

Autism and the homeless: An overview.

by Peter Crosbie

Earlier this year, a major study into autism in France by the national audit body, established that while over 600 000 adults were on the autism spectrum*, only 75 000 of them had a diagnosis. This led to a certain amount of head-scratching as to where the “missing” 525 000 were, without any definitive answers. But we in the autistic population know where they are: struggling to keep a job or queuing up in the unemployment office having lost one. Or battling with social services over benefits, or with a landlord over an apartment.

And there’s somewhere else you’ll find us: on the streets.

A recent study by a team from University College London found that over 12% of the 106 rough sleepers they screened met diagnostic criteria for autism. A further 8% had significant autistic traits. Add to that people who were so isolated from support networks that it was impossible to collect any data, and you’ll understand why the researchers suggest that their figure of 12+% is probably an underestimation. This replicates results in a 2015 study by the Welsh government, plus a smaller study in Devon in 2010 which found that 9 out of 14 rough sleepers met autism diagnostic criteria. Yet amongst the people in these studies, almost none of them had a diagnosis of autism, or were even aware that they could be autistic.

(One point re the UCL study is that it excluded non-UK nationals. We have no information on prevalence of autism amongst the migrant or refugee homeless populations.)

This large sub-population doesn’t end up on the streets because they’re autistic. They end up on the streets for the same reasons that everyone ends up on the streets. And if you look at what those reasons are and juxtapose them with the situation that many autists find themselves in, you end up with one of those Venn diagrams where the two circles largely overlap. Exclusion from the family home or family breakdown. Tick. Long term unemployment.

Tick. Rent or mortgage arrears. Tick. Lack of social support. Tick. Poor mental health (e.g. depression, anxiety). Tick.

Sparrow Rose Jones, who spent much of his adult life homeless, writes:

"I had a very hard time in school and left unprepared for independent living, higher education, or a career. I could make it through an interview for a minimum wage job but couldn't manage to keep those jobs for more than a couple of weeks before I was "let go" with no explanation. Since my lack of formal education only qualified me for the lowest income employment to start with, I couldn't keep a roof over my head."

Being on the autism spectrum also brings additional risk factors.

The first is a difficulty in managing "paperwork". Anything that pops through your letterbox in an envelope with a clear window can spell trouble, the kind of trouble you put in a box by the door to eventually take around to your sister to sort out. If you're still on speaking terms with your sister. Sometimes you open the letters and realise that you've missed a payment, or been overcharged, or had benefit payments withheld - the kind of thing that could be sorted out with a phone call. But many of us have trouble with phone calls, so manageable issues get out of hand, setting you on a slippery slope to losing your home or income.

Similar problems arise for anything that requires forms to be completed. I'm married with a family and a stable career, but filling out a cheque and addressing and stamping an envelope is about my limit, and can take me two or three attempts.

Another factor that comes into play here is that most autistic people are subject to bullying and harassment, ranging from physical and sexual abuse through to economic exploitation and mate crime. Such as the "friends" who only ever turn up on the day you receive your unemployment benefit. If you've watched The Good Doctor TV series, you might remember the episode where the neighbour "borrows" Shaun's cable TV connection - without asking. People sense our vulnerability and communication difficulties and

exploit them. Which then leads to autistic people seeking to minimise contact with others, not so much through choice, but for self-preservation. Paradoxically, living on the streets may offer a place of relative safety from abuse and exploitation.

Finally, most autists have sensory sensitivities. Light, sound, smell or touch, can all be overwhelming. As the Welsh study points out: *“Sensory difficulties mean presenting in a noisy, busy housing office is a challenge and can even deter some people with ASD from presenting at all.”*

All of these factors combine to lead to homelessness. But they also contribute to its maintenance, both through a reluctance to engage with support services and through associated practical difficulties. For example, in France, the procedure for getting access to a shelter is to call 115 - but if you're someone who has difficulty making phone calls? Similarly, you could be eligible for housing or financial support, but if you can't complete the forms?

So what does this population look like? There's a saying that if you've met one person who's autistic, you've met one person who's autistic. While we all have the same underlying autistic neurology, how that manifests can be vary enormously from person to person. It can also be quite different from some of the preconceived notions about autism: yes, we do have a sense of humour, as anyone who saw the autistic comedians Robert White on Britain's Got Talent or Hannah Gatsby at the Emmy Awards could verify.

The kinds of behaviours you might see in a homeless autistic person could include:

- fixed routines, e.g.:
 - tendency to gravitate around one location, have specific sleep sites, or follow the same routes
 - having routines around organisation of belongings
 - eating a limited range of foods, and/or having routines around eating, such as using a specific plate or cup
 - being sensitive to touch, including a sensitivity to clothing (textures, but also tight/loose) which may result in unconventional clothing choices

- being more/less sensitive to heat or cold (e.g. wearing an overcoat in summer, or going bare-footed in winter)
- being sensitive to light or noise, though this can vary enormously from person to person, and even within the same person, e.g. sensitivity to sudden noises but not sustained ones
- having specific interests such as collecting, or specific areas of knowledge or expertise. The UCL study cites someone who collected broken electronics
- having difficulty maintaining conversation or responding to questions, or conversely, monopolising the conversation (talking in monologues)
- avoiding social contact in general, including from support workers
- being less likely to have friends or family contact
- being more likely to suffer abuse
- being less likely to use drugs or alcohol

As you can see from the above, this is a very vulnerable population. So how best to reach them?

Homeless Link UK is one of the few organisations in this field to have taken concrete steps. They provide briefings and training in autism awareness and in how to interact with autistic clients to their frontline staff. Their general guidelines are available on their site, and while I have reservations regarding some of their recommendations, it's an excellent place to start.

Even a basic understanding of what to say - or more to the point, what not to - can make a real difference. For example, one of the worst ways to start a conversation with someone who's autistic is any variant of "how are you going?" For us, questions like that are vague and confusing. What exactly do you mean by "how"? The Homeless Link guidelines suggest avoiding open-ended 'what', 'why', 'where', 'who' or 'how' questions.

The basic idea to keep in mind is that for us, the world comes at you pretty fast, and so anything you can do to avoid adding to that sense of being permanently overwhelmed can help. This means reducing the cognitive load you might impose on people, for example by minimising choices, or by allowing people more time to respond - be patient, we have a lot to process. As Homeless Link suggest, when it comes to seeking information "*Ask one*

very clear and direct question at a time, then just stop talking!”

Another suggestion I'd make is to consider using text/SMS instead of spoken speech, even when someone is right next to you. Which is an ideal place for them to be in any case: it's a good idea to minimise face-to-face exchanges. This also helps avoid direct eye contact, which is painful or difficult for many of us.

You can also explore using images in preference to speech. For example, if you want someone to come into a shelter, take out your phone and show pictures of what it looks like. Ideally, these should be in a walk-through format, starting from the front door. Similarly, if you have a hot drinks cart, show images of the cart and its surroundings. But don't stop there - have pictures of the cups you use and the people who'll be serving.

(The reason for this is that we tend to use a bottom-up form of information processing. You might think “shelter”, and fill in the details afterwards. For us it's the other way round, we need the details first, and we use them to build up a global picture.)

Of course, in an article like this, it's impossible to do more than just scratch the surface. But I would encourage those of you who are interested to explore this further. I've included references to a couple of books on autism below, though the best way to learn about autism is from autistic voices themselves, and there are plenty of great autistic bloggers and vloggers out there.

In more practical terms: Dr. Will Mandy, who was involved in the UCL study, is also leading a major study of autism in the eating disorder (ED) population, where we're also seeing a large percentage (25%) of autists. Recommendations out of this are that in each ED team there's at least one person with a working understanding of autism. This could also be a good starting point for teams supporting the homeless.

They also recommend automatic autism screening for anyone who comes into contact with ED services, though this may prove impractical with a long-term homeless population. One of the standard screening tests is the

Autism Spectrum Quotient (AQ Test - link below). An alternative could be to use the DATHI test, which is completed by support workers. This is included in the UCL study, and transposes autism diagnostic criteria to the specificities of a homeless population. Even if you don't use it rigorously, it may prove helpful in identifying possibly autistic individuals.

Of course, these screening tests are not in themselves diagnostic tests. But they are valid as tools, and will reliably exclude people who are not autistic.

Whatever approach you take, identifying possibly autistic rough sleepers is a first step in being able to provide person-centred care, whatever form that might take. Getting a diagnosis might be one way, as it could lead to eligibility for financial and/or housing assistance under provisions for the disabled. On the other hand, not all autistic people want a diagnosis, or would be able to get through one. But if you have clients who you suspect are on the spectrum, you can at least start to tailor your support accordingly.

Bear in mind here that in almost all these cases, these are people who do not know that they're autistic. As such, they're not always going to be aware of precisely what their difficulties are, nor capable of articulating them. The feeling for most of us who receive an autism diagnosis later in life is "ah, so that's why ...". When you're on the autism spectrum, you recognise full well that the world seems to be on a different wavelength to you, but you have no idea why, much less what you could do about it.

For us, the problem isn't autism per se, but living in a non-autistic world that neither recognises us nor understands our needs, which become barriers to participation. The social model of disability shifts responsibility for facilitating access away from the person concerned and onto society and individuals. As someone who's autistic, I know what a difference it makes if you can take that first step towards us. Because if you do make the effort to join us in our world, it makes it so much easier for us to join you in yours.

*Autism is now technically diagnosed as Autism Spectrum Disorder, ASD

for short, or more and more commonly, Autism Spectrum Condition. Asperger's Syndrome, which you may have heard of, was abolished as a diagnosis in 2013, and is now covered by ASC. According to the U.N., *"Autism is a neurological condition characterised by its unique social interactions, non-standard ways of learning, keen interests in specific subjects, inclination to routines, challenges in typical communications and particular ways of processing sensory information."* Note that autism isn't a mental condition, mental illness or mental disorder, though mental conditions, especially depression and anxiety, are common in the autistic community.

Citations:

Évaluation de la politique en direction des personnes présentant des troubles du spectre de l'autisme:
<https://www.ccomptes.fr/sites/default/files/2018-01/20180124-rapport-autisme.pdf>

University College London Study:
<https://journals.sagepub.com/doi/abs/10.1177/1362361318768484>

Shelter Cymru (Wales) Study:
<https://sheltercymru.org.uk/wp-content/uploads/2015/02/Piecing-together-a-solution-Homelessness-amongst-people-with-autism-in-Wales.pdf>

Sparrow Rose Jones:
<https://www.rootedinrights.org/autism-and-homelessness-the-real-crisis/>

Homeless Link UK:
<https://www.homeless.org.uk/sites/default/files/site-attachments/Autism%20&%20HomelessnesOct%202015.pdf>

Autism Spectrum Quotient (AQ) Questionnaire:
English: <https://psychology-tools.com/autism-spectrum-quotient>
Other languages and scoring guide:
https://www.autismresearchcentre.com/arc_tests/ which also includes AQ-10, which may be more useful as it's quite short (10 questions).

Books:

Neurotribes, by Steve Silberman:

https://www.amazon.co.uk/NeuroTribes-Legacy-Autism-Smarter-Differently/dp/1760113646/ref=sr_1_1?ie=UTF8&qid=1544717854&sr=8-1&keywords=neurotribes

Autism and Asperger's Syndrome in Adults, by Luke Beardon:

https://www.amazon.co.uk/Autism-Asperger-Syndrome-Adults-Beardon/dp/1847094457/ref=sr_1_1?s=books&ie=UTF8&qid=1544717880&sr=1-1&keywords=Luke+Beardon

Me:

Background on autism and some of my other writing on my blog:

<http://autism-advantage.com>