difficulties and how to support them to access their service.

Helpful links and sources of further information

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 identified 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 029 2046 8600). 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 your email address to the WLGA ASD Regional Support officers (ASDinfo@wlga.co.uk).
- In 2010 The Welsh Assembly Government announced that it will be working with Local Health Boards in Wales to establish an All-Wales Network for the assessment and diagnosis of adults with ASD. Also in 2010 The Welsh Assembly Government also commissioned an evaluation into children's ASD assessment and diagnostic services.
- Also in Wales from 2010 the new Wales Autism Research Centre (WARC) was launched and is located in the School of Psychology, Cardiff University. The Director of the autism research team is Professor Sue Leekam, Chair in Autism. The research centre's website is www.cardiff.ac.uk/psych/home2/warc/
- Autism Cymru operates www.awares.org a bi-lingual information site for autism in Wales and this site also hosts the world on line autism conference every autumn which includes many of the world's most prominent clinicians, researchers and practitioners in the field of autism.

Links outside of Wales:

The National Autistic Society website contains very useful guidance and advice for health practitioners 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.

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