

Assisting People with Autism

Guidance for Local Authority Housing Officers



NDA

National Disability Authority
Údarás Náisiúnta Míchumais

Part of this guidance document is based on text contained in the publication: **‘A guide for criminal justice professionals’**, produced by the National Autistic Society Northern Ireland and the Department of Justice in Northern Ireland in 2014.

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How this Guide can help

- This guide provides background information about autism and aims to assist those working in the housing-related areas of local authorities to understand autism, especially those who may come into contact with someone who has autism or cases where a member of the household has autism, in order to better communicate with and support them¹.
- The guidance aims to be a useful and practical resource for housing officers who may come into contact with people with autism and/or their families applying for social housing or for a housing adaptation grant.
- This guide is informed by the experiences of people with autism and those who work with and for people with autism.
- This guide is also informed by the experiences of local authority housing officials.
- It is produced by the National Disability Authority (NDA) with inputs from a range of bodies and individuals. The guide is designed to be used by housing officers as a regular reference.

A range of additional resources are available from autism support organisations².

Autism actions under the National Disability Strategy

The National Disability Strategy Implementation Plan (NDSIP) sets out a programme of actions for implementation by government departments and public bodies with the goal of ensuring a whole of government approach to advancing the social inclusion of all persons with disabilities, including those with autism.

The Programme of Actions on Autism is in keeping with the cross-disability, whole of government, social model of disability approach set out in the NDSIP. It recognises that an increased understanding of autism across the public sector is required to ensure that effective implementation of the NDSIP.

This document meets one of the commitments in the Programme which states that the NDA will develop guidance for housing officers on housing needs for people with autism.

1 The guide draws on the NDA paper **Reasonable Accommodation for people with Autism Spectrum Disorder (2015)** for some of the characteristics of autism

2 See Appendix A

Legislation

It is important to be aware of the requirements in legislation and the rights of people with disabilities (including people with autism) relevant to making public services accessible including:

- Disability Act 2005
- Equality Acts
- Assisted Decision Making (Capacity) Act 2015
- as well as the access to advocates provided by the National Advocacy Service.

What is autism?

Autism, including Asperger syndrome, is a lifelong condition that affects how a person communicates with, and relates to, other people. It may also affect how a person makes sense of the world around them. It is a spectrum condition, which means that, while people with autism share certain difficulties, their condition will affect them in different ways and to differing degrees.

Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist support to varying degrees. People with autism may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours.

Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They may have fewer problems with speech but may still have difficulties with understanding and processing language.

Characteristics and prevalence of autism

It may not be immediately obvious that a person has particular needs. His or her behaviour may invite the attention of others, but in general autism is a hidden disability.

It is important to note that how a person's condition manifests itself differs from individual to individual. The explanations below may not be applicable to everyone with this condition.

A person on the autism spectrum may have some or all of the following characteristics.

Social interaction

He/she may:

- appear to be indifferent to others or socially isolated
- be unable to read social cues
- behave in what may seem an inappropriate or odd manner
- appear to lack empathy
- avoid eye contact when under pressure

Social communication

He/she may:

- have difficulty in understanding tone of voice, intonation or facial expression
- make a literal interpretation of figurative or metaphorical speech (for example, the phrases “has the cat got your tongue” or “he’d make mincemeat of you” could be alarming to a person with autism)
- find it difficult to hold a two-way conversation
- become agitated in responses or come across as argumentative or stubborn
come across as over-compliant, agreeing to things that are not true
- use formal, stilted or pedantic language
- have poor concentration and thus poor listening skills
- be honest to the extent of bluntness or rudeness

Social imagination

He/she may:

- have difficulty in foreseeing the consequences of their actions
- become extremely anxious because of unexpected events or changes in routine
- like set rules, and overreact to other people’s infringement of them
- often have particular special interests, which may become obsessions
- find it difficult to imagine or empathise with another person’s point of view

According to the National Council for Special Education almost 14,000 students in schools have been diagnosed with autism – this is 1 in every 65 students in schools and is in line with prevalence rates recently reported in the UK and US³.

Although it is not definitively known, the prevalence rate may be as high in adults, especially adults with Asperger syndrome, due to lower rates of diagnosis and lower awareness of autism when those adults were children. It is also estimated that between 40% and 69% of people who have autism also have an intellectual disability.

Mental health difficulties are a common feature among people with autism. The prevalence rates vary but about 70% of children with autism are estimated to have a psychiatric co-morbidity⁴, of which the most common is anxiety (Skokauskas and Gallagher, 2012)⁵. Other studies have estimated around 30% of adults with autism have obsessive compulsive disorder (Russell et al, 2013)⁶ and between 5% and 34% have depression. Mental health difficulties can be difficult to diagnose in people with autism. They can be over diagnosed due to overlap between autism symptoms and those associated with the mental health difficulty. People with autism and a mental health difficulty can see a worsening of the autism symptoms which can impact on education and behaviour.

The housing application process

A supportive application process⁷

People with autism are individuals with their own particular ways of relating to others, and no two people with autism are likely to display all the characteristics outlined in this guide. It is recommended that the housing application process is made as supportive and accessible as possible to everyone. This will benefit all applicants.

A situation may present itself whereby to process a housing application - or an application for a housing adaptation grant – a face-to-face interview with a person with autism may be required; this could be with the applicant, or with someone supporting them. Some of the following guidance might be of assistance.

- 3 http://ncse.ie/wp-content/uploads/2016/07/1_NCSE-Supporting-Students-autism-Schools.pdf
- 4 Crow B, Salt A (2015) “Autism: the management and support of children and young people on the autism spectrum (NICE Clinical Guideline 170)”, *Archives of Disease in Childhood - Education and Practice*. 100/1, pp20-23
- 5 Skokauskas N, Gallagher L (2012) “Mental health aspects of autistic spectrum disorders in children” *Journal of Intellectual Disability Research*. 56/3, pp248-57
- 6 Russell AJ et al (2013) “Cognitive behaviour therapy for comorbid obsessive-compulsive disorder in high-functioning autism spectrum disorders: A Randomised Control Trial”, *Depression and Anxiety* 30/8, pp697-708
- 7 This guidance may be a good starting point in making the application process accessible: <http://universaldesign.ie/web-content-/written-communication-toolkits-energy.pdf>

Stress and anxiety leading up to an interview

Be aware that people with autism can find changes in routine very difficult to handle. They may be anxious about going to the local authority offices. Even planned events, such as an interview with a housing officer, may be very stressful for them. An individual may also be extremely anxious in a strange environment, such as an interview or waiting room.

Some people with autism are hypersensitive to noise and light, while others are fearful of crowds. They often have difficulty in waiting their turn or understanding social conventions such as queuing. An individual may be unable to tolerate such an experience, their anxiety leading them to become agitated or disruptive. If an individual is in this type of situation, an interview to facilitate the completion of an application process may not always be possible.

Guidance for an interview

Since autism can have an impact on someone's ability to communicate, it might not be possible to gather all the information required during one interview. It might be necessary to have more than one interview in order to build up familiarity with the individual.

The support of a family member, advocate, etc., for a person with autism, can be helpful. If further assistance is required, it may also be useful to contact one of the organisations listed in Appendix A. It is recommended that anyone brought in to provide support has the specialist knowledge and skills to support someone with autism.

The following tips may also help during an interview.

Keeping the environment as calm as possible

- The individual may be more relaxed if they are interviewed in a familiar place, with a familiar person present.
- If known, explain how long the interview is likely to last and what will happen at the end of the session.
- Ensure there are no background noises which could provide a distraction during the interview.
- Some people with autism often have an attachment to a particular object, such as a piece of string. They may wish to hold the object or possibly twiddle or flap with it during the interview. Research suggests that sometimes this helps them to concentrate and removing the object may cause the person unnecessary distress.

- You may see the person use repetitive movements – such as hand-flapping or rocking – which are known as “stimming”. These should be permitted, since they often have a calming effect, though they can also indicate agitation or that the person may need a break.

Conducting the interview⁸

- Talk calmly in your natural voice, keeping language as simple and clear as possible. Use only necessary words. Try not to exaggerate your facial expression or tone of voice as this can be misinterpreted.
- Keep gestures to a minimum, as they may be a distraction. If gestures are necessary, accompany them with unambiguous statements or questions that clarify their meaning.
- Use the individual’s name at the start of each question so that they know they are being addressed.
- Cue the individual in to the language you are about to use, preparing them for the instructions or questions that might follow. For example, “John, I am going to ask you a question.”
- Give time for the person to respond; don’t assume that silence means there is no answer forthcoming.
- Where appropriate, avoid open questions: closed questions are more likely to be understood. The individual may not be able to judge exactly what the interviewer needs to know
- People with autism can have a very literal understanding of language. Avoid using irony or sarcasm.
- Back up questions with the use of visual aids or supports. People with autism often understand visual information better than words.

Interviewee response

- Allow the individual extra thinking time to respond to each question. People with autism often take longer to process information. If there is no response at all, try rephrasing the question. A person with autism may not be able to inform you when they don’t understand what you have asked: be prepared to prompt the individual in order to gather sufficient relevant information.

⁸ A toolkit produced by the NDA’s Centre for Excellence in Universal Design contains some useful, generic information and checklists: <http://universaldesign.ie/Products-Services/Customer-Engagement-in-Tourism-Services/Face%20to%20Face.pdf>, pages 3-15.

- People with autism may have better expressive language skills than receptive language skills. Be aware that some individuals may not comprehend fully what is said to them.
- Some people with autism have echolalia: they may echo and repeat the words of others without understanding the meaning of those words.
- Don't expect an individual to necessarily make eye contact during the interview.
- Remember that people with autism may speak in a monotone, and/or use very stilted language.

Housing solutions for people with autism

Criteria for accommodation required

People with autism and their families can have very particular accommodation requirements. These requirements could be dealt with as part of a broader universal design (UD) approach to housing in Ireland⁹.

The provision of UD Homes can have a positive impact on the planning and delivery of quality homes and sustainable communities. The focus is on the wider neighbourhood context of home location, recognising the importance of social interaction, community and local services.

Local authorities should consider building, acquiring or adapting suitable housing stock with a view to make them suitable for as many potential occupants as possible. This would make them adaptable and sustainable over a longer period, thus reducing the need for frequent and costly works.

What follows is a list that covers issues that will be important when considering an application from a person with autism or a family where a member or members have autism, for housing or for a housing adaptation. As you will see, there are many items on this list that are applicable to other people with disabilities going through the housing application process.

- Location
- Type of House
- Space
- Considerations regarding shared and single accommodation
- Safety and security

⁹ <http://universaldesign.ie/Web-Content-/Introduction.pdf>

- Maximising familiarity, stability and clarity
- Minimising sensory overload
- Allowing opportunities for controlling social interaction and privacy
- Adequate choice and independence
- Enhancing dignity and promoting wellness and health
- Ensuring durability and accessibility

Case Study

A young man with a diagnosis of Asperger's syndrome was at significant risk of homelessness following a sudden change in his circumstances. The unexpected change and the uncertainty of his future exacerbated co-existing conditions such as depression and anxiety. A relative of the man contacted the Housing Department and outlined his situation. Initially his only potential housing option was shared private rented accommodation. The case was reviewed by the Housing Welfare Social Work Section and the view was taken that it was unlikely that he would be able to cope with the challenges of shared accommodation. It was suggested that he would be more suited to sheltered accommodation. A nomination was made to an approved housing body that provides accommodation within a secure complex. The man's relative supported him through the interview and induction process and he was successfully transitioned into his new accommodation.

Some of the issues particular to people with autism are dealt with below.

Safety and security

Safety and security will be a key factor in some housing applications. Some children and adolescents with autism can be prone to run away if they are left unattended or when carers are otherwise occupied. It is not easy to understand why they do this.

Children and adolescents with autism often do not recognise danger. They may not, for example, observe boundaries, may run into oncoming traffic, climb into a neighbour's garden, enter unlocked vehicles or sheds, or peer into other people's windows. Water sources such as ponds, fountains, rivers and canals may be of particular fascination, and therefore danger, to the individual. Running away is often called "bolting".

In these cases, it would be important to select accommodation that would help their families minimise the risks attached to this behaviour.

Impact of the environment

Many people with autism have difficulty processing everyday sensory information. Any of the senses may be over- or under-sensitive, or both, at different times. These sensory differences can affect behaviour, and can have a profound effect on a person's life.

Sometimes a person with autism may behave in a way that can't be immediately linked to sensory sensitivities. A person who struggles to deal with everyday sensory information can experience sensory overload, or information overload. Too much information can cause stress, anxiety, and possibly physical pain. This can result in withdrawal, challenging behaviour or meltdown.

The environmental "triggers" which can cause upset to some people with autism are highly individual. The reason why existing accommodation or a potential accommodation option may not be suitable for an individual or family may be particular to that person with autism.

Some people with autism would benefit from having some outdoor space to spend time in while other may be helped by having some extra space indoors to spend some time in.

Social interaction and privacy

While local authorities may face challenges around the range and type of accommodation on offer, in the case of people with autism and/or their families some needs are best catered for by an "extra room" because there are many people seeking housing supports who are living in overcrowded and unsuitable accommodation.

An extra room may be needed for a carer for overnight stays.

It can often be the case that it isn't the person with autism who needs extra space but a sibling(s) who is kept up all night as a result of the person with autism's behaviour. Such situations may not lend themselves to "medical" justifications for why supports are needed.

Conclusion

As autism is a hidden condition, the needs of people with autism spectrum disorder may not be as obvious as other disabilities or conditions. These Guidelines are part of a larger, whole-of-government approach to improve autism awareness across the public sector and to improve the experience of people with autism when they try to access public services.

Raising awareness about autism is essential in order to change attitudes towards it. It is important that housing officers are equipped with the skills to meet the needs of a person with autism as they would with any person with a disability.

The strategy for adults with autism in England emphasises that raising awareness within the public services and employers is a good starting point to raising awareness in society¹⁰.

The National Disability Authority has developed an eLearning tool that gives a good grounding in engaging with and supporting customers with disabilities¹¹.

Local authorities can also avail of autism awareness training and materials that have been funded under the Department of Justice and Equality's Disability Awareness Grant Scheme¹².

¹⁰ HM Government (2010). Fulfilling and rewarding lives. The Strategy for adults with autism in England Available from www.dh.gov.uk/publications.

¹¹ <http://nda.ie/Resources/eLearning/>

¹² <http://www.autismawareness.ie/>
<https://asiam.ie/>

Appendix A – Autism Organisations

<p>Autism Ireland</p>	<p>Coole Road Multyfarnham, Mullingar, Co. Westmeath N91 WC67</p> <p>Phone: 044 9371680</p> <p>Email: info@autismireland.ie</p>
<p>Aspire – Asperger Syndrome Association of Ireland</p>	<p>Carmichael Centre, Coleraine House, Coleraine Street, Dublin 7.</p> <p>Phone: 01 878 0027</p> <p>Email: info@aspireireland.ie</p>
<p>Irish Society for Autism</p>	<p>Unity Building, 16/17 Lower O’Connell Street, Dublin 1.</p> <p>Phone: 01 874 4684</p> <p>Email: admin@autism.ie</p>
<p>Shine Ireland</p>	<p>The Shine Centre, Weston View, Ballinrea Road Carrigaline, Co.Cork.</p> <p>Phone: 021 4377052 Email: info@shineireland.com</p>
<p>AsIAm.ie</p>	<p>Please visit the website: AsIAm.ie</p>

Appendix B – Supporting information

If you wish to learn more about accessible home design, here are some publications that may be of interest.

- **Building for Everyone: A Universal Design Approach**
(<http://universaldesign.ie/Built-Environment/Building-for-Everyone/>)
- **Universal Design Guidelines for Homes in Ireland**
(<http://universaldesign.ie/Built-Environment/Housing/>)
- **Universal Design Guidelines: Dementia Friendly Dwellings for People with Dementia, their Families and Carers**
(<http://universaldesign.ie/Built-Environment/Housing/Dementia-Friendly-Dwellings/>)
- **Making Homes that Work A Resource Guide for Families Living with Autism Spectrum Disorder + Co-occurring Behaviors**
([http://parenttoparentnys.org/images/uploads/pdfs/Making_Homes_That_Work_A_Resource_Guide_\(2\).pdf](http://parenttoparentnys.org/images/uploads/pdfs/Making_Homes_That_Work_A_Resource_Guide_(2).pdf))
- **Living in the Community: Housing Design for Adults with Autism**
(http://www.hhc.rca.ac.uk/CMS/files/1.Living_in_the_Community.pdf)
- **Advancing Full Spectrum Housing: Designing for Adults with Autism Spectrum Disorders**
(<https://sustainability.asu.edu/stardust/project-archive/advancing-full-spectrum-housing/>)

nda

National Disability Authority

Údarás Náisiúnta Míchumais

25 Clyde Road,

Dublin 4.

Tel/Minicom 01 608 0400

Fax 01 660 9935

Email nda@nda.ie

www.nda.ie