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Autistic Spectrum Disorder

A Guide to Housing Management
for Practitioners and People
in Rented Housing

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Who is this Awareness Guide for?

This awareness guide is written for staff who manage rented housing i.e. registered social landlords, Local Authority housing departments or landlords in the private rented sector. It is designed to provide an insight into autistic spectrum disorders (ASD) for housing managers and landlords and to provide some practical ways of responding to people who may have ASD. It also contains an appendix summarising the occupant's responsibilities for people who may have ASD.

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. Living in a communal setting, for example, could be extremely difficult for someone with ASD, as sharing space with people they have not chosen to be with can cause discomfort. Also, situations that most people would find tolerable can become unbearable because of extreme sensory sensitivity, for example, busy waiting rooms/areas or noisy neighbourhoods. 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. 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 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

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.

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 the beauty of Samurai swords 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 such as setting and keeping appointments, notice of maintenance visits, and not allowing access to a property. 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 at a home visit.

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 A:

Mr A is in his 30s and has no contact with Supporting People (SP) or social services until he loses his job following closure of the factory where he works. Loss of the routine and pattern created by regular employment causes loss of self esteem and high anxiety; he has difficulty filling his days. He worries excessively about finding employment, withdraws from the very limited social contact he previously had and neglects self care and physical wellbeing. Following a referral to the Social Services Department ASD development worker, Mr A is diagnosed with Asperger syndrome and his support needs are assessed using the Unified Assessment process. Mr A is unsure whether he is a tenant or a home owner; he does not know who is responsible for repairs at his home, internally or externally and when something is broken he does not know what needs to be done in order to mend it. He has spent the whole winter in an unheated flat because the heating is not working and he does not know how to fix it. One window is broken and will not close. Mr A does not open his post, is unsure how to respond to bills and letters and is not able to apply for and manage benefits independently. The SP service arranges a worker to support Mr A, who does not want a social worker or further contact with statutory services, and they agree to meet fortnightly until the identified issues about tenancy, finances and repairs to the property are resolved.

Some typical difficulties that could be seen as anti-social behaviour:

Sometimes individuals with ASDs might come to the attention of 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 physical problems e.g.
 - 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 apply for benefits or deal with bills can lead to lack of income and arrears and even homelessness.
 - 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 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 B

Mr B lives with his mother but is at risk of becoming homeless when she sells the house they live in and moves; both agree that he should not move with her into her new house. The house sale goes through very quickly and Mr B enters temporary accommodation for homeless people with Supporting People funded support from a tenancy support team. Staff at the hostel are aware that it will be an unpredictable and stressful environment for Mr B and, following consultation with an ASD development worker, they draw up a clear set of guidelines for Mr B about use of the communal kitchen. They help him to understand what to expect of other residents. They assure him about the privacy and safety of his bedroom and they identify a key member of staff on every shift so that he always has someone to ask if he is worried about something. Because Mr B is sensitive to the feel of dust or lint on his clothes he changes them several times a day, so the staff set up a routine for use of the washing machine and dryer. When Mr B moves into a flat, the staff ensure he can maintain this routine until his own washing machine is plumbed in and working. Mr B copes remarkably well in the shared temporary accommodation; the first step toward living in a flat of his own. He is proud of his ability to cope and later says the experience has given a boost to his self esteem.

Communicating with and interviewing people with ASD

The person with 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. It may be the case that the housing manager or landlord should:

- Not diagnose ASD or discuss it with them unless it is to identify if they have an NAS Autism Alert card or 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 visual aids or written instructions 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 as an occupant.
- If you suspect that the person may have ASD you could ask if they carry some form of identification such as the Autism Cymru's Attention card and if you could see it.
- As moving into a property is stressful they might not be able to take in or understand all this new information at once; follow up visits would be a good idea.

Case study C

Mr C has been supported for some time by staff at an SP floating support service for people affected by mental ill health. Mr C lives in a privately rented flat which he is not motivated to keep clean and his tenancy is at risk. He has great difficulty keeping track of his money and may be easily persuaded to buy things for other people who don't pay him back. He is unkempt and does not eat a healthy diet and as he does not engage in efforts to improve his situation, he is seen as non compliant. The manager of the team has some knowledge of Asperger Syndrome and suspects some aspects arising from AS are making Mr C seem difficult to support. With Mr C's agreement, the manager and team invite the ASD development worker to meet him. After several meetings Mr C and the staff agree that he probably does have Asperger syndrome; Mr C says he is "85 to 90% certain" but he does not want to see a doctor or a consultant for a formal diagnosis. The support workers decide that they will do some awareness training in ASDs, and will support Mr C with the specific needs that may arise from Asperger syndrome in mind. The support focuses on helping Mr C to maintain his tenancy and manage his finances; trying to understand Mr C's thoughts, actions and functioning from an ASD specific point of view helps people to realise that he is not deliberately non compliant or difficult to work with.

The Autism Cymru Attention Card Scheme

People with ASD are vulnerable adults in the eyes of the law. 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 NAS have a similar card - the NAS Autism Alert card.

The person who you suspect may have ASD should be asked if they carry some form of identification such as the NAS Autism Alert card or 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 (tel 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

Further Reading:

Bowen M, and Plimley L (2008) ' The Autism Inclusion Toolkit', London: Sage Publications.

Plimley, L. and Bowen, M. (2007) 'Social Skills and Autistic Spectrum Disorders', London: Sage Publications.

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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 A: Housing management and housing responsibilities for occupants

If you are a person living in rented housing you may be a tenant, licensee or occupant depending on the legal agreement with the landlord.

A landlord is a person or an organisation that owns a house and rents it to other people to live in.

Throughout this Guide we will refer to you, the person living in rented housing, as the occupier or occupant.

A tenancy agreement or licence that you may have with your landlord is a legal document.

A tenancy agreement tells you about your rights and responsibilities while you are living in your home.

It also tells you what your landlord must do for you.

Your tenancy agreement tells you the following:

- The date you can move into your home.
- How much you pay to live in your home.
- How many people are allowed to live in your home.
- What you must pay for, including:
 - Water.
 - Heating.
 - Lighting.
 - Council Tax.

Your landlord will:

- Talk to you if there is a problem.
- Listen to your views.
- Make sure heating, plumbing and lighting work.
- Repair your home.
- Enter your home in an emergency (e.g. gas leaks, burst pipes etc).

You will need to:

- Tell your landlord when they need to come and fix your home.
- Give your landlord 4 weeks notice if you want to end your occupancy agreement.

What you MUST do:

- Pay your rent.
- Keep your home clean and tidy.
- Keep your garden tidy if you have one.
- Keep to house rules if there are any.
- Talk to your neighbour if they are upsetting you.
- Let your landlord in when they need to meet with you or fix your home.

You may also be responsible for practical things such as:

- Keeping sinks and waste pipes clear.
- Replacing plugs and chains on sinks, basins and baths.
- Replacing electrical plugs.
- Replacing shower riser rails, hoses and heads.
- Replacing cords to light fittings.
- Replacing light bulbs and fluorescent tubes.
- Replacing domestic fuses and resetting trip switches.
- Keeping smoke detectors clean and free from dust.
- Keeping vents clean.
- Keeping gutters clear.
- Replacing toilet seats.

What you MUST NOT do:

- Don't damage your home.
- Don't fight with your neighbours.
- Don't play your music loud.
- Don't put the volume too loud on your TV.
- Don't have a pet without asking your landlord if it is OK first.
- Don't let anyone else move in with you without asking your landlord if it is OK first ("Move in with you" means someone who lives with you all the time).

If you have any problems or queries about your home - contact your landlord.

