

Number: WAG10-12024



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

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Autistic Spectrum Disorder

A Guide for Homelessness Practitioners
and Housing Advice Workers

March 2011

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Who is this Awareness Guide for?

This awareness guide is written for staff who work in homelessness and housing advice services i.e. Local Authority Housing Options, housing advice units, advice bureaux, law centres and offices. It is designed to provide an insight into autistic spectrum disorders (ASD) for housing advice workers and to provide some practical ways of responding to people who may have ASD in addition to being homeless or threatened with homelessness.

This is important for homelessness and housing advice workers as people with ASD are significantly more likely to be faced with homelessness than the general population. This is evidenced by research in 2010 involving entrenched rough sleepers in an English county which identified that 9 out of 14 rough sleepers were assessed as being on the autistic spectrum.

The guide also contains a simple checklist that can be used in communication with people who may have ASD. This is attached as an appendix and designed for daily use by staff who work in homelessness and housing advice services.

The following case study demonstrates the type and complexity of issues that people with ASD may present.

Case Study A

Ms A presented herself at the Local Authority Housing Options in a state of extreme distress. She lived in a 1 bedroom ground floor flat and had not come to the attention of statutory services in the past. She stated that a rat from rubbish in an adjoining neighbour's garden had entered her home and she was adamant that could not return home (which she kept spotlessly clean) as the flat was 'contaminated', 'filthy' and 'unhygienic'.

The advice worker recognised that she was also distressed by the waiting environment of the Housing Options and saw patterns in her behaviour and language. The advice worker urgently sought the help of an ASD worker who confirmed that whilst Ms A did not appear to have a diagnosis of ASD she demonstrated behaviours consistent with Asperger syndrome.

It was identified that Ms A would definitely not return to her flat that night. There was discussion about ineligibility, whether any duty, and if so which duty, was owed under Part 7, and priority need regarding disability. Temporary supported accommodation was arranged short term whilst a longer term solution was worked out.

A Brief Description of ASD

For many people with ASD the world can feel unsafe and confusing – just coping with daily life can be a challenge. Having your own home or space can help to improve quality of life, but getting it wrong can cause extreme anxiety and stress which may lead to some people becoming homeless by their actions. Living in a busy, noisy neighbourhood, for example, could be unbearable for someone with ASD, as noise can be painful for somebody who may have hyper-sensitive hearing, and unpredictable interruptions can cause problems for somebody who likes routine and order. However, for some people with ASD, noisy neighbourhoods or communal living with varying levels of environmental noise and bustle can provide a welcome sense of security and community. Each individual will have different needs and it is important that this is recognised.

ASD is a complex ‘spectrum’ disorder, which includes Asperger Syndrome. It affects around 1 in 100 people in very different ways and they are under diagnosed in the current population, especially in adulthood, and many people with ASD do not know that they have it. In addition some individuals may have particular signs of ASD without necessarily having the full spectrum of ASD that would result in a diagnosis and support from health or social care professionals. Many of the people that housing advice workers, housing managers and landlords come into contact with may not be aware that this is why they are experiencing difficulties and they may be regarded as ‘difficult’ or ‘anti social individuals’ so it is therefore important to have an awareness of the signs of ASD and how to respond appropriately.

People on the autism spectrum experience three main areas of difficulty, known as the Triad of Impairments (Wing L. and Gould J. (1979), Wing, L. (1996).

- **Social Interaction** – difficulty in social relationships, for example, appearing aloof and indifferent to others.
- **Social Communication** – difficulty with verbal and non-verbal communication, for example, not fully understanding the meaning of common gestures, facial expressions or tone of voice.

- **Social Imagination** – difficulty in the area of imagination and flexibility of thought, for example being interested in a limited range of activities which may be copied or pursued rigidly; difficulty with understanding what others think and feel.

In addition to the triad, people who have ASD may show a resistance to change and experience sensory sensitivity. Many people with an ASD experience either hypersensitivity or hyposensitivity in at least one of the senses (vision, hearing, olfactory, gustatory, proprioception, vestibular and touch). Someone with heightened sensory sensitivity might find noise that other people would not notice intolerable, for example the noise from an electric light, a vacuum cleaner or a dog barking; another person might find that looking at certain patterns or colours on walls causes them distress. They may have problems or anxieties when they feel too hot or when things seem very bright. Meanwhile, someone with reduced sensory sensitivity might not respond quickly to pain, which could leave physical problems to persist or worsen.

People with a diagnosis of Asperger Syndrome share the difficulties with social interaction, social communication, social imagination and their sensory system, but generally have fewer problems with language, often speaking well. Those with Asperger Syndrome also often have average or above average intelligence.

Impact of ASD in everyday life and implications for housing and homeless advice services

Difficulties in Social Relationships

Such difficulties can lead to feelings of isolation and even depression. Some individuals with an ASD can have mental health issues. Strategies of how to make and maintain friendships and relationships with neighbours may need to be learned especially as, on the surface, some individuals can be considered insensitive or egocentric. Individuals with ASD can be very honest - they like to tell it as it is and can often cause offence without being aware. They can also find it very difficult to understand how to react to other people's feelings and can respond in an inappropriate way in a sensitive situation e.g. if a friend or neighbour is bereaved. Sometime their inappropriate behaviour in a public place can get them into serious trouble and their desire to make friends can mean they get into the wrong crowd. Eagerness to please the wrong crowd may lead to susceptibility to illegal behaviour including drug taking.

Rigidity of thought and Special Interests.

Many special interests can be quite harmless e.g. stamp collecting, whilst others can be misconstrued or potentially hazardous. A person with a fascination for weapons such as whips, samurai swords or knives may have a collection with no intention of using them but the fact of ownership could be seen as threatening by others. It is important therefore to look at special interests in a wider context, e.g. a strong liking for pulling electronic equipment apart and putting it back together again is fine if the equipment belongs to them but this could be hazardous and misunderstood. People with ASD are rarely a danger to others.

Difficulties in understanding rules, regulations jargon, legal documents and interactions with authority.

Difficulty understanding or being fearful of correspondence particularly with legal jargon may lead to them not responding to letters and appointments or not opening correspondence at all. This will lead to difficulties in maintaining accommodation and has led to homelessness for some people with ASD. Some people with ASD may also have difficulty understanding official bodies e.g. local authorities, and how they work.

Insistence on rules and routines

Some people with ASD like structure in their lives and respond very well to rules and routines particularly if written down or clearly communicated. They may find it very difficult to cope with sudden changes in their daily routine or if others do not follow the rules.

Transfer of skills

Skills learnt in one situation are not automatically transferred/ generalised to another similar situation. This transfer of skills can also apply to social interaction as people may only be recognised if seen in the same context and wearing the same clothes, so somebody who is usually seen in an office appointment may not be recognised in another setting.

Meltdown

People with ASDs might be highly sensitive to certain sensory experiences and this in turn can sometimes lead to what might appear as an aggressive outburst. Sensory overload-or indeed social stress leading to extreme unusual behaviour is referred to as 'Melt Down'. Melt Down may result in behaviour that could appear like a temper tantrum in younger children or anti-social behaviour in older people.

Under such circumstances, it is important for other people to remain calm and speak softly using direct short sentences. It is not wise to stand too close, approach from behind or touch the person with ASD. Once it starts it must run its course but afterwards the person needs to recover in quiet, safe surroundings away from others.

Case study B

Mr B has been street homeless for approximately 20 years. His father left home when he was aged 13 and Mr B ceased to attend school but would remain at home with his mother. His mother remarried when he was 16 and he left home as he did not get on with his new step-father.

Mr B has spent time in various places and likes sleeping beside the sea although would spend some time in direct access hostels during winter months. He would spend the day with street drinkers and 20 years of drinking cheap alcohol has led to dental and digestive health problems which in turn led to hospital admission via Accident and Emergency.

In addition to treating his health issues hospital staff assessed that although Mr B did not appear to have a diagnosis of ASD he demonstrated behaviours consistent with being on the autistic spectrum: he found social interaction very difficult and would take everything said to him literally e.g. when asked 'Can you take your shoes off' he said 'yes' without understanding that this was a request; he carried a collection of lighters that he did not like anybody else to touch; he would cry out if staff touched him; he was upset by the noise and bustle of a hospital ward.

Mr B understood and acknowledged that his health was not good enough to return to living and sleeping outdoors and agreed to attend an appointment at the Local Authority Housing Options.

Some typical difficulties that could be seen as anti-social behaviour and could result in homelessness

Sometimes individuals with ASDs might come to the attention of housing advice workers, housing managers or landlords because of the nature of their social difficulties, their trusting and open personality, their particular 'special interests' or their sensitivity to sensory experiences. The following examples could be misunderstood by family, neighbours and officials and could potentially lead to problems with neighbours and even homelessness:

- A lack of knowledge of appropriate and inappropriate interactions with people e.g. neighbours can lead to reactions that could be interpreted by others as harassment and stalking although this is unlikely to be the case.

- Activities appropriate in childhood can be perceived as inappropriate in adulthood e.g. touching, asking inappropriate, highly personal questions, pushing into people and not apologising and temper tantrums/outbursts in public places.
- A difficulty understanding official processes may lead to obvious problems e.g.
 - Not knowing how to apply for benefits or deal with bills can lead to lack of income and arrears and even homelessness.
 - Not knowing how to repair or report a repair to a broken window may be visible to others and attract vandalism.
 - Not knowing how to respond to a heating breakdown can lead to problems for the person and the property if frozen pipes are the consequence.
 - Not opening the door if they are not sure who is there or if there is no prior arrangement.
- Behaviour may mimic the effects of drug abuse or mental illness.
- Bizarre or disruptive behaviour such as lining up objects,
- Involvement in altercations e.g. they may commit a crime without realising what they have done wrong.
- A strong dislike such as the sound of a baby crying or a dog barking could lead to an aggressive outburst that could cause problems in a neighbourhood.
- Unexpected violence and outbursts provoked by certain triggers in the environment that are not directly evident.
- A fascination or 'special interest' could be misunderstood e.g. an interest in fire or weapons, or an interest in dismantling electrical items even if they do not belong to them.

Efforts to address these issues by a housing advice worker, housing manager or landlord may be exacerbated because of perceived anti social behaviour of the individual with ASD, who may, for example:

- Behave in an extremely socially inappropriate way.
- Cause offence without being aware they are doing so.
- Appear aloof, rude, egocentric or insensitive.
- Not know how to react to certain unknown situations and other people's feelings.
- Have difficulty understanding and using non-verbal communication.
- Not like being touched.
- Have extreme intolerance to certain sounds and smells or other sensory stimuli.
- Take things literally.
- Not be able to understand implied meaning or follow a long set of instructions.

Case study C

Mr C was admitted to hospital with a range of medical issues and a relative raised concerns about his living environment and ability to live independently.

Mr C lived in the family home, a Local Authority tenancy, after the death of his mother several years previously. He had poor literacy/ numeracy skills but a great knowledge of a variety of historical facts. He was reasonably self-caring but lacked a range of independent living skills such as managing finances. He had difficulty forming relationships with others; there were concerns about making appropriate choices.

When Mr C's mother died she left him several thousand pounds but most of this money diminished due to poor budgeting skills. He had significant rent arrears and eviction and homelessness were threatened. Mr C was receiving only Job Seekers Allowance and had not made a Housing benefit/council tax benefit claim.

Mr C's home was found to be in a very unhygienic state and there were significant environmental concerns. The house was cluttered with lager/ beer cans, empty food wrappings, used tins, meat bones and large piles of wood. Furthermore the living room ceiling by the light fitting had a hole in it as a result of a leaking upstairs pipe and there was evidence of a chip pan fire. There was a critical risk of fire and vermin hazard.

There was discussion about statutory responsibility as Mr C did not fit local authority eligibility criteria and could be viewed as intentionally homeless. Following discussion Mr C was accepted as a vulnerable adult. He was assessed and moved to sheltered accommodation where the structured type environment suited his needs. He received intensive Tenancy Support to assist with budgeting, claiming the relevant welfare benefits, maintaining his environment, developing external network, and to give up drinking and improve his health. Mr C is now self sufficient after intensive intervention.

The Autism Cymru Attention Card Scheme

Legally, people with ASD are vulnerable adults. Autism Cymru, in conjunction with local police forces, have launched a card for people with autism. If somebody with autism comes into contact with any emergency service, they can produce the credit card-sized 'Attention Card' which will not only inform the professional that they have autism but also offer pointers on how to communicate with them more effectively. The card also provides telephone numbers for emergency service personnel to call for further advice, support and information about autism.



Feedback on the use of Autism Cymru's Attention card to date has been very positive:

'In case I get apprehended wrongly and get stressed'.

'Could use it if you got lost.'

'I could be in the wrong place at the wrong time and the police might ask questions and get the wrong idea. I would probably react worse than the ones committing the crime. A few years ago I might have hit someone.'

'I'd use it in tricky situations or when I am too traumatised to speak.'

'It will help me stay out of trouble.'

'Someone with Autism or Asperger's could be stuck without this card.'

The person who you suspect may have ASD should be asked if they carry some form of identification such as the Autism Cymru's Attention card, and if you could see it.

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 (029 2046 8600). Sign up for regular email copies of the WLGA ASD Strategic Action Plan newsletter, which updates autism progress and practice throughout Wales, by sending your 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 Criminal Justice Service, Teachers, GP surgeries, Clergy etc, and this Guide should be read in conjunction with those. Each autumn there is the world online autism conference featuring many of the world's leading educators, clinicians, and researchers: www.awares.org

Detailed information about housing management in supported housing is contained within Home First: A Guide to Housing Management in Supported Housing which is available from Community Housing Cymru, <http://www.chcymru.org.uk> or by emailing enquiries@chcymru.org.uk

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.

References

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Further Reading

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Autistic Spectrum Disorders: A Guide for Criminal Justice System Practitioners in Wales.

Autistic Spectrum Disorders: Information for Practitioners who have an interest in Developing Property or Services for Housing and /or Day Opportunities.

Appendix 1

Checklist for communicating with and interviewing people with ASD

The person with or suspected of having ASD may have a high level of verbal communication skills; however, this may mask the true level of understanding that they have of the situation and setting they are in. In this instance the housing advice worker should:

- Not diagnose ASD or discuss it with them unless it is to identify if they have an Autism Cymru's Attention card (see below).
- Keep language, clear, calm, short and directive.
- Keep your voice neutral. Avoid raising your voice or using language that may be construed as provocative.
- Keep facial and hand gestures to a minimum.
- Address the person by name, if known, at the start of every sentence if you need to be sure that you have their attention and if there are other people present.
- It is advisable that any meetings/ interviews are highly structured and when possible planned in advance. It is further advisable that meetings are cut into a series of short blocks with breaks frequently being taken.
- Always allow extra time for the person to process the request that has been made of them. Repeating the request too soon may lead to confusion and delay or prohibit the response that is desired.
- Avoid speaking hypothetically, making jokes or employing sarcasm. Many people with ASD will take what is said to them very literally.
- Do not touch the person if this can be avoided. Many people with ASD find touch an unpleasant or even painful sensation.
- If possible, use lists, timetables, visual schedules or written instructions even for intellectually able people to reinforce what is being said / is expected of the person. It is commonly accepted that many people with ASD are visual thinkers, that is to say, people who process information visually rather than verbally.
- Avoid using acronyms and abbreviations when talking to the person with ASD.
- Written communications should be kept simple and brief. As with verbal communication, written communication should be free from acronyms or abbreviations and only the information that is necessary should be included.

- Always keep the individual informed of what is happening. If a date for a further meeting is to be set, inform them of this as soon as possible.
- Give warning as to what will be discussed dealt with at every stage, including in advance of further contact where possible.
- Do not change times/ dates for future meetings if at all possible. When this does happen, give good advance notice.
- Try and see things from their perspective and avoid unnecessary confrontation.
- Provide them with a clear, explicit and unambiguous list of their responsibilities in the process. Too much choice, including too much unstructured time poses difficulty for a person with an ASD. Housing advice staff may need to be more directive, prescriptive and blunt than they might normally be.
- Don't take it personally if the person is rude, blunt, dismissive, or appears to be uncooperative.
- Recognise that alcohol and drug use poses high risk because it brings disinhibition but no increase in social understanding.
- Follow up contact would be a good idea to check understanding and progress.