Autism and Homelessness Toolkit

resources for

Supported by:









Contents

Acknowledgements	Page 3
Introduction	Page 4
What is autism?	Page 5
Autism and links with homelessness	Page 7
Recognising possible autism	Page 8
Working with people who show signs of autism	Page 11
Helping autistic people to take up and stay in accommodation	Page 14
Resources	Page 19
Appendix	Page 20
References	Page 22

I. Acknowledgements

This Autism and Homelessness Toolkit was prepared by a number of individuals and organisations who contributed time, expertise and materials without fee. The project was led by Dr Alasdair Churchard and guided by a multi-disciplinary steering group who ensured balance and impartiality. Special thanks are due to the National Autistic Society, Homeless Link and Resources for Autism for their keen support and permissions to use published materials in this Toolkit. Special thanks are also due to contributors with lived experience. Grateful thanks to Victoria Aseervatham at Westminster City Council for assistance in promoting the project; to Nayer Ravandi at St Mungo's for logistical support; to Leigh Andrews at Change Communication for guidance on toolkit creation; to Dawn Rivers from Julian House for her suggestions which were incorporated into section 7 of this toolkit; and to the St Mungo's Communications team for the typesetting and design of this Toolkit.

Autism and Homelessness Toolkit Steering Group

Leigh Andrews (Change Communication), Victoria Aseervatham (Rough Sleeping Commissioning Manager, Westminster City Council), Dr Alasdair Churchard (Clinical Psychologist), Liza Dresner (Resources for Autism), Dr Paula Grant (Clinical Psychologist), Dr Andrew Greenhill (Clinical Psychologist), Leah Lansdown (contributor with lived experience), Tasmin Maitland (Homeless Link), Phoebe Myers (contributor with lived experience), Tim Nicholls (National Autistic Society), Jon Paxman (2020health), Nayer Ravandi (St Mungo's), Dr Morag Ryder (Clinical Psychologist), Piers Wright (National Autistic Society).

Anonymisation of case studies

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. The case study 'A woman with autism's experience of homelessness' was kindly provided by the individual concerned for inclusion in this toolkit.

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. 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.



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. All autistic people share certain difficulties, but being autistic will affect them in different ways. 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 sort of support, all can be helped to live a more fulfilling life of their own choosing.

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 the 'right' 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.



Sensory sensitivity

Autistic people may experience over or under-sensitivity to sounds, touch, tastes, smells, light, colours, temperatures or pain. For example, they may find certain background sounds, which other people ignore or block out, unbearably loud or distracting. This can cause anxiety or even physical pain. Or they may be fascinated by lights or spinning objects.

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.



For more details see: www.autism.org.uk/ about/what-is/gender.aspx

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

n... D13×

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}

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 a recent academic paper found that 12% of a group of people experiencing homelessness showed strong signs of autism (Churchard et al., 2017).^{viii} 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. This can lead to relationship breakdown and social isolation, therefore reducing support networks and creating difficulties in accessing help (family breakdown may be a particular issue 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).^{ix} 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.^x

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: Doreen

Doreen had an instinctive and remarkable facility with mathematics and geometry, and worked as an engineer for a number of years. Though she was sociable and a gifted linguist, she found how others used language (e.g. hypothetically or sarcastically) rather baffling and she struggled significantly with telephone calls. She experienced profound and enduring mental health difficulties, and gradually lost touch with friends and family. She was later hospitalised, after which she did not return to work.

Doreen had arranged her life into a series of interlocking rituals. When these were interrupted she would become highly distressed and would 'freeze', finding it almost impossible to address any problems which arose in her life. As a consequence, she struggled to maintain mortgage payments and lost access to her benefits. Eventually her home was repossessed. Thankfully, she was rapidly re-housed by a social worker knowledgeable about autism, who also put her in touch with a drop-in service, designed specifically for people on the spectrum. This provided her with easy access to someone who would be able to make difficult phone calls on her behalf. This meant that when she was faced with problems, such as changes in her benefits, she was much less frightened by the prospect of sorting them out. She therefore did not 'freeze' but actively sought help.

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. The tool presented opposite is therefore **not intended to help give a definitive diagnosis, but rather an indication as to whether or not your client may be autistic**.

If a person is autistic we would expect to see signs of this in 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 will have a tendency towards being repetitive and rigid.

Table I 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 following criteria to 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.



Table I: 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.

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

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: www.autism.org.uk/about/what-is/ broaching.aspx#%23adult



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 of how to find your local learning disability team are in section 8 of this document.

Links for finding out more about related conditions: www.autism.org.uk/about/what-is/ related-conditions.aspx https://www.autism.org.uk/about/ health/mental-health.aspx

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.

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 checking 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 what the client's priorities are for your work with them
- 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. Below are a number of approaches you can take when supporting people who may be autistic.



Working with clients who show signs of autism

Adapt how you build relationships

• Move from offering infrequent long sessions to seeing someone for short regular sessions. You could begin with five minutes at the same time each day

Be consistent in approach

- See the client at the same time and in the same place
- Tell them about any changes as much in advance as possible

Slow down

- Allow time for the individual to process what you are asking or telling them
- Slow down how long you take to engage the person; allow it to take months to get to know them and make as few demands as possible over that time

Reduce choice and minimise demands

- Reduce the amount of choice you are offering; be more directive than you usually would be with clients
- Getting rid of paperwork altogether may be helpful in some cases where engagement is particularly difficult

Make communication clearer and use images

- Ask one very clear and direct question at a time then just stop talking!
- Make instructions (e.g. when a service charge must be paid) as clear and minimal as possible
- Provide images to illustrate what you are telling them (e.g. a picture and description of you, pictures of a hostel)
- Break down information into small chunks
- It may be helpful to email a record of conversations to the person, so they can process these in their own time
- Make your language clear, concise and unambiguous. Avoid using idioms, irony, metaphors and words with double meanings; for example, 'It's raining cats and dogs out there'

Be aware of differences in sensory sensitivity and take steps to make the person more comfortable

- If some or all of their senses are more sensitive than usual, be aware of anything in the environment they might find overwhelming and take steps to help them be more comfortable (e.g. is there is an extremely bright light as soon as you enter the hostel? Is the fire alarm due to be tested while you see them?)
- If some or all of their senses are less sensitive than usual, they might seek out stimulation (e.g. tactile use of small objects like blu-tac or 'fidget cubes'); if this is the case see if there is any way you can meet this need

Use strengths-based approaches

- Focus on their strengths to develop communication (e.g. talk with them about a specific interest of theirs – this can be anything from art or music to chess, trains or computers)
- Recognise the person's passions and learn how to become part of, and share in, their world, rather than trying to shift their interests to meet social norms. You may be able to help them expand their activities by building on an existing interest

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. More details about demand avoidance can be found here:

www.autism.org.uk/about/what-is/pda.aspx

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 your encounters through with your team to help maintain your ability to stay self-aware and empathetic.

Case study: David

David 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.

David'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 David was in hospital the team began to work in a much more directive way, limiting the choices David 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.

Case study: 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 (p.15/16) may help you think about what changes need to be made.



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

Overall area to consider	Specific issues	Notes
Do they engage in any behaviours which appear ritualised or obsessive? If so, what can the service do to accommodate these behaviours?	• Try to establish clear and explicit rules with the person of how those behaviours will be accommodated (see case study of Jim, page 18, for an example of this)	
Do they have any highly-focused interests which need to be accommodated?	 Again, clear and explicit rules are essential 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. They may otherwise be less sensitive, and as a result want more stimulation (e.g. loud noises, extremes of temperature). Think about all the senses 	
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 rigidity, 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 (for an example of this see the case study of Jim, page 18), and keep them under review. This approach aligns with personalised approaches encouraged in the homelessness sector.

For more information about these approaches see: https://www.homeless.org.uk/connect/ blogs/2018/sep/26/positive-approaches

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 15 and 16, 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.



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 talk 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 be very '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 his 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 in a row, 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: Jim

Jim was a middle-aged man who had spent years in and out of accommodation, which he often lost because of his hoarding of 'beautiful things'. He preferred to sleep rough rather than stop collecting, which was an absolute necessity for him.

A new supported living flat was identified and, before the tenancy was signed, a rule created between him and his key worker. The rule stated that he could keep 'beautiful things' as long as these remained on the shelves in his room. He could have many shelves, but his collection could not spread out.

This rule was reinforced visually with a line drawn round the flat. He had visual reminders of the rule and if his collection would exceed the line he could choose items to put in a box for his support worker to remove every week. As the disposal was too difficult for Jim he could be out when this happened, as it took place on the same day every week.

Jim has maintained his tenancy for nearly a year – the longest yet. Whilst there were some difficulties it was important for all involved to understand that he could and should not be asked to stop collecting. Instead, by creating the rule, his need to hoard was valued but limited in a way he could control.

8. Resources

Finding learning disability services: There should always be a local learning disability service. Information about these services should be online (i.e. for services in Westminster you would simply search 'learning disability service westminster' on an online search engine), 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. You should be able to find more information on your CCG's website.

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

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

- www.streetsupport.net/
- www.homeless.org.uk/facts/homeless-england
- www.homeless.org.uk/resources

Appendix: case studies

Case study: A woman with autism's experience of homelessness

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

Jack, 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 attempts to interact with him, 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. They attended an anonymised consultation at the local autism assessment service. After outlining the circumstances and behaviour of Jack, 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 Jack 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 manner. This approach, and the consistency of the staff, meant that Jack was prepared to stay in the hostel.

Case study: Working effectively with someone on the autism spectrum

Steve 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 11 am should he wish to meet with her.

Steve was interested in finding accommodation and 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, Steve 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 did not always make appointments on Wednesdays. 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 Steve 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 Steve was ready to move in, everything was in place.

References

- ⁱ Brugha T, Cooper SA, McManus S, Purdon S, Smith J, Scott FJ, Spiers N, Tyrer F. (2012). Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey. Leeds: NHS Information Centre for Health and Social Care
- ⁱⁱ National Autistic Society (2016), Autism Employment Gap report
- iii APMS, 2007. Autism Spectrum Disorders in adults living in households throughout England. Report from the Adult Psychiatric Morbidity Survey 2007
- ^{iv} MacKay, T., Knapp, M., Boyle, J.M., Lemmi, V., Connolly, M., & Rehill, A. (2017). The microsegmentation of the autism spectrum: Economic and research implications for Scotland. Edinburgh: The Scottish Government
- V Bancroft K., et al (2012). The Way We Are: Autism in 2012. London: The National Autistic Society
- vi Lever, A. G. & Geurts, H. M. (2016) Psychiatric Co-occurring Symptoms and Disorders in Young, Middle-Aged, and Older Adults with Autism Spectrum Disorder: Journal of Autism and Developmental Disorders. 46, 6, 1916–30
- vii National Autistic Society (2016), Too Much Information Report
- viii Churchard, A., Ryder, M., Greenhill, A., & Mandy, W. (2018). The prevalence of autistic traits in a homeless population. Autism, 1362361318768484
- ix National Autistic Society (2016), Autism Employment Gap report
- × National Autistic Society (2013), Push for Action report



For further information please contact

The Westminster Homelessness and Health Coordination Project www.westminsterhhcp.org



All images of people used in this toolkit are stock photos and are for illustrative purposes only.

Supported by:









