# Autism and Homelessness Toolkit

## Edition 2

Supported by:

City of Westminster

resources for autism

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autistica

homeless link

St Mungo's
Ending homelessness
Rebuilding lives

# Contents

# 1. Acknowledgements

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**Contributions to the Autism and Homelessness Toolkit**

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## Case studies and quotes

All but one of the case studies in this toolkit have been anonymised. Certain details have been altered or removed so that these case studies do not include any personally identifiable information. Stories marked with an asterisk (*) were produced as part of interviews with autistic individuals with experience of homelessness and were conducted as part of two studies, one led by Dr Georgia Lockwood Estrin (University of East London), the other by Dr Beth Stone (University of Bristol).

## Language used in this toolkit

In this toolkit, when we refer to autism, we are talking about the whole autism spectrum. We have used identity-first language (describing people as 'autistic' or 'on the autism spectrum') as research suggests that this is the preference among autistic adults (**www.autism.org.uk/describingautism**). In the case studies, we have used the language the individual prefers as this should always take precedence.

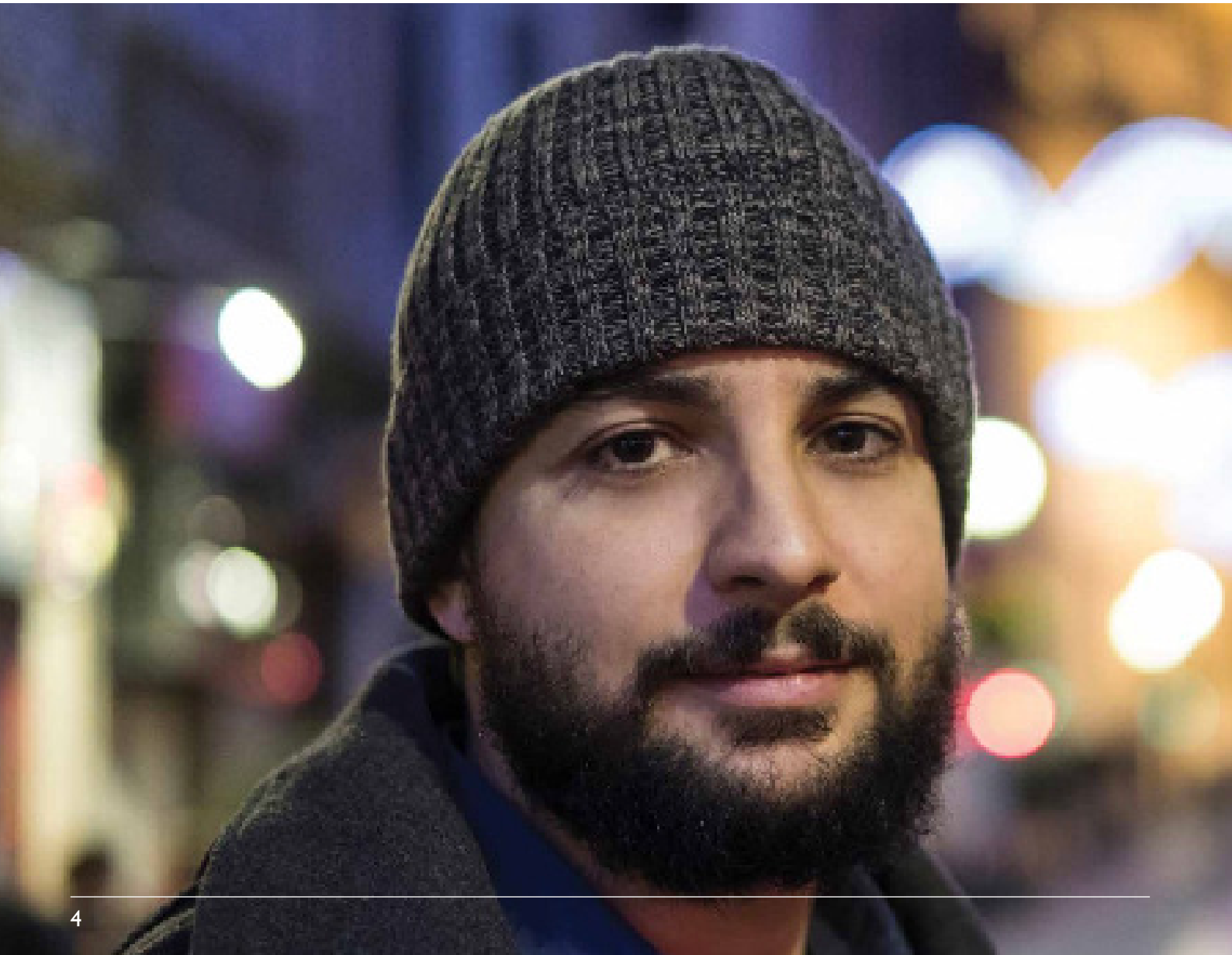
# 2. Introduction

There is increasing awareness that autistic people may be at higher risk of homelessness. This has not previously been recognised, and as a result services may not be meeting the different needs of autistic people experiencing homelessness.

Autism is a lifelong disability that affects how people perceive the world and interact with others. It is likely that autistic people are not only more at risk of becoming homeless, but also more vulnerable once they are on the streets. They may also find it more difficult to move into new accommodation. Neglecting the needs of autistic homeless individuals can exacerbate personal challenges and mental health crises, while also imposing greater healthcare and social service costs, thereby undermining their potential to thrive.

Drawing on the expertise of people with lived experience, charities, professionals and academic researchers, this toolkit is aimed at staff and organisations who work with people experiencing homelessness in England. It describes what autism is, how to recognise it, and how to work effectively with people who are known to be autistic or who staff think could be autistic.

Staff working in the homelessness and supported housing sectors can use this toolkit by incorporating appropriate elements into their work processes and services, as required. Managers and other staff may also wish to use the toolkit as a basis for presentations or workshops on autism and homelessness. Additionally, staff can distribute this resource among various partner sectors to emphasise the increased risk of homelessness faced by autistic individuals but also help other sectors learn about autism.



# 3. What is autism?

Autism is a lifelong developmental disability that affects how people perceive the world and interact with others.

Autistic people see, hear and feel the world differently to other people. If a person is autistic they are autistic for life; autism is not an illness or disease and cannot be 'cured'.

Autism is a spectrum condition. Autistic people share certain difficulties, but like everyone each individual has their own strengths and differences. Autism can impact anyone regardless of their gender, ethnicity or race. Some autistic people also have learning disabilities, mental health issues or other conditions, meaning people need different types and levels of support. All people on the autism spectrum learn and develop, and with the right support in place, all autistic people can achieve a happy and fulfilling life.

## Characteristics of autism

### Social communication

Most autistic people have difficulties with interpreting both verbal and non-verbal language like gestures or tone of voice. Many have a very literal understanding of language and think people always mean exactly what they say. They may find it difficult to use or understand facial expressions, tone of voice, and jokes or sarcasm, and they may also need longer to process verbal information.

### Social interaction

Autistic people often have difficulty 'reading' other people – recognising or understanding others' feelings and intentions – and expressing their own emotions. This can make it very challenging for them to navigate the social world, and they may struggle to form friendships.

### Repetitive behaviour and routines

The world can seem a very unpredictable and confusing place to autistic people, who often prefer to have a daily routine so that they know what is going to happen every day. It may be difficult for an autistic person to take a different approach to something once they have been taught a preferred way to do it, and they may not be comfortable with the idea of change.

### Highly-focused interests

Many autistic people have intense and highly-focused interests. These can be anything from art or music to trains or computers. Highly-focused interests can be a source of enjoyment and relaxation, but can become obsessive and be prioritised over and above other needs. Therefore, autistic individuals may need help with moderating this engagement.

### Sensory sensitivity

Autistic people may experience over or under-sensitivity to sounds, touch, tastes, smells, light, colours, temperatures or pain. For example, they might perceive background sounds, which others filter out, as unbearably loud or distracting, potentially causing anxiety or even physical pain.

## Understanding the autism spectrum

### The needs and abilities of autistic people differ greatly, and as a result each autistic person should be supported in the context of their life.

It is important to understand that many autistic people can live independently, while others cannot live without support. This is why autism is seen as a spectrum. People often form misconceptions about autism based on an individual's outward appearance or behaviour. As a result, people can often think someone is either less autistic or more autistic. Unfortunately, viewing the autism spectrum in this way can lead to a misunderstanding of the complexity of autism. This, in turn, can result in unhelpful assumptions about the capabilities of autistic individuals and may lead to inappropriate or inadequate support. Therefore, the autistic community prefers that people view the autism spectrum as a spiky profile.

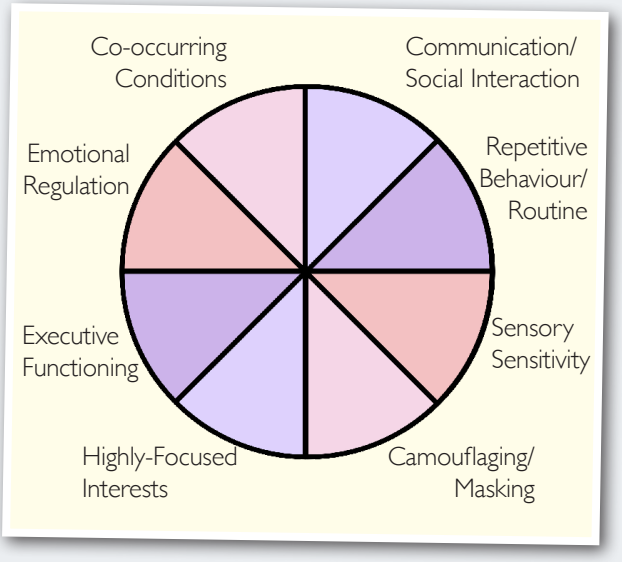
## The spiky profile

This view attempts to illustrate that each autistic person has unique strengths, and also unique challenges. The spiky profile aims to develop a holistic understanding of an individual by considering key areas, some of which are strengths and other areas which may be a challenge. This enables support to be tailored accordingly.

For example:

- An autistic person could have strengths in their attention to detail. This could mean they are able to do certain things that other people cannot do. As a result, less or no support would be required in this area.
- That same autistic person could however struggle with traditional verbal communication. This would mean support or reasonable adjustments are required in this area.

It is therefore very important to understand which areas an autistic person may have strengths in and difficulties in, as it enables person-centred tailored support.



## Autism and gender

Studies have traditionally indicated that autism is much more common in males than females, and more men and boys than women and girls receive an autism diagnosis. However, it is now recognised the male/female ratio is much closer, with the latest research putting it at around 3:1. Studies show that autistic people are more likely to be non-binary, or gender non-conforming than the general population.

For more details see: **https://www.autism.org.uk/advice-and-guidance/what-is-autism/autism-and-gender-identity**

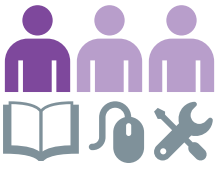
## Strengths of autistic people

It is important to recognise the strengths and skills autistic people may have. Some possess detailed knowledge about things they are interested in, or have particular skills in subjects such as maths, IT or art. They may have a good eye for detail, an excellent memory, and be able to concentrate well on a specific activity. Autistic people are often direct, truthful and reliable.

An estimated

**1.1% of people are autistic in the UK.**

People from all nationalities and cultural, religious and social backgrounds can be autistic (Brugha et al., 2012)[i]



Only

**one-third**

of autistic adults are in some form of paid **employment**, full or part-time (National Autistic Society, 2016)[ii]

**8%** of men in social **housing** are identified with an autism spectrum condition (APMS, 2007)[iii]

Autism can co-occur with a **learning disability**, but at least half of people on the autism spectrum do not have a learning disability (MacKay et al., 2017)[iv]

**70%**

of autistic adults say they do not get the help they need from **social services** (National Autistic Society, 2012)[v]

**79%**

of autistic adults have had a **mental health problem** during their life (Lever & Geurts, 2016)[vi]

**79%**

of autistic people say they feel **socially isolated** (National Autistic Society, 2016)[vii]

## Autistic women

While autism affects individuals of all genders, there has been a growing recognition of the unique experiences and challenges faced by autistic women. Historically, autistic women have been underrepresented, their distinct perspectives often overlooked, and their needs frequently misunderstood.

Recognition of the distinct experiences of autistic women and girls, as compared to their male counterparts, is increasingly being discussed. Among these differences, a prominent issue emerges: many autistic girls and women often face delayed, missed, or incorrect diagnoses, with some receiving diagnoses much later in life or not at all. This delay in diagnosis correlates with increased mental health challenges and social difficulties, factors that likely contribute to the higher prevalence of co-occurring conditions among autistic women[viii] (for more details, refer to page 11). Undiagnosed or late-diagnosed autistic women and girls frequently grapple with feelings of isolation and misunderstanding, particularly during adulthood or adolescence. Moreover, they may employ camouflaging or masking techniques to conceal their autistic traits (page 9), further complicating the identification of autism in this demographic.

Autistic women and girls may have:

- **Difficulty forming friendships:** Autistic women may encounter greater challenges in forming and maintaining friendships compared to men. This is because traditional female friendships often involve more social and emotional exchanges.
- **Strategies to hide their autism:** Many autistic women feel the need to hide their autistic traits to fit in with non-autistic peers, which can lead to burnouts and meltdowns.
- **Increased vulnerability:** Autistic women are at increased risk of sexual victimisation and exploitation, partly due to challenges in interpreting social cues and asserting boundaries.[ix]
- **Highly-focused interests:** Autistic women often develop special interests that might be perceived as more socially acceptable than those of autistic men. For example, collecting facts about bands, re-watching the same film or re-reading the same book again and again.
- **Greater rates of mental health challenges:** Autistic women have an increased likelihood of experiencing some mental health difficulties, such as anxiety, compared to autistic men. [viii]
- **A misdiagnosis of other mental health conditions:** The distinct presentation of autism in women can often lead to them being diagnosed with complex mental health conditions instead of autism, stemming from a lack of understanding about how autism manifests uniquely in this demographic.

For more information on autism in women: **https://www.autism.org.uk/advice-and-guidance/what-is-autism/autistic-women-and-girls**

These factors contribute to the unique challenges faced by autistic women and girls, highlighting the importance of understanding and addressing their specific needs for better support and inclusivity.

## Camouflaging in autistic people

Camouflaging (also known as masking), is a common strategy used by autistic individuals to blend into social situations, and is particularly prevalent among autistic women. While everyone may occasionally put on a social "mask," autistic people often find themselves "masking" constantly, especially when interacting with others or navigating unfamiliar environments.

Unfortunately, the persistent effort of camouflaging takes a toll on the mental and emotional well-being of autistic individuals.[x] Research shows that it leads to heightened stress, anxiety, and emotional exhaustion. This burden can even trigger "autistic burnout", characterised by overwhelming fatigue and emotional breakdown due to prolonged camouflaging (page 12).

Moreover, the consistent use of camouflaging can make other individuals doubt the diagnosis making it hard for autistic people to access support. To support them, it's crucial to create a safe and inclusive environment where autistic individuals can "unmask". Encouraging open communication, reducing societal stigma, and providing tailored support are essential steps in promoting their well-being and helping them embrace their true identity (pages 16/17).

### Types of camouflaging in autistic people

**Compensation:**
Compensation involves actively addressing social challenges by observing and mimicking others' body language, facial expressions, and social cues. It includes learning from various sources to improve understanding and navigation of social interactions.

**Masking:**
Masking refers to concealing autistic characteristics and attempting to present oneself as non-autistic. This may involve suppressing stimming behaviours, adjusting facial and body expressions, and making deliberate efforts to establish eye contact. Masking demands significant mental and emotional energy.

**Assimilation:**
Assimilation entails adapting and conforming to social norms to better fit in with others. It may involve engaging in pretence or acting to meet social expectations and selectively seeking or avoiding interactions based on comfort levels. The goal is to minimise social rejection or misunderstandings.

*"It's really energy consuming doing that and being somebody that really you're not."*

*"...you morph yourself into what you see around you so that you can fit in and go under the radar..."*

*"…I can't keep it up and the mask just comes down sometimes because you reach breaking point…camouflaging is one of the things I think has impacted my health more than anything."*

## If and how to talk to the person about autism

If you do think it is likely that the person is autistic it may be helpful to talk to them about autism, but it is important to consider when and how to do this. For some people the suggestion that they may be autistic could be helpful for developing their understanding of why their life has been particularly challenging, and this may be a very important moment for them. However, there are some instances where discussing this may have a negative impact. This may be the case for people who have a history of disengaging from services. Either way, it is crucial to focus on the relationship and build engagement and trust with the client. In many cases, only then will you be able to judge whether talking to the person about autism might help end their homelessness. In the meantime, it is important to begin adapting your communication and approaches with the client – as well as your expectations (see sections 6 & 7).

For more information on how to broach the subject see here:

**https://www.autism.org.uk/advice-and-guidance/topics/diagnosis/broaching-the-subject**

## Co-occurring conditions

Autistic people are more likely to struggle with a range of mental health conditions. This may make it harder to assess whether or not the person is on the autism spectrum. If you think the person shows signs of autism it is worth following this up with adjustments to the support offered, even if there is evidence of co-occurring mental health problems.

Autistic people may also have a learning disability, or multiple learning disabilities. If the individual has a learning disability then they should receive an assessment from their local authority of their care and support needs, and depending on their care needs they may be eligible for further support. More details are provided in section 8 of this document. For further details on co-occurring conditions, see the link below and page 11.

Links for finding out more about related conditions:

**https://www.autistica.org.uk/what-is-autism/what-is-autism/signs-and-symptoms-of-autism**

## Data protection considerations

When gathering or sharing information about whether a client is or might be autistic it is important to bear in mind considerations around data protection. Please refer to your organisation's policies around data protection and information governance as a guide.

## Autism and co-occurring conditions

There are some conditions that are very common in autistic people, and these co-occurring conditions can often make supporting an autistic person much more complicated. In such cases, comprehensive and tailored support is essential to address the diverse needs of individuals effectively. Please note that the following list is not comprehensive; additional conditions may co-occur with autism.

### Examples of Co-occurring Conditions

#### Anxiety

Around 40% — 50% of autistic people are diagnosed with anxiety.[xi] Causes of anxiety may differ to non-autistic people. Anxiety for autistic individuals is often experienced in response to changes in routine, social situations, sensory environments, and even due to difficulty understanding their own emotions (alexithymia).

#### Depression

Daily life can be particularly challenging for autistic individuals, often resulting in feelings of being misunderstood, strained relationships, and isolation, all of which can contribute to depression.

#### Eating disorders

Around 20% of those with anorexia meet the diagnostic criteria for autism.[xii] However, anorexia is not the only eating disorder that co-occurs in autistic individuals; binge eating, and avoidant restrictive food intake disorder (ARFID) can also co-occur. Eating disorders in autistic people may occur for different reasons compared to non-autistic people. [xiii, xiv]

#### Attention deficit hyperactivity disorder (ADHD)

ADHD is one of the most common co-occurring conditions in autistic individuals, and autistic individuals with ADHD have a higher risk of suicide, depression, anxiety, as well as higher levels of unemployment and drug and alcohol abuse compared to those who are only autistic or have ADHD alone. [xv]

#### Learning disabilities

Autistic individuals may also have one or multiple learning disabilities, such as dyslexia and dyscalculia, which require tailored and adapted support for their learning capabilities. Some autistic people also have moderate to severe learning difficulties which affect their literacy, communication, and independent living skills across all aspects of daily life.

#### Obsessive compulsive disorder (OCD)

A key characteristic of autism is repetitive behaviours, which can often resemble OCD. However, they are not the same. OCD consists of unwanted behaviours performed out of fear, while repetitive behaviours in autistic individuals can have a soothing function. Differentiating these types of repetitive behaviour can be difficult when OCD co-occurs with autism.

## Meltdowns, shutdowns, burnout, and sensory overload

Autistic individuals often face unique challenges in their daily lives. Among these challenges are the experiences of meltdowns, shutdowns, burnout, and sensory overload. These represent intense emotional or physical responses, withdrawal, and exhaustion that can significantly impact the well-being and capacity of the individual. It is important to remember that meltdowns, shutdowns, burnout, and sensory overload are not deliberate behaviours but rather responses to overwhelming circumstances/experiences. Below highlights how to recognise meltdowns, shutdowns, burnout and sensory overload. Page 17 highlights ways to support your autistic clients.

### Meltdown:

- Intense emotional outbursts, often triggered by overwhelming sensory stimuli, frustration, or anxiety.
- Difficulty in self-regulation, with individuals appearing inconsolable and unable to calm down.
- Heightened sensory sensitivities, leading to covering ears, avoiding touch, or seeking isolation.
- Verbal or non-verbal expressions of distress, such as shouting, crying, or repetitive vocalisations.

### Shutdown:

- Withdrawal and social disengagement, avoiding eye contact or conversation.
- Slowed or limited speech, difficulty responding or initiating communication.
- Loss of interest or motivation in activities previously enjoyed.
- Physical and mental fatigue, appearing lethargic or unresponsive.
- Increased sensitivity to sensory stimuli, seeking quiet and dimly lit environments.

### Burnout:

- Physical and mental exhaustion, often accompanied by chronic fatigue.
- Reduced cognitive functioning, difficulty concentrating or making decisions.
- Emotional depletion, feeling overwhelmed, anxious, or depressed.
- Loss of interest or enjoyment in previously favoured activities.
- Increased sensitivity to stress, becoming easily irritable or frustrated.

### Sensory overload:

- Autistic individuals may have differences in sensory processing, which means they may experience sensory stimuli more intensely or differently. What may be a minor annoyance to someone non-autistic, such as a buzzing sound or bright lighting, can be extremely overwhelming for an autistic individual.
- Sensory overload occurs when the brain receives an overwhelming amount of sensory information and the autistic individual has difficulty processing and filtering it effectively.
- During sensory overload, individuals may experience:
    1. Feelings of distress, anxiety, irritability, or even physical discomfort.
    2. Behaviours such as covering their ears, avoiding eye contact, and becoming withdrawn.
    3. A need to escape the overwhelming situation.
    4. Meltdowns, shutdowns and burnout.

# 4. Autism and links with homelessness

Autistic people vary greatly in their support needs. Some live independently, while others need help with certain tasks or even 24-hour specialist support. Unfortunately such support is often lacking, and autistic adults on average struggle to attain sustainable employment and housing. This probably raises the risk of homelessness for autistic people.

## Prevalence in the homeless population

Research into this area is still developing, but an academic paper found that 12% of a group of people experiencing homelessness showed strong signs of autism (Churchard et al., 2017).[xvi] The prevalence of autism in the general population is estimated to be 1.1%, so this would suggest that rates of autism were raised among the people in this research. This builds on other studies that have also suggested a link between autism and homelessness.

## How autism might lead to homelessness

Personal social challenges, a lack of community understanding and support, and employment disadvantage and discrimination are likely to be key reasons why autistic adults may be more at risk of homelessness. Autistic people can experience challenges in communicating and interacting with others. As such, they are more vulnerable to relationship breakdown, social isolation, and reduced support networks, which can create difficulties in accessing help (family breakdown may be a particular struggle for some autistic people). Research by the National Autistic Society also suggests a lack of social care and welfare support for autistic people. For example, some autistic adults have said that staff undertaking Work Capability Assessments (WCA) do not always understand autism, and the majority of autistic adults report negative experiences at Jobcentre Plus. For autistic adults in employment, more than one third consider workplace adjustments for their condition to be poor or very poor (National Autistic Society, 2016).[xvii] National Autistic Society surveys have also found that 71% of autistic adults feel that they do not have enough social care support to meet their needs.[xviii]

## Homelessness and increased vulnerability

While more research needs to be done in this area, it seems likely that autistic people may be particularly vulnerable when they are homeless. Many experience social isolation, which raises risks to health and wellbeing, and may also reduce chances of engaging with homelessness services. Furthermore, because autistic people have difficulty in understanding and predicting the behaviour of others, they may be more susceptible to violence and abuse. For instance, they may not understand that someone who appears friendly may actually have ulterior motives.

### *Case study: E

E's journey into homelessness began when she moved to be closer to work. She emphasised that due to her autism, quiet and predictable environments are paramount for her, as noise impacts her health and well-being. Initially, she found herself surrounded by very quiet neighbours and she felt safe and secure. E's life was disrupted when her neighbours changed, leading to overwhelming and distressing experiences. Their noisy and disruptive behaviour triggered anxiety and major discomfort for E. In an attempt to address the situation, she approached her neighbours, seeking a peaceful resolution. Unfortunately, her request resulted in an altercation with one of the neighbours, who threatened her life.

This experience caused E's mental health to plummet. Although the neighbour who threatened her had been given a restraining order, E felt unable to leave the house due to fear of walking past his door to leave the building. As such, she had to take time off work. Growing increasingly desperate and unable to tolerate her current living environment, E resorted to couch surfing at friends' houses. Despite privately renting, she struggled to find somewhere else to live as support services, such as social workers and the council, had difficulty grasping her sensory requirements. Moreover, her sensory challenges meant that taking public transportation was difficult, so finding a suitable location close to work was also challenging. During this time, E reconnected with her ex-partner who had initially been a source of unhappiness to her and moved back in with him. Despite her acknowledgement that he groomed her, she expressed her fear of being homeless again, which overrode her desire to leave him and his home.

# 5. Recognising possible autism

Recognising that a person shows signs of autism may be critical in helping them get off the streets or maintain residency in new accommodation. This section presents a procedure to help identify if any of your clients might be autistic.

In some areas there may be an NHS and/or local authority specialist autism service that can provide you with consultation. In the Appendix of this document there is a case study of how this type of consultation has helped keyworkers to adjust their practice, and there are details of how to find out about local specialist autism services in section 8.

## Identifying autism

Autism is a very varied condition and even autism specialists often find it challenging to diagnose. Homelessness will complicate the picture further.

If a person is autistic we would expect to see signs in these two areas. The first area is in their social relationships, where they will face challenges in communicating and getting on with others. The second is in their behaviour and interests, which may show a preference for sameness and predictability. Recognising autism can be difficult as traits may be concealed by behaviours such as masking or might be less obvious during short encounters.

**Table 1** presents check-boxes against attributes in each area. If your client's presentation matches up with at least some aspects in both areas (columns A & B), they are showing signs of autism. It would then be helpful to look into this further and consider adjustments to the support you offer. You do not need to wait for a formal diagnosis to start making these adjustments. Autism is a very varied condition so a person does not need to match all or even most of the criteria to be autistic. The tool presented (Table 1) is **not intended to help give a definitive diagnosis, but rather an indication as to whether or not your client may be autistic**.

If the person is autistic then they will have been autistic for their entire life, so it could be helpful to gather evidence of how they were in the past by talking to people who worked with them previously and looking at their case history.

*"Our disability depends on the amount of energy tokens we have … sometimes they're there and it reaches the end of the day, and you can still cope, but most of the time they're quickly gone."*

## Table 1: Checklist of autistic traits tool

If your client's presentation matches up with at least some aspects in both columns (A & B) they are showing signs of autism. It often requires time to recognise these traits. Please note that whilst these are traits associated with autism, they also may be indicative of other experiences or conditions, such as trauma or attachment disorders (which can co-occur in autistic individuals) - this is something you should consider when working with your client.

| A | Difficulties with social communication and getting on with others | B | Restricted and repetitive behaviours and interests |
|---|---|---|---|
| | **Marked difficulties with social interaction** | | **Repetitive behaviours** |
| ○ | On first meeting either does not say hello, or does so in an unusual way | ○ | Repetitive movements |
| ○ | Does not engage in back-and-forth conversation or takes longer to reply to a question | ○ | Repeats the same phrase many times |
| ○ | Comes across as awkward, overly blunt or over-friendly when interacting with others | ○ | Monotonous tone of voice |
| ○ | Easily overwhelmed by social situations and experiences 'meltdowns' (i.e. loses control of their behaviour and expresses this verbally and/or physically) | ○ | Uses formal or pedantic language |
| | **Differences in body language** | | **Routine** |
| ○ | Unusual eye contact (looks away or has a very fixed stare) | ○ | Prefers to maintain the same routine and has difficulty coping with even small changes |
| ○ | Seems to have limited facial expressions | ○ | Likes to do things in a certain way and can become anxious or distressed when this is not possible |
| ○ | Unusual body language (e.g. little use of gesture) | ○ | A strong need to control interactions or situations |
| ○ | Does not recognise body language used by other people (e.g. has to be told when a meeting is over) | ○ | Avoidant of every day demands, sometimes to an extreme extent |
| | | ○ | Likes to cling to a specific object or objects |
| | **Difficulties with relationships** | | **Highly-focused interests** |
| ○ | Does not adjust their interaction depending on who they are around | ○ | Fixation on an interest to an unusual level (this can be any interest) |
| ○ | Can appear overfamiliar with strangers or can show little interest in other people | ○ | Repetitive themes that they like to talk about or collect facts on |
| ○ | Few or no friendships | | **Differences in senses** |
| ○ | Finds it hard to maintain friendships | ○ | Over- or under-sensitivity to sounds, touch, tastes, smells, light, colours, temperatures or pain |
| | | ○ | Seeks out sensory stimulation (e.g. attracted to loud noises, touching objects) |

# 6. Working with people who show signs of autism

## Is a formal assessment appropriate?

If you think your client shows signs of autism then you need to decide on realistic next steps. In some cases it may be helpful for the client to have a formal assessment from an NHS autism service. It is important to consider if your client would want to go through an autism assessment and discuss this with them.

There are pros and cons to getting a formal assessment. For some people this can be a moment of realisation, helping them understand why they experience the world in the way they do. A diagnosis can also make it easier to access a range of support services that may be available locally, and it may supersede a previous diagnosis, or address a previous misdiagnosis such as schizophrenia. However, a formal assessment may not be the right option for your client at this time. Assessment services are not always easily accessible and often have long waiting lists. The assessments themselves can be time-consuming and depending on the service may require multiple appointments, which may not be feasible for some clients. They also generally rely on speaking to family members and getting a full history, and if this is not available then making a diagnosis will be more difficult. In any event, you should not wait for a formal diagnosis of autism before considering what reasonable adjustments or support could be offered. Details of how to find out about local NHS arrangements for adult autism assessment are provided in section 8 of this document.

Whether or not you and your client decide to look into a formal assessment, it will still be helpful to consider adjusting the support you give to someone who you think may be autistic.

## Adjusting the support you provide

Many of the best practice 'psychologically informed' approaches in the homelessness sector are still key in working with autistic people. These include:

- Highlighting and celebrating the client's strengths
- Focusing on the client's priorities for your work together
- Recognising the importance of relationship building

However, in the case of autistic adults, conventional approaches may need adaptation. For instance, in the homelessness sector it is good practice to give a person choices, but this might actually result in the autistic person feeling overwhelmed and disengaging. A better approach may be to limit the number of choices you present them with. Table 2 offers a number of approaches you can take when supporting people who may be autistic.

## Table 2: Checklist for Working with Clients Showing Signs of Autism

To provide the best support for your autistic client, you can make adjustments and accommodations. It's important to note that these are suggestions; adopting a person-centred approach will help you determine which ones are most useful.

| | **Routine** | | **Sensory Sensitivities** |
|---|---|---|---|
| ○ | See the client at the same time and in the same place | ○ | You can ask your client about their sensory sensitivities and what they may need from you |
| ○ | Inform them about any changes as far in advance as possible | ○ | Consider if they have heightened sensitivities (bright lights, loud sounds, strong smells etc.) |
| ○ | Follow their lead; enable them to control the when, where, and how of the situation and/or give clear and specific choices | ○ | Enquire about specific triggers that may cause them to feel overwhelmed |
| ○ | Try to provide a clear timeline or "action plan" so that your client does not become overwhelmed. Be explicit about when timelines or plans may need to change or remain flexible | ○ | Inform them about any planned disruptions (e.g. fire alarms, building work) |
| | | ○ | Enquire if they have any specific tools or objects, such as fidget cubes or stress balls, that they find helpful for focus and relaxation during interactions |
| | **Communication/Social Interaction** | | **Processing** |
| ○ | Ask very clear, direct questions one at a time, then pause to allow for a response | ○ | Processing 'in the moment' can be challenging, so slow down and take pauses to allow time for the individual to process what you are asking or telling them |
| ○ | Make instructions as clear and minimal as possible | ○ | Allow time to engage with the person; it may take months to build a relationship and cover the necessary content |
| ○ | Break down information into small, manageable chunks e.g., lists or bullet points | ○ | If necessary, provide an agenda and questions before the meeting |
| ○ | Provide images to illustrate what you are saying (e.g., pictures and descriptions of yourself, pictures of a hostel) | ○ | Provide information on what you discussed after the meeting |
| ○ | Use clear, concise, and unambiguous language. Avoid using idioms, irony, metaphors, and words with double meanings; e.g., avoid saying, 'It's raining cats and dogs out there' | ○ | Reduce the number of choices you offer; be more directive than you usually would be with clients |
| | **Acceptance** | | **Strength-based Approaches** |
| ○ | Accept the diagnosis, be open-minded; autism doesn't have a specific appearance | ○ | Focus on their strengths to facilitate communication (e.g., talk with them about a specific interest of theirs, which can be anything from art or music to chess, or computers, to bands or books) |
| ○ | Accept that you may need to adjust your approach | ○ | Recognise the person's passions and learn how to become a part of and share in their world, rather than trying to redirect their interests to meet social norms. You may be able to help them expand their activities by building on an existing interest |
| ○ | Continue to follow your client's lead | | |
| ○ | Be flexible in your approach, struggles can vary person to person but also day to day | | |

## Autism and demand avoidance

A tendency towards extreme avoidance of everyday demands and expectations may be seen in some autistic people. This is rooted in an anxiety-based need to be in control. It is important to recognise this distinct behaviour profile as it has implications for the way a person is best supported.

An example of how to work with clients fitting this profile can be found in the case study of 'K' in section 7 below.
**https://www.autism.org.uk/advice-and-guidance/topics/behaviour/demand-avoidance**

## Be reflective and seek out opportunities to talk things through with others

During the process of finding an approach that feels like a good fit you will need to be reflective and self-aware, gauging what works and what does not. You will also need resilience and patience if some approaches evoke a negative response, but being flexible and adapting your approach to meet individual needs (even if there are some rejections along the way) generally does pay dividends.

This is not straightforward work, so use reflective practice and talk to your encounters through with your team to help maintain your ability to stay self-aware and empathetic.

## Case study: D

D had been rough sleeping for many years. He was always easy to locate, having set routines and places he wanted to be at certain times of the day, and whilst friendly he would never engage in a meaningful way with the support available. He was completely socially isolated.

D's health began to deteriorate and there was concern that he would not survive another winter on the streets. A suitable accommodation option was identified for him; he was given information and photos and the project manager came to meet him. He still wouldn't accept the offer, and he was eventually taken into hospital.

While D was in hospital the team began to work in a much more directive way, limiting the choices D was given which they thought were confusing him. Instead they simply told him he would be moving to a particular accommodation project, and instead of describing it verbally they showed him images. When he moved there the outreach team visited him daily to help him establish a new routine. He is now settled and has no desire to return to the streets, despite the team later finding out he had been there for decades.

## Example Support Service: Helping autistic people avoid homelessness

The Westminster Floating Support Service, delivered by the homelessness charity SHP (shp.org.uk), has introduced a new prevention service in recognition that autistic people may be at elevated risk of homelessness. A team trained in autism awareness offers a dedicated advice surgery for autistic people, providing practical help with any aspect of maintaining accommodation, including benefits, bills and landlord matters. Attention has also been given to the setting of the surgery so this is as comfortable as possible for autistic people. It is hoped that this targeted approach will reduce accommodation breakdown and prevent autistic people from becoming homeless in the first place.

# 7. Helping autistic people to take up and stay in accommodation

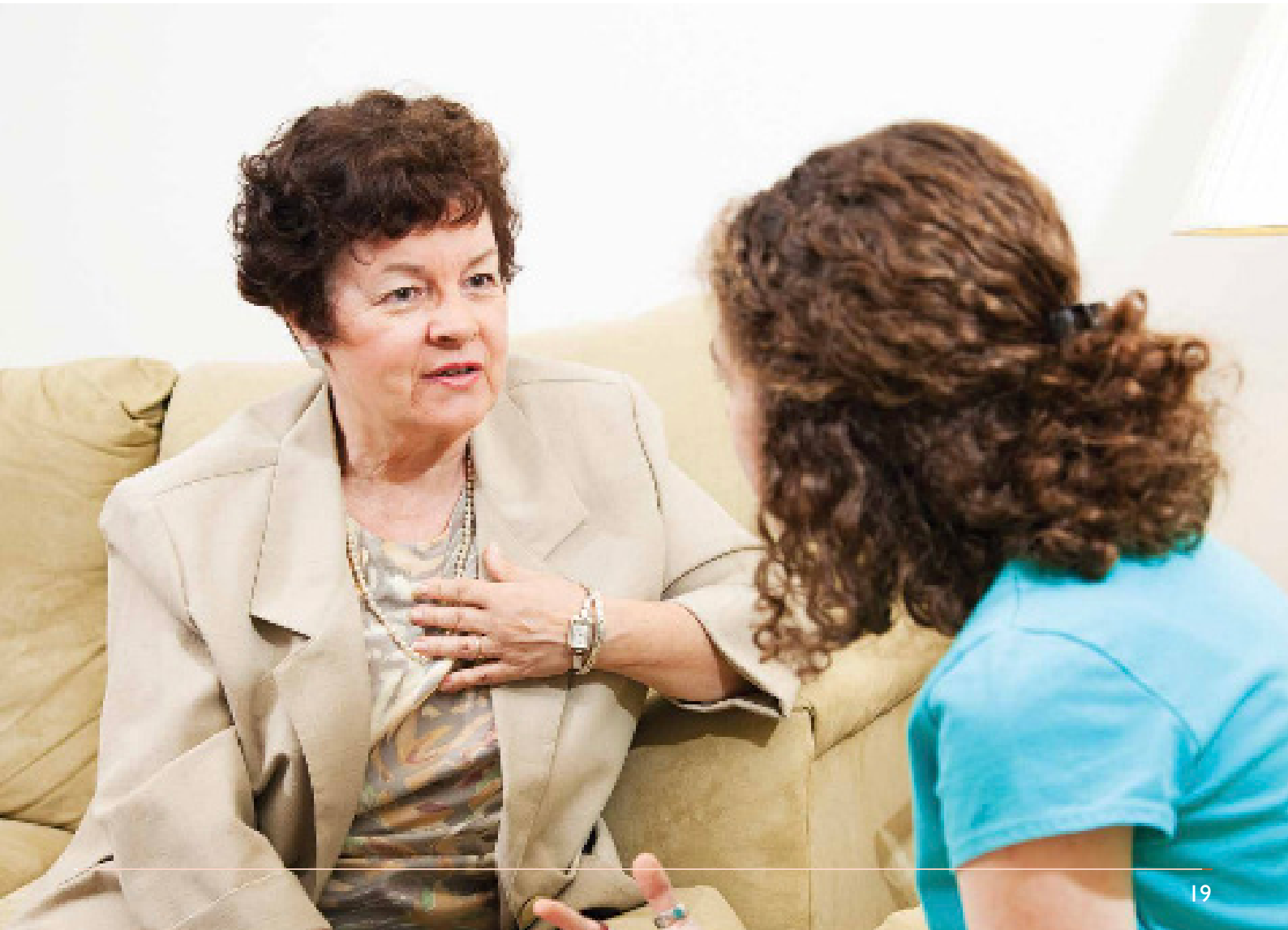
There are two key principles to follow here: adjust the way the service is run to meet the needs of the autistic person, and make sure they receive as consistent a service as possible.

## Adjusting the service

A clear understanding of the individual is crucial. Every autistic person is different, so their needs when they enter accommodation will be different. It is important to remember that transition is a challenge for many autistic people. Going through the accommodation form (Table 3, p.20/21) or working with the autistic clients checklist (p.17) may help you think about what changes need to be made.

*"I really cannot cope with the unknown. I need to know what's going on. I need to see the picture. I need to be able to feel like I can, I can be in control of, of situations and if I'm out of control then it really throws me for a loop…"*

*"I would just like, keep checking in, keep staying on the radar, keep going back gently, gently rather than just 'you must do this'… like it's just really overwhelming and you just wanna run away."*



## Table 3: Accommodation considerations for people who are or may be autistic

| Overall area to consider | Specific issues | Notes |
|---|---|---|
| What are their needs in terms of social contact? | • Do they want to talk to and spend time with others, or would they rather be on their own? Depending on their response, what would be the best accommodation option for them?<br>• Would they benefit from having regular contact with someone, such as a befriender? | |
| How can you adapt your communication for this client? | • Can you use pictures to make communication easier (e.g. a picture of the hostel/accommodation on offer)?<br>• Think about the key things you need to tell them, and how you can make this information as clear and simple as possible<br>• Some autistic people take a little longer to process information – try not to rush autistic people into replying, wait for their response | |
| Can any of the actions or protocols the service normally expects be dropped, or done in a different way? | • Some autistic people find signing forms very difficult<br>• Can welfare checks be done differently? (E.g. noting when they are seen on CCTV) | |
| Does your usual approach to support planning need to be adapted to meet the person's needs? | • Are all the forms you use necessary / do they all have to be filled out with the individual?<br>• What is the priority of the person receiving the support? | |

| Overall area to consider | Specific issues | Notes |
|---|---|---|
| Do they engage in any behaviours which appear repetitive? If so, what can the service do to accommodate these behaviours? | • Try to establish clear and explicit rules with the person on how their behaviours can be accommodated | |
| Do they have any highly-focused interests which need to be accommodated? | • Again, clear and explicit rules are essential,it is important to accomodate different behaviours<br>• Can you better engage the person by focusing on these interests? | |
| Are there any sensory sensitivities to be aware of? | • Things most people would not even notice (e.g. a slightly brighter light) can be overwhelming for some autistic people<br>• They may otherwise be less sensitive, and as a result want more stimulation (e.g. loud noises, extremes of temperature)<br>• Think about all the senses and be mindful that needs can change based on the situation and environment | |
| How can you help them manage change? | • Helping the person move on from the service will need substantial preparation | |

## Rules and personalisation

Some people experiencing homelessness have difficulty maintaining accommodation because they find it challenging to understand certain rules. This may be particularly true for autistic people. Autism is associated not only with a tendency towards sameness, but also with difficulties in understanding social behaviour, such as personal boundaries and other people's wishes. The autistic person may therefore struggle to adapt to new rules and even struggle to understand why a particular rule has been made. One way to make adjustments easier for the autistic person may be to agree a set of rules with them when they enter accommodation and keep them under review (see case study of S, page 26). This approach aligns with personalised approaches encouraged in the homelessness sector.

For more information about these approaches see:

**https://homeless.org.uk/knowledge-hub/autism-and-homelessness/**

## Being consistent and predictable

Autistic people tend to find structure and consistency helpful. It is important that all members of staff treat the autistic person in the same way, as differences in approach can be confusing and anxiety-provoking. And never promise anything that you cannot deliver!

## Behaviour that challenges

If the person's behaviour is challenging, even aggressive, it may be helpful to remind yourself that this may be motivated by anxiety and distress on their part. Their experience of homelessness is likely to have made them more defensive and feel more isolated and vulnerable. It may be useful to return to the form on pages 20 and 21, and section 6 to identify if there is anything you or the service can do differently to help them feel more comfortable.

## Hostels can be difficult environments for autistic people

It is important to recognise that even with your best efforts many hostels will still be challenging environments for autistic people. They are likely to find it difficult being around other hostel residents, and parts of the environment which may be beyond your control, such as bright lights, may make them feel very uncomfortable. If the person does not take up the accommodation, or only maintains it for a brief period, this does not mean they are unsuited to accommodation. This could be an opportunity to learn more about the autistic individual's needs, and finding out why this particular accommodation option did not work for them may help you to identify a more suitable option in the future.

*"How was I supposed to look? How was I supposed to behave? How long was I meant to be there? Are there going to be other people there? Are they going to look at me? Are they going to talk to me? And it's like a million questions I've had about new situations since I was as tiny as I remember. Always this."*

## Case study: K

K is an older man with a long history of rough sleeping and being evicted from hostels. The reasons for these evictions included failing to engage with his keyworker, failure to cooperate with fire drills, withholding his signature from benefits forms, not paying service charges, and verbal aggression towards staff. When he slept out he would sleep standing up in telephone boxes. On a good day K is funny and engaging, enjoying word play, crosswords and talks about his love of television programmes. He has an exceptional memory and remembers the price of everything along with dates and times. But he can also become 'irrationally' angry and turn away staff with whom he previously had a good relationship.

K has now been in his supported accommodation for three years. Key to this has been understanding that his challenging behaviour was driven by anxiety and a need to control his environment (K was a client who showed signs of demand avoidance; see section 6 above for more details of this).

In planning his new accommodation, the team took a full history of what had and hadn't worked in the past, got advice from the local autism assessment psychologist and used this to minimise conflict points. They put in place:

- Communication learning. For example, never asking 'How are you?' K disclosed he hates this with a passion!
- Direct deductions for his service charge from his pension.
- Welfare checks by noting sightings on CCTV rather than checking on him in person.
- Agreements with senior managers and commissioners that support planning would not be attempted. Instead a befriender visits him and purely focuses on his priorities (shopping, cooking, a bit of hoovering, chatting).
- Incremental processes. The befriender works with the team (behind the scenes) to take small steps to increase K's self-care and quality of life, and create 'low pressure' opportunities to do this. Sometimes K rejects the befriender, sometimes in a very forceful way for a number of weeks, but she has a thick skin and keeps returning, and is gladly accepted by him again.

This flexibility, forward planning, and 'rethinking' the supported housing offer has kept K indoors.

## *Case study: J

**J, who is now middle aged, experienced homelessness from around her mid-adolescence and early twenties. She received her autism and ADHD diagnoses when she was in her forties, following her son's diagnosis.**

J's childhood was marked by anxiety and social isolation. Her family had complex dynamics, with her parents showing traits consistent with autism. Her mother had meltdowns, while her father was emotionally distant. This left her feeling unsupported. Around 13, J turned to drugs and alcohol to cope with her anxiety, leading to a destructive relationship with an older man. This relationship strained her family bonds. At 16, her father asked her to move out so that she wouldn't influence her siblings with her alcohol and drug use, leading to her first experience of homelessness.

J ended up in a hostel, and her time at the hostel proved to be quite challenging. Upon reflection, she realised that her experience was, in part, influenced by her autism. She acknowledged that her difficulties with communication and her struggle to engage with support services due to social anxiety made it incredibly challenging to access the help she needed while staying at the hostel. She recalls the hostel being a *'terrifying'* place, especially during mealtimes, with people visibly struggling due to their substance use or other issues. Her social anxiety led her to skip meals and hide in her room.

J remained at the same hostel for around a year and was able to secure a council house. She now works in the homeless sector supporting those with complex needs.

# 8. Resources

**Finding learning disability services:** There should always be a local learning disability service. Information about these services should be online (e.g. for services in Westminster you would simply type into the search engine 'learning disability service westminster'), and GPs or mental health teams should also have information about how to access these services.

**Finding your local autism diagnostic pathway and consultation:** There is not always a specific or separate local diagnostic service for autistic adults, but every area is obliged to have an adult diagnosis pathway through the NHS. Some diagnostic teams accept self-referrals, but in most areas, a GP's referral is required. You should be able to find more information at https://www.autism.org.uk/advice-and-guidance/topics/diagnosis/pre-diagnosis/adults

The National Autistic Society website contains much more information about autism: **www.autism.org.uk** as does Autistica: **www.autistica.org.uk**

For information about autism in women:

- **https://www.autism.org.uk/advice-and-guidance/what-is-autism/autistic-women-and-girls**

For information about autism and co-occurring conditions:

- **https://www.autistica.org.uk/what-is-autism/what-is-autism/signs-and-symptoms-of-autism**

For information about autism and communication techniques/tools:

- **https://www.autism.org.uk/advice-and-guidance/topics/communication**

For information about autism and meltdowns and shutdowns:

- **https://www.autism.org.uk/advice-and-guidance/topics/behaviour/meltdowns/all-audiences**
- **www.ambitiousaboutautism.org.uk/information-about-autism/behaviour/meltdowns-and-shutdowns**

For information about homelessness services in your local area, the following databases may be helpful:

- **www.streetsupport.net/**
- **https://homeless.org.uk/knowledge-hub/autism-and-homelessness/**

For information on advocating for priority need in homelessness legislation for autistic indiviudals refer to page 21on the link below:

- **https://homelesshealthnetwork.net/wp-content/uploads/2022/01/Neurodiversity.pdf**

# Appendix: case studies

## Case study: A

I have been homeless on two occasions. The first period of homelessness was due to family issues, the second was because the accommodation I was living in was demolished and I was not given any help to find somewhere else to live. Throughout this time I found it difficult to find the right support; even after I was diagnosed with autism there did not seem to be any services to help me avoid becoming homeless.

After becoming homeless for the second time I ended up sleeping on the floor of someone's house for several months. This had a massive impact on my mental health as I was very close to not wanting to wake up any more. Being on the autism spectrum makes any type of move difficult, but I had to manage moving to three different houses in the space of five months.

Many health professionals saw me before the autism was diagnosed. When I was given the diagnosis I was unsure how I felt; I had no understanding of autism and I was not given anything to help me understand more about this diagnosis. Over time I met people who were able to support me, and eventually I did manage to get housed. I am now working and I have graduated receiving a 2.1 BA Hons in Early Childhood Studies.

My story highlights the importance of support being available for individuals like myself. All I needed was people who were willing to accept me for who I am. I was completely let down by the system, it took 20 years and many breakdowns for professionals to actually do something. Why should it be that we have to get to crisis point to receive a diagnosis, and why are services not better at meeting the needs of people on the autism spectrum?

## Case study: Consultation with an autism professional

O, a middle-aged man, had been known to homeless services for many years. He had been very difficult to engage with, and had resisted many attempts to re-house him. It was known that he had started rough sleeping after the death of his parents 15 years ago. He had worked as a sorter for the Post Office prior to that, and though he liked his own company he had been a diligent and efficient worker. After the death of his parents, somehow he lost the tenancy of their home, started to sleep rough, and stopped going to work. He was never seen begging, but seemed to manage by going to various drop-ins for homeless people. He had occasionally been seen sleeping in telephone boxes. His voice was very monotonous, speech repetitive, and he never made eye contact.

Attempts to re-house him had foundered because he seemed distressed by staff interactions, and he always seemed uncomfortable in busy hostel environments. During his brief stays in hostels it was noted that he always slept in an arm-chair, and that his few belongings were arranged in a 'tidy but peculiar' way. It was also noted that he only accepted places at hostels when the weather became extremely cold.

The homeless services involved suspected that he was on the autism spectrum, but also knew that trying to encourage him to participate in an assessment was a non-starter. Staff attended an anonymised consultation at the local autism assessment service. After outlining the circumstances and behaviour of O, it was concluded that there was a strong chance he was on the spectrum. It seemed apparent that interaction was difficult and aversive for him, and this was something that would have to be respected. Also, it was likely that O found noise difficult to cope with. It was agreed that the approach should be to wait until the weather deteriorated, such that he was willing to accept a hostel placement. This happened the following February. He was found a room in a secluded and quiet corridor. It was agreed that he be 'left alone' – the team kept an eye on him, but did not approach. After a couple of weeks he started to approach the staff with small requests (e.g. 'How does the washing machine work?'). They would not try to ratchet these interactions into something more significant or progressive, but instead met his requests in a low intensity and direct

## Case study: Working effectively with someone on the autism spectrum

S had been rough sleeping for several years. It was believed that he was on the autism spectrum, and his outreach worker took a specific approach in her contact with him:

- At the initial meeting she kept it brief and to the point.
- They agreed that future meetings would last for only 10 minutes and that he was under no obligation to make these.
- The worker informed him that she would go to the day centre every Wednesday at 11am should he wish to meet with her.

S was interested in finding accommodation. The worker showed him photos of a place to live, which he was positive about, but it was some time before anything further happened. He did not always make the Wednesday appointments and one major issue was that he seemed reluctant to make a claim for benefits, but he would not say why.

Some time passed before they met again. When they did, S disclosed his fears around a benefit issue and felt he was in 'big trouble'. He agreed for his outreach worker to look into this. In fact, the problem was not his fault and was easily resolved, but he had built it up into a much bigger issue. He was relieved when this was cleared up and had much more trust in his worker.

Despite this, he still often missed the Wednesday appointments. After some time, his worker saw him when, coincidentally, there was an accommodation opportunity at the project he had seen in the photos. He agreed to visit on the understanding there was no pressure to accept.

The hostel made him feel very welcome, gave him simple and clear information, and showed an empty en-suite room. He was offered the chance to stay the night on the understanding that he could hand the key back in and leave if he did not like it. This went well, and he decided to stay and moved in formally the next day.

What can we learn from this case study?

- The outreach worker appreciated how to work with someone who is on the autism spectrum, keeping things brief and to the point with no pressure, and always being consistent.
- Unravelling and understanding what S felt (e.g. the benefits issue) was an important first step in enabling him to cope with a move into accommodation.
- Collaborative work between the hostel, day centre, and his outreach worker enabled details to be worked out behind the scenes. Once S was ready to move in, everything was in place.

## *Case study: M

M grew up with his mother and two sisters. He developed obsessive routines and became upset when plans changed. He was bullied in primary and secondary school; however, he was permanently excluded at fifteen after a fight with a classmate. Family conflicts led his mother to ask him to move out at sixteen. M experienced sofa-surfing and then stayed in a hostels on and off from 16 to 25. In the hostels was where he had his first panic attack. Over the years, he moved between hostels, lived briefly with a girlfriend, and stayed with his alcoholic father. At nineteen, he began an apprenticeship but lost his placement due to marijuana use, returning to the hostel.

At twenty-two, M moved in with his girlfriend, who became pregnant, only for him to later discover the child wasn't his. As a result, he moved out and he experienced street homelessness, struggling to find shelter and resorting to self-harm and substance use.

Returning to a hostel, M continued substance use and heavy drinking as a coping mechanism for anxiety and to help him sleep. During this time he learnt that a family member was abused by a partner. While the partner had served a short prison sentence, during a chance meeting in the street, he beat up the man, leaving him with severe injuries. M was arrested and was sentenced to several months in prison. Whilst M liked the routine of prison, his mental health significantly worsened, and he began experiencing blackouts.

At twenty-five, M was living in a hostel. His mother, after working with autistic children, suggested he might be on the autistic spectrum. He received an autism diagnosis, but was forced to move to a higher support hostel due to a misunderstanding with a support worker. This meant he could no longer bid for independent housing. This made M feel like he was back at square one. He stopped using substances and aimed to obtain a driver's license and run a van-based odd-job business. He recognised the need to address self-confidence and anxiety for a "normal" life.

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* Case studies with the asterix next to them are stories which illustrate the narratives of individuals who have lived experiences of homelessness and have generously shared with us their experiences. All names have been changed to respect each individual's privacy, but the stories presented are real and represent the voices of people experiencing homelessness today. These case studies represent the work from two institutions: the University of East London, led by Dr Georgia Lockwood Estrin and funded by Autistica, and the University of Bristol, as part of a ESRC PhD project by Dr Beth Stone.

## For further information please contact

**The Westminster Homelessness and Health Coordination Project**

**https://groundswell.org.uk/westminster-hhcp/**

**#autismtoolkit**

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