Autism & Homelessness

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Aims

- ▶ To highlight high rates of undiagnosed autism in adults

- ▶ To describe our study of autism in a homeless population

- ▶ To explore how to help autistic people experiencing homelessness, focusing on the Autism & Homelessness Toolkit

- ▶ To share ideas from practice in the UK for inspiration

The 'lost generation' of autistic adults

The 21ˢᵗ century evolution of autism

20ᵗʰ Century View	21ˢᵗ Century View
Autism is rare	Autism is relatively common (1-2% of population)
Autism is usually associated with intellectual disability	Autism is usually associated with IQ in the normal range
Autism is a categorical condition	Autism is a dimensional condition
Autism is just about having difficulties	Autism is a form of neurodiversity characterized by strengths and difficulties

Autism: the 20ᵗʰ century view

A [rare and severe] neurodevelopmental disorder, [usually associated with intellectual disability and delayed language development], and [categorically distinct] from normal development and from other disorders.
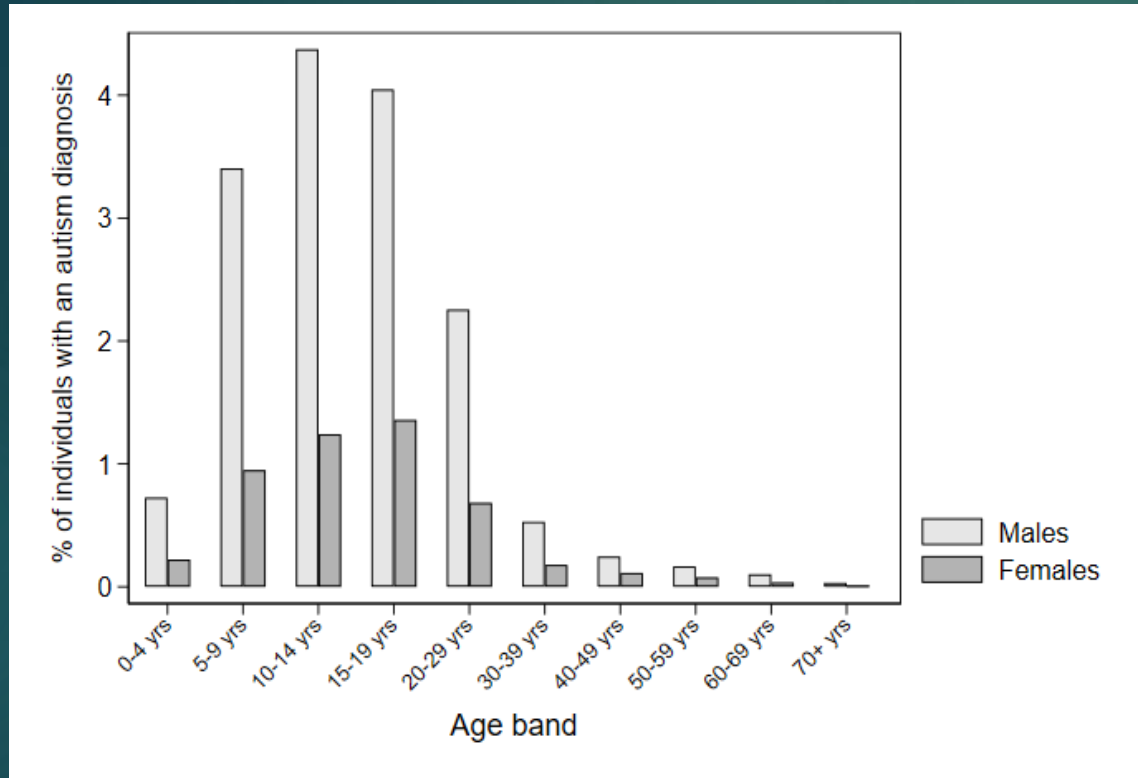
Autism: the new consensus

A relatively common, neurodevelopmental condition, usually associated with normal-range IQ, that represents a form of natural human variation, bringing both challenges and strengths.

Some clinical implications

- Data from THIN – primary care records
- Shows proportion of population with autism diagnosis in 2018
- Note: preliminary, not yet subjected to peer review

From work lead by Dr Liz O'Nions and Dr Josh Stott (UCL), funded by Dunhill Medical Trust

The **'lost generation'** of autistic adults (Lai & Baron-Cohen, 2015)

The 'lost generation'

- Brugha et al. (2015) found 19 adult autism cases after screening population…none had a prior diagnosis

- Undiagnosed autistic adults are common in:

  - Mental Health services

    - Eating Disorders ~ 20% (e.g., Westwood, Mandy & Tchanturia, 2017)

    - OCD ~20% (Wikramanayake et al., 2018)

  - Other high-need contexts

    - People who died by suicide ~10% (Cassidy et al., 2022)

And what about in the homeless population?

Are autistic people over-represented amongst the homeless?
- Anecdotal reports from London Homelessness team
- Risk factors for homelessness are common amongst autistic people
  - MH difficulties
  - Independent living difficulties
  - Educational and occupational attainment
  - Isolation / limited networks
- Some previous audits / reports in the grey literature
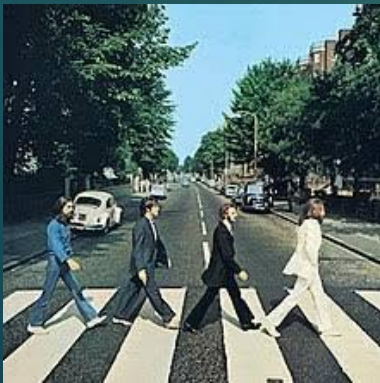
Screening homeless population for autism / autistic traits

We never pretended it would be easy!

- Adult assessment
- Difficulty engaging potential participants…and relevant informants
- Complications from substance misuse, MH problems, head injuries etc.
- Lack of relevant measures of how autism might present in specific context of homelessness
- …and so on….

Our approach

1. Acknowledge that we can only estimate likely autism diagnosis / high autistic traits…not a definitive study
2. We used informant reports from key workers
   1. Coverage of whole caseload
   2. Keyworkers know their clients well from sustained working (average=2.9 years)
3. We invented a measure – the 'DSM-5 Autistic Traits in the Homeless Interview' (DATHI)
   1. Worked with a range of experts to 'translate' DSM-5 to a homeless context
   2. Iterative process using piloting
   3. Reliability testing (Kappa=.69, 95% CI 0.37,1.0)
   4. Criterion validation against the ASDASQ (r=.81, p<.001)

Criterion	Prompt questions	Answers	Trait present?

B4: Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment	Does the client show an odd response or seem unduly sensitive to any sensations? Ie. Sight, sound, taste, touch, smell
	• Specific prompts
	  ○ Loud noises / wears ear protectors?
	  ○ Bright lights
	  ○ General levels of stimulation (eg. daycentre, canteen)
	  ○ Refusing to wear certain clothes because of the feel of the material
	  ○ Clothes need to be a certain level of tightness / looseness, have a favourite bit of clothing
	  ○ Commenting on smells that most people would not notice
	  ○ Eating
	
	Does the client have a particularly strong interest in any sensory stimuli? Ie. Sight, sound, taste, touch, smell
	
	Does the client appear to find any everyday sensory stimuli painful or distressing?
	
	Does the client appear under-reactive to certain sensations?
	• Specific prompts
	  ○ Pain ie. injuries going untreated
	  ○ Cold / heat
			○ Present
			
			○ Possibly present
			
			○ Not present
			
			○ Present but attributable to cause other than ASD
			
			○ Insufficient information to classify

What did we find?

- 137 initially screened
  - 106 eligible for the study
    - 13 screened positive for autism (12.3%; 95% CI 7.0, 20.4) (11 men, 2 women)
    - 9 identified as possible / marginal evidence of autism
    - 72 not showing evidence of autism
    - 12 insufficiently well known to services to be classified

Distinctive characteristics of those identified as likely or possibly autistic

Those who were identified as likely or possibly autistic, compared to those identified as probably not autistic were:

- More socially isolated
  - More likely not to have a friend
  - More likely to have no family contact
  - More likely to be 'totally socially isolated'
- Less likely to have substance abuse problems

The prevalence of autistic traits in a homeless population

⑤SAGE

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Abstract

Anecdotal evidence suggests that autistic people experience an elevated risk of homelessness, but systematic empirical research on this topic is lacking. As a step towards filling this gap in knowledge, we conducted a preliminary investigation of the prevalence of *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.) autism symptoms in a group of long-term homeless people. The entire caseload ($N = 106$) of a UK homeless outreach team was screened (excluding individuals born outside of the United Kingdom or Republic of Ireland) using an in-depth, semi-structured interview with keyworkers, based on *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.) diagnostic criteria. This showed adequate inter-rater reliability, as well as evidence of criterion and construct validity. Of the sample, 13 people (12.3%, 95% confidence interval (7.0, 20.4)) screened positive, meeting *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.) autism criteria by keyworker report. A further nine people (8.5%, 95% confidence interval (4.5, 15.3)) were 'marginal', having autistic traits that were not quite sufficient to meet *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.) criteria. Those with elevated autistic traits, compared to those without, tended to be more socially isolated and less likely to use substances. This study has provided initial evidence that autistic traits are over-represented among homeless people and that autistic homeless people may show a distinct pattern of characteristics and needs. Further investigation is required to build upon these provisional findings.

To find out more about this study…check out the paper, which is open access

Social differences we observed

▶ 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.

Fixated interests we observed

- ▶ 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.

Sensory differences we observed

- When fire alarm went off unexpectedly seemed like they would scream, always has curtains closed, burnt hand badly but seemed under-reactive to pain (waited 1 week to seek treatment).

Inflexibility & repetitive behaviours we observed

- 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.

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.

Supported by:

Recognising possible autism

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

Distinguishing from other conditions

▶ Can be challenging even for specialists and homelessness context increases complexity

▶ 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
- Do not need to 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 best practice of homelessness field:

    ▶ 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
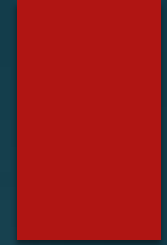
Applying an 'autism lens' across homelessness services in Westminster*

- Started with rough sleeping teams – bitesize training
- Added a screening question/prompt on assessments
- Created a regular 'advice clinic' format for workers to meet with the Westminster Autism Assessment Psychologist to discuss strategies
- Identified which accommodation options work well
- Awareness and communication training for Housing workers
- Prevention

Thanks to Victoria Aseervatham (Rough sleeping commissioning manager, Westminster City council) for these slides

Top Tips from Westminster*

▶ Get started and spread awareness – don't be overwhelmed

▶ Have autistic people at the heart of your work

▶ Really pay attention to all forms of communication (speech, info leaflets, forms etc)

▶ Use a strengths-based and trauma-informed approach

Thanks to Victoria Aseervatham (Rough sleeping commissioning manager, Westminster City council) for these slides

Further details

▶ Paper on autism & homelessness: https://doi.org/10.1177/1362361318768484

▶ The toolkit can be found at:
http://westminsterhhcp.org/Resources(4)/Autism_Homelessness_Toolkit.pdf

▶ Article about research: http://theconversation.com/autistic-people-at-greater-risk-of-becoming-homeless-new-research-97227

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