Autism & Homelessness

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Aims

- To give a brief recap on what autism is and how it may be linked to homelessness
- To share ideas about how this links to broader policy
- To explore how to help autistic people experiencing homelessness, focusing on the Autism & Homelessness Toolkit

Being autistic

- A disclaimer - things that make my experience easier than lots of other autistic people:
- - I did not experience deprivation growing up
- - I do not have a cooccurring learning disability or physical health issues
- - I am able to speak
- - I am employed
- - Whilst my mother is Arab, I am white passing.

Being autistic – a potted history

- I did not respond to my mother, and I did not speak until I was 3.



Being autistic – a potted history

- My mother, a Palestinian and new to the country, took me to the doctor convinced that I was deaf.
- This was the first time she tried to get help for me. She was told by our GP:

"Your child isn't deaf Mrs Chapple, she's just stubborn".

Diagnosis = Stubborn



Being autistic – a potted history

- At primary school, I would run away and hide in the rhododendrons.
- My mother was told that I was too emotional.



Diagnosis = Emotional

Being autistic – a potted history

- I wasn't doing very well with my literacy and numeracy (hiding in bushes is not conducive to learning one's times tables).
- Also, my auditory working memory is pretty terrible so I found it difficult to recite the alphabet and times tables.
- My handwriting was, and is, very poor because my motor skills are shaky
- My mother was told that I was a bit 'slow'.



Diagnosis = Slow

Being autistic – a potted history

- At secondary school, when I no longer had to remember sequences of things and recite them out loud, I started doing really well and getting straight A's.
- I would become quite fixated on my learning.
- In class, I was excited to answer questions and show what I knew – this annoyed my peers and teachers.
- My mother was told that I was 'precocious' and 'bolshy'



Diagnosis = Precocious and bolshy

Being autistic – a potted history

- I did not understand the other girls **at all**. I was bullied and isolated.
- The stress and the lights at school gave me migraines.
- My mother was told that I was 'attention seeking'.



Diagnosis = Attention seeking

Being autistic – a potted history

- I began to experience what I now recognise as very intense anxiety but I did not have the emotional literacy to understand that at the time.
- I developed an eating disorder and began self-harming.
- I attempted suicide.
- My mother was told that I was ‘clever enough to know better’.

Diagnosis = Clever enough to know better

Being autistic – a potted history

- My mother was increasingly frustrated by my behaviour because I was:

"slow"

"precocious"

"stubborn"

"clever enough to know better"

"emotional"

"attention seeking"

"bolshy"

Being autistic – a potted history

- I was punished frequently for being:

"stubborn"

"slow"

"precocious"

"clever enough to know better"

"emotional"

"attention seeking"

"bolshy"

Being autistic – a potted history

- After many years of unhelpful interventions from professionals, with neither of us knowing that I was autistic, my relationship with my mother broke down.

- She could not help but see me through the lens of what she had been told I was.

- I could not be anything other than what I was.

How professionals talk about people really matters.

Being autistic – a potted history

- I spent large parts of my late teens homeless.
- Sometimes my mother made me leave and sometimes I left of my own volition.
- I relied on the kindness of parents of friends, sofa surfing and trying to complete my A-Levels.
- I got a place at a Russel Group university and escaped the challenges of home and school.



Being autistic – Much, much later

- An autism diagnosis (well, duh!)
- Lots, and lots, and lots of therapy!
- Sertraline.
- 10 years spent working as a specialist SEN teacher (depressed to realise that not much has changed for autistic girls).
- A very nice partner and an equally nice cat.
- Go to art classes every Wednesday with my mum.
- Now working in the voluntary sector as a Business Development Manager for a homelessness charity.



Being autistic – Take aways

- The trajectory towards homelessness started very early.
- The way professionals talked about me coloured how I was seen by others and how I saw myself.
- Lack of diagnosis exacerbated relationship issues.
- It took a very long time to recover from the impacts of it all.

What is autism?

- Atypical social understanding and interaction
- Perceived inflexibility
- Sensory differences
- Lifelong condition

Homelessness research

1.1% OF GENERAL POPULATION ARE AUTISTIC

PUBLISHED PAPER: 12% OF PEOPLE EXPERIENCING HOMELESSNESS SHOWED STRONG SIGNS OF AUTISM

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.

Remember strengths too!

Ending Rough Sleeping For Good September 2022

- No specific mention of autism; however:
  - We will prevent rough sleeping wherever possible – ensuring that the experience is rare. **A 'prevention first' offer.**
  - Ambition that **no-one is released from a public institution** to the streets.
  - Aim is for everyone experiencing rough sleeping to have an **appropriate** and timely offer of support, **tailored to their needs** and the services they are eligible for, and that all agencies have the tools they need to unlock this support
  - Support both **housing-led approaches and Housing First**, and make sure specialist homes are in place for those experiencing rough sleeping.
  - We will **improve the support available to help people** with experience of rough **sleeping into employment**

National strategy for autistic children, young people and adults: 2021 to 2026

- The development of **Oliver McGowan Mandatory Training** for health and care professionals. Once finalised, this can be adapted to other public servants, including the police or **housing officers**.

- **Improve autistic people's access to housing and social care that meets their needs**, by increasing the provision of supported housing, enabling more people to access adaptations to their homes and reforming the social care system so it is fit for purpose.

- To **ensure autistic people, as well as disabled and older people, have better access to supported housing**, commitment that 10% of the homes built via the £11.5 billion new Affordable Homes Programme will be supported housing by 2026.

- Guidance on identifying local demand and developing services for autistic people was published alongside the 2021-26 autism strategy including detail of the **Level 5 Commissioning for Wellbeing with a focus of autism and LD.**

Health policy

- The Health and Care Act 2022 introduced a new legal requirement for **all health and social care service providers registered with the Care Quality Commission to provide employees with training on autism and learning disabilities (called Oliver McGowan Training).**

- **The NHS Long Term Plan set a target to reduce inpatient provision for autistic people and people with a learning disability by 50%** (compared to 2015 levels) and support more people in the community by 2023/24.

- **In July 2022, the DHSC published an updated Building the right support for people with a learning disability and autistic people: action plan**, focusing on six areas to develop community services and reduce reliance on inpatient mental health beds.

Building the right support for people with a learning disability and autistic people: action plan

- Lack of suitable housing is considered a significant reason for delayed discharges. Assuring Transformation data shows that in April 2022, 45% of delayed discharges indicated a lack of suitable housing provision as one of the reasons for delay.

- Not having the right home, whether that is general needs housing, supported housing or residential care, can also contribute to people having unmet needs and being admitted into a mental health hospital.

- Building the Right Support Delivery Board has identified the need to address the adequacy and provision of housing as one of its priority areas of work.

- Building the Right Home sets out guidance and principles for housing for people with a learning disability and autistic people that need specialist and supported housing.

Oliver McGowan draft code of practice

- Oliver McGowan code of practice on statutory learning disability and autism training provides Care Quality Commission (CQC) registered providers with guidance to meet the new legislative requirement for staff to receive learning disability and autism training appropriate to their role.

- Currently in consultation. The consultation closes at 11:59pm on 19 September 2023

- All staff receive training that covers a minimum curriculum of capabilities from the 'Core capabilities framework for supporting people with a learning disability' and the 'Core capabilities framework for supporting autistic people' on the Skills for Health Supporting autistic people and/or people with a learning disability page.

Autism & Homelessness Toolkit

- A practical guide for staff and organisations who work with people experiencing homelessness.
- Includes what autism is, how to recognize it, and how to work effectively with autistic people experiencing homelessness.
- Plan to update

Supported by:

homeless link

resources for autism

City of Westminster

St Mungo's
Ending homelessness
Rebuilding lives

National Autistic Society

Recognising possible autism

- Indication not definitive diagnosis.
- Look for signs of autism in two areas:
  - Social relationships
  - Behaviour and interests

Social differences

- Two areas:
  - Social understanding
  - Social interaction

Examples

- *This client does not initiate social interaction and displays a rigid smile when greeted. They give tangential responses and speak in stilted sentences.*
- *This client does not make eye contact, has a blank facial expression, and has to be told when interactions are finished as they would not pick up on this otherwise.*

Behaviours & interests 1: fixated interests

- Intense and highly focussed
- Can be anything from art or music to trains or computers.

Examples

- *For this client everything they buy has a particular animal on it. They like one colour a great deal and painted their room an intense shade of this colour.*
- *This client makes lists of obscure musicians and has a large collection of broken electronics.*

Behaviours & interests 2: sensory differences

- Over or under-sensitivity to sounds, touch, tastes, smells, light, colours, temperatures or pain.
- Can lead to sensory-seeking behaviours.
- Think about all the senses.

Sensory differences video



Behaviours & interests 3: inflexibility & repetitive behaviours

- Often want to know exactly what is going to happen every day: routines and rituals
- Change can be very hard
- Repetitive movements and use of language

Examples

- *Items in this client's room are organised in rows. Their day follows a precise routine of when they sleep and watch TV. They always take the same route to the shop and have rules about where shopping can be placed in their flat.*
- *This client repeatedly moves their arms in a very particular way. They speak in an old-fashioned way and have a stereotyped old-fashioned way of saying goodbye.*

Distinguishing from other conditions

- Can be challenging even for specialists
- Even if unsure it's reasonable to try out changing support and see if this works: it's unlikely to do any harm
- Distinguish from other conditions on basis of behaviours and interests, as social difficulties are widespread beyond autism

Pursuing a diagnosis

- Pros:
  - Can be a moment of realization
  - Potential access to support services
  - May supersede previous misdiagnosis e.g. schizophrenia
- Cons:
  - Services not always easily accessible and often have long waiting lists
  - The assessments themselves can be time-consuming and may require multiple appointments
  - Generally rely on speaking to family members and getting a full history
- **You should not wait for a formal diagnosis of autism before considering what reasonable adjustments or support could be offered.**

Adapting support

ADJUSTING SUPPORT

ADJUSTMENTS TO ACCOMMODATION

General principles

- Continue following PIE best practice:
  - Highlight and celebrate the client's strengths
  - Focus on what the client's priorities are for your work with them
  - Recognise the importance of relationship building
- BUT adapt approaches to meet the specific needs which come with autism

Engaging with clients who show signs of autism

- Adapt how you build relationships - short and regular
- Be consistent
- Slow down
- Reduce choice and minimise demands
- Make communication clearer and use images
- Be aware of differences in sensory sensitivity
- Use strengths-based approaches
- Be reflective and resilient

Overall area to consider	Specific issues
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? • 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)? • 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
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 • 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? • What is the priority of the person receiving the support?

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
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 • 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

Enter your email if you would be interested in taking part in a service design workshop

(We will only contact you in relation to the above)

Slido.com

#autism

Further details

- Paper on autism & homelessness: https://doi.org/10.1177/1362361318768484
- Email Alasdair for a copy of the toolkit
- Article about research: http://theconversation.com/autistic-people-at-greater-risk-of-becoming-homeless-new-research-97227
- Alasdair's details: alasdair.churchard@hmc.ox.ac.uk
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