Guidelines for supporting autistic clients in inclusion health work

London Network of Nurses and Midwives Homelessness Group

The London Network of Nurses and Midwives Homelessness Group

This document was produced by the London Network of Nurses and Midwives Homelessness Group, who are a charity who support professionals working in inclusion health. We also welcome students and people with lived experience.

We put on events and publish guidance and other documents. We also hold a yearly conference, offer informal supervision and networking, and influence policy at a local and national level.

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Change Communication is a not for profit organisation helping people talk and listen. They support people who are homeless, and the organisations that work with them, to achieve their goals. We have had input on communication from **Leigh Andrews, Lisanne Go** and **Grace Paul.**

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Language and labels

Identity first language

This document uses 'identity first' language (autistic person) rather than 'person first' language (person with autism).

The most recent research indicates that identity first language is preferred by most autistic people over person first language (Kenny et al, 2015).

Some autistic people may prefer person first language. If you are building a relationship with an autistic client then it is appropriate to ask them what their preference is and use it.

Some definitions

It is important to note that definitions around autism are sometimes contested and often in flux.

For example, some people argue that a person cannot be 'neurodiverse' in the same way that a person cannot be 'diverse' and that only a group of people can be neurodiverse.

Below are some dictionary definitions of some words used around autism as they are currently defined, all from the Collins English Dictionary (2021). Autism itself is discussed in more detail further on.

Neurodivergent / neurodiverse: "Exhibiting behavioural traits and brain function that society regards as unusual or exceptional"

Neurotypical: "Exhibiting behavioural traits and brain function that society regards as normal"

Neurodiversity: "Variety in human behavioural traits and brain function, viewed as normal variation within the population; used especially with reference to autistic spectrum conditions"

Why is this guidance needed?

Significant numbers of people in the UK have neurobehavioural differences that affect their experiences. Autism is one of these.

There is increasing evidence that autistic people are likely to be in inclusion health groups at a higher proportion than they are in the general population, and that they face a lack of understanding from staff and significant additional barriers to accessing appropriate care alongside a relatively high level of physical and mental health need.

There is evidence that children with different developmental trajectories are more likely to be exposed to social conditions which are detrimental to their development and wellbeing in addition to the challenges of having an atypical neurotype. (Emerson, E. 2010). This is one possible reason why autistic people will often show up in inclusion health populations.

The National Institute for Health and Care Excellence (NICE) explains:

> "A significant proportion of adults with autism across the whole autistic spectrum experience social and economic exclusion. Their condition is often overlooked by healthcare, education and social care professionals, which creates barriers to accessing the support and services they need to live independently.
>
> In addition, people with autism are more likely to have coexisting mental and physical disorders, and other developmental disorders. Some may have contact with the criminal justice system, as either victims of crime or offenders, and it is important that their needs are recognised."
> (NICE, 2016)

This guidance seeks to support workers to understand autism in the context of inclusion health populations and how to best support and work with autistic people, whether diagnosed or not, in inclusion health settings.

Mortality

Autistic people experience disproportionately poor health outcomes and high early mortality, even before the consideration of additional challenges as a result of being in inclusion health populations (Hirvikoski, T. et al, 2015).

Autistic people die an average of 16 years earlier than the general population. For autistic people with co-occuring learning difficulties, the gap is 30 years (Autistica, 2015).

Furthermore, the mortality of autistic people is also likely to be, in part, related to how healthcare systems understand and support autistic people, and this misunderstanding is likely to be compounded for those who fall into inclusion health groups.

Reports of poor experiences

80% of GPs reported that they needed more guidance and training to be able to identify and support autistic patients.
(National Audit Office, 2008)

74% of autistic people surveyed felt they received a 'worse' or 'much worse' health service than people who are not autistic.

75% of autistic people felt that health professionals 'rarely' or 'very rarely' understood their autism, and how it affects their physical and mental health.
(The Westminster Autism Commission. 2016)

Improving inclusion health staff's understanding is an important aspect of improving care for autistic people in inclusion health populations. An understanding of autism and the experiences of autistic people is important for those working in inclusion health if we are going to effectively reduce barriers to care and improve outcomes.

What is autism?

"Autism is a way of being that affects how a person perceives and reacts to the world. This includes socially, physically and emotionally. It is likely to be more prevalent than generally thought" (The NHS Information Centre, 2012).

There are a number of models of autism, from the increasingly contested illness and disability model to the more recent neurodiversity model (Sonuga-Barke & Thapar, 2021), which positions autism as a naturally occurring difference with strengths as well as deficits and questions the usefulness of the primacy of mainstream systems of diagnosis and treatment.

In their diagnostic guidance, NICE outlines areas that are required for official diagnosis.

These are as follows:

<u>One or more of the following:</u>

- Persistent difficulties in social interaction
- Persistent difficulties in social communication
- Stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests,

<u>And one or more of the following:</u>

- Problems in obtaining or sustaining employment or education
- Difficulties in initiating or sustaining social relationships
- Previous or current contact with mental health or learning disability services

"Autism is not an illness. Being autistic does not mean you have an illness or disease. It means your brain works in a different way from other people. It's something you're born with or first appears when you're very young. If you're autistic, you're autistic your whole life. Autism is not a medical condition with treatments or a "cure". But some people need support to help them with certain things. Autistic people can live a full life. Being autistic does not have to stop you having a good life. Like everyone, autistic people have things they're good at as well as things they struggle with." (NHS, 2021)

Prevalence

Current global data puts the prevalence of autism at 1.035% worldwide. (Scottish Government, 2017.) In the UK autism is identified in an estimated 1.6% of children. (Taylor B. et al., 2016.)

However, it is likely that there is significant underdiagnosis, and research suggests that this may be particularly the case for adults not diagnosed as children (Kapp, S. K. et al., 2013), women (Loomes, R. et al., 2017) and some ethnic minorities. (Hussein, A. M. et al. 2019).

A note on disability and 'difficulties'

Although autism is often described as a disability, autistic people may not identify as disabled, and 'difficulties' can be seen as differences which are only difficult in relation to a world built around neurotypical needs. Nick Walker, an autistic academic, referring to the social model of disability which says that people are primarily disabled by their context says:

“Despite underlying neurological commonalities, autistic individuals are vastly different from one another. Some autistic individuals exhibit exceptional cognitive talents. However, in the context of a society designed around the sensory, cognitive, developmental, and social needs of non-autistic individuals, autistic individuals are almost always disabled to some degree." (Walker, 2021).

Supporting a client with diagnosis

Clients who think that they could be autistic and want a diagnosis should be referred to specialist teams for proper assessment and diagnosis, following NICE guidance.

The first point of call will often be their GP, unless you are in a position to make a direct referral to an assessment service.

As outlined earlier in this document, GPs may not have a thorough understanding of the various ways autism presents. If somebody wishes to pursue a diagnosis, it could help them speak to their GP if you support them to complete a screening tool to take with them, to plan what they are going to say, or to attend with them or arrange for somebody else to do so.

Not everyone will want to be diagnosed, but some people find that it helps them understand their differences and can be very positive. It can also make access to support and accomodations easier.

Misdiagnosis and missed diagnosis

It is important for professionals to know that autism can go unnoticed, both due to autistic "masking", where autistic people have learned to adapt their behaviour to minimise their experiences and fit in, and due to misunderstanding of the wide range of ways that autism affects people. This is especially the case for autistic women (Bargiela et al. 2016). It is important to note that the evidence suggests that being socially conditioned to mask traits increases poor mental health including suicidality (Cassidy et al, 2020). Autism can also be misdiagnosed as a mental health problem such as a personality disorder (Dudas. R.B et al. 2017), which can lead to inappropriate treatment being offered. Professionals should be aware that the people they are supporting are within their rights to request second opinions or reassessment of their needs.

A note on self identification

There are many reasons why people may choose not to pursue a diagnosis of autism. These include an awareness of the stigma autistic people face and previous negative experiences of healthcare settings. Furthermore, waiting lists are very long so those seeking a diagnosis may not get one for months or years. If somebody tells you they are autistic but they do not have a diagnosis, or they suspect it, it is likely that strategies you would use to work with people with a diagnosis will also be useful for them, and that validating their experience will help you build a supportive relationship.

A note on Aspergers Syndrome

Aspergers is a subcategory of autism which is no longer defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). This is a diagnostic manual that psychiatric or neurobehavioural professionals are likely to refer to. People who would have previously been diagnosed with Apergers in the UK are likely to now just be diagnosed as autistic.

People who have been diagnosed with Aspergers, or feel that the term describes their experience of autism may understand this as an important part of their identity and their preferences around how they would like to describe themselves should be respected.

'Levels' of support, specifiers and functioning labels

The National Autistic Society explains that:

> "DSM-5 has introduced specifiers to help the clinician to describe associated or additional conditions, eg intellectual impairment, language impairment, genetic conditions, behavioural disorder, catatonia.
>
> One of the specifiers relates to the 'severity' of social communication impairments and restricted, repetitive patterns of behaviour. There are three levels: requiring support, requiring substantial support, requiring very substantial support. This can allow the clinician to give an indication of how much someone's condition affects them and how much support an individual needs.
>
> DSM-5 explains that 'severity' levels may vary by context and also fluctuate over time, that the descriptive severity categories should not be used to determine eligibility for and provision of services, and that 'these can only be developed at an individual level and through discussion of personal priorities and targets'."

Though they are still heard in reference to autism, people are no longer disgnosed with 'functioning' labels such as 'high functioning', and their use is considered by some to be undesirable as what counts as 'function' is arguably socially defined in relation to things like being able to work full time or have certain kinds of interactions rather than, for example, whether somebody is able to lead a fulfilling life of their choosing.

Access to healthcare

Dr Mary Doherty describes the outcomes of a study, which is currently in pre print, about the barriers autistic people face when engaging with primary care. Though the study was not focussed on inclusion health populations, the barriers described are likely to be compounded by additional deprivations such as homelessness or lack of access to public funds.

"First, we surveyed attendees at an autism conference, Autscape, in 2018. We asked open ended questions about what autistic people wished GPs knew about autism and the difficulties faced when accessing healthcare and received responses from 72 autistic people attending the event. Using the results of this project we created an online survey which asked about barriers to healthcare, and we compared the experiences of autistic people with non-autistic people. We received 1271 survey responses from autistic people.

Our results show that 4 out of 5 autistic people have difficulty going to a GP when they need to. Autistic people were more likely to need help to go to the doctor, but less likely to have a support person to help them.

The most common barrier for those who answered our survey was difficulty using the telephone to make an appointment.

Other common problems included not feeling understood, difficulties communicating with the doctor or with the receptionist and difficulties planning appointments in advance.

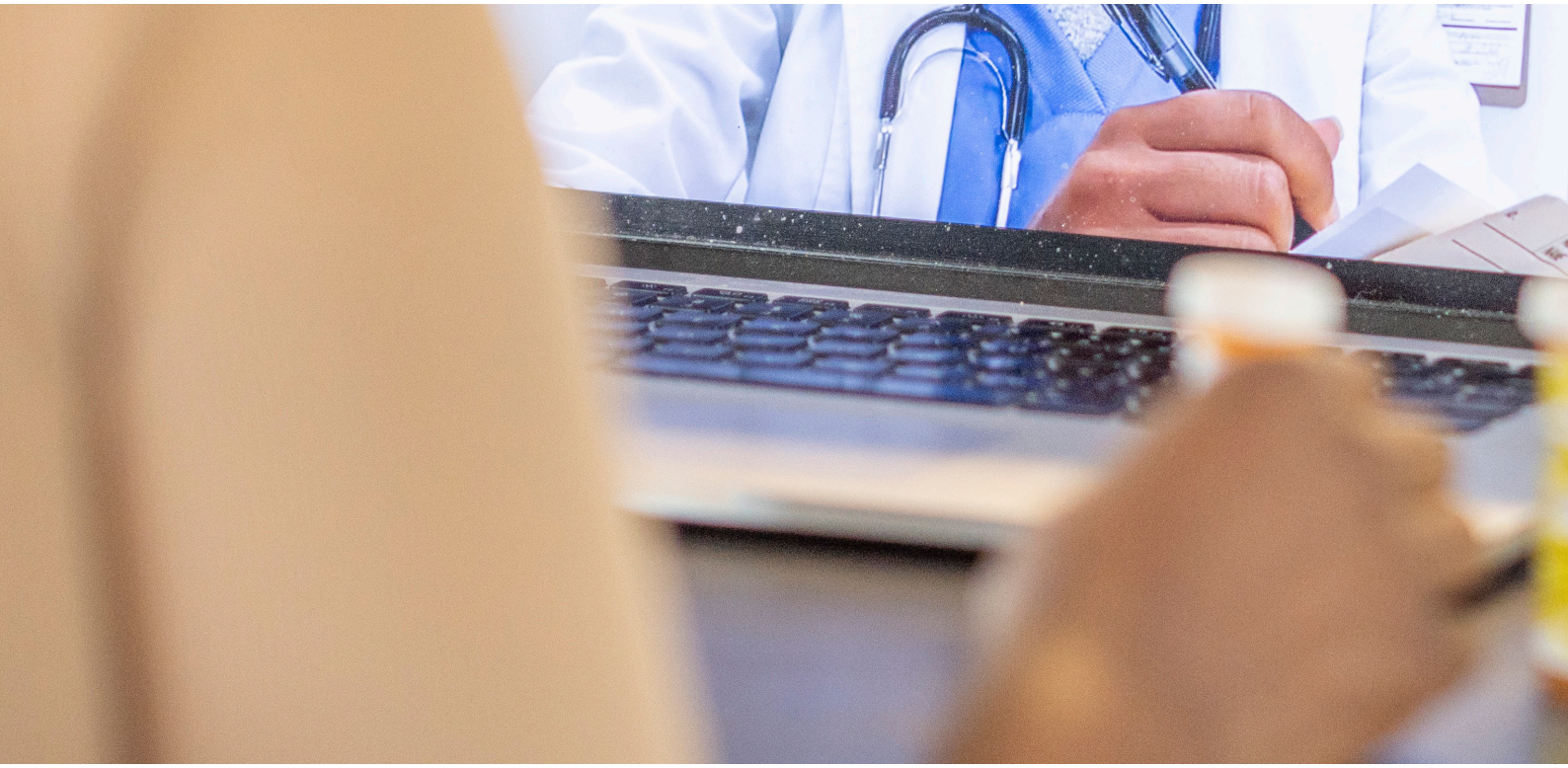
It can be difficult for autistic people to

- Organise and plan an appointment,
- Tolerate uncertainty
- Cope with the waiting room environment
- Feel like they will be taken seriously or have their experiences validated
- Ask for help
- Discuss mental health in particular
- Describe or express pain, particularly under pressure

Autistic people are more likely to have untreated health problems. Those who have difficulties going to the doctor are more likely to delay seeking healthcare until health conditions are more advanced and possibly harder to treat. Untreated physical and mental health problems are common, and often autistic people do not go for healthcare even for serious or life-threatening conditions.

Autistic people are more likely to use hospital emergency departments and to be admitted to hospital from the emergency department. Most worryingly, autistic people are more likely to die even in hospital.

When healthcare providers understand the barriers faced by patients it is easier to provide effective care. Having negative experiences with healthcare is a known barrier to future care for autistic people, and this may be particularly true for those experiencing homelessness or who are otherwise marginalized. Dedicated Inclusion Health Services can help autistic people to access care in a timely manner and improve healthcare outcomes, particularly when staff understand their autistic patients."



Autism and Migrant Communities

It is difficult to generalise about migrant communities and autism as different cultures will understand autism differently. In a situation where you believe it will be useful to speak to someone from a migrant community about autism, it may be helpful to first research how autism is understood by their community, ensure you are allowing the person to lead the conversation if they are autistic and are talking to you about this, and to get support from autistic peers and a range of other professionals if possible. If there is a language barrier it will be important to obtain translation services.

Autism and homelessness

Autistic people are very probably at higher risk of homelessness. The poor understanding of, and support for autistic people which is described earlier in this document will raise the risk of homelessness, as will the well-documented poorer outcomes in terms of employment, housing and mental health. For instance only one third of autistic adults are in some form of paid employment and 79% of autistic adults have been found to have had difficulties with their mental health at some point in their life (National Autistic Society, 2016).

The evidence base on autism and homelessness is still being developed, but an initial study by Churchard et al. (2019) showed that 12% of a homeless population had pronounced autistic traits.

In this section we will cover how autism might present in a homelessness context and also adaptations that can be made to support. This is based on the Autism and Homelessness Toolkit which was co-developed with a multi-disciplinary steering group with expertise in autism and homelessness including autistic people with lived experience of homelessness.

How autism might present in a homelessness context

Diagnosing autism in the general population can be challenging, and these challenges will be even greater in a homelessness context. With some clients autistic traits may be quite obvious. With many you will have questions around differential diagnoses such as personality disorder and psychosis. You do not have to reach a firm diagnosis to start adapting support: if you think that the client could be autistic then it is reasonable to trial some autism-friendly adaptations, as these are unlikely to do any harm and may make a significant difference to how the individual is engaged and supported.

When considering whether a client you are working with might be autistic, you should first return to the diagnostic criteria in this document. However you should also think about the specific context of homelessness and how that might impact on how those autistic traits present.

The following table shows two main clusters of traits which make up autism and how they might present in a homelessness context. This is intended to be a brief summary to begin to orientate you to this area rather than a comprehensive checklist.

"Difficulties with social communication and getting on with others"	Think about how differences in how autistic people communicate verbally (e.g. monologues, tangential responses) and non-verbally (e.g. blank facial expression, not picking up on body language) will affect their life on the streets. Also consider differences in making and understanding relationships and how that will impact on their safety and their ability to engage with support.
"Stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests"	The preference for repetition and sameness seen in some autistic people is highly likely to affect autistic people's experience of homelessness. Stereotyped speech could make a person stand out and probably increase their vulnerability (for instance one person in the Churchard et al. (2019) study was described as talking like a character from a 19th century novel). Fixed interests can have a significant impact on the experience of homelessness. A case study in the Autism and Homelessness Toolkit describes a man called Jim who hoarded 'beautiful things'. The sheer quantity of the objects he had collected was a major obstacle to maintaining accommodation, and it was only when this was sensitively worked with that he was able to stay in accommodation for a prolonged period of time. Autism is often characterised by a liking for routine. This will obviously require a great deal of effort to maintain in the chaotic context of homelessness. One individual in the Churchard et al. (2019) study had a routine which involved walking their trolley along a set route every day, but when the trolley was stolen they were devastated. Sensory issues are also key. Many homelessness services may be quite sensorily overwhelming even for neurotypical individuals (e.g. bright lights, loud noises), so do consider how these might affect autistic people and whether they might be a barrier to supporting them. Suggestions for making adjustments around this are made later in this document.

Autism and Substance misuse

There is emerging evidence that some autistic people have an increased risk of substance misuse(Butwicka. A et al. 2017), and that the same is likely to be true for people with autistic traits but without a diagnosis (De Alwis D. et al. (2014).

There is little research available about the reasons why autistic people might use substances. Many of the reasons will be the same as for people who are not autistic.

Reasons for substance misuse specific to autism could include wanting to reduce the intensity of sensory experiences, coping with co-occuring physical or mental health problems such as anxiety or pain, or as a response to stress. Identifying why somebody is using substances can help to make a good plan with them to support them to stop.

Substance misuse services may have quite a formulaic offering, for example expecting people to attend groups as a central part of their support, which may not be a good support method for an autistic person. If you are working in substance misuse, maximising flexibility in your care planning for autistic people is essential, and if you are working with an autistic person who is accessing a substance misuse service alongside your service then it may be useful to offer to advocate for them if they are not being offered flexibility around access and service provision

You can use the suggestions later in this guidance to develop a plan with an autistic person who has substance misuse support needs.

A note on ‘dual diagnosis’

Though it is recognised that poor mental health and substance misuse often co-occur, people who need support in both areas often find themselves excluded from support for either or both (Public Health England, 2017). The need for better inter-organisational working by mental health support providers is highlighted by the Care Quality Commission (2015).

As autistic people report relatively high levels of poor mental health, autistic people with substance misuse support needs are likely to need to navigate addiction services alongside needing mental health support. When you are supporting autistic people, working to put multidisciplinary processes in place can be very useful.

Autism and Gypsy, Roma and Traveller Communities

Friends, Families and Travellers (FFT) estimates that there are around 300,000 Gypsies and Travellers in the UK.

Even before taking into account autistic community members, Gypsy and Traveller communities are known to face some of the starkest health inequalities in the UK (Parry et al, 2007), even when compared with other ethnic minorities, with life expectancies on average ten years shorter than the general population (Equalities and human rights commission, 2009).

Many Gypsy and Traveller people struggle to access health services as a result of structural inequalities. This means that autistic Gypsy and Traveller people are likely to face a range of barriers to accessing relevant assessment, formal diagnosis, and support.

Some of the key barriers to services faced by Gypsy and Traveller communities include

- Refusal of registration with primary care services
- Refusal for nomadic patients in primary healthcare as a result of no fixed address or ID
- Barriers relating to high levels of digital exclusion
- Failure to provide accessible communications for those with low or no literacy

(FFT, 2018).

Patients who are nomadic are often disadvantaged by waiting lists for secondary care services. Without record sharing and mechanisms in place to ensure people are able to retain their place on waiting lists whilst travelling, many patients find that they must move to the bottom of an NHS waiting list when they travel to a new area. For services with particularly long waits, and where provision varies by area such as autism assessments, people who are travelling may never reach the top of a waiting list to access formal diagnosis and support.

As a result of these structural inequalities in access to services, as well as experiences of discrimination, many Gypsies and Travellers may be reluctant to engage with statutory services and it can often take time to build trust with members of Gypsy and Traveller communities. Community members may not be aware a service is available, may not be sure if they will be welcome there or may not feel confident that it will be delivered in a culturally appropriate way (FFT, 2020).

Within Gypsy and Traveller communities, there is a strong cultural emphasis on the centrality of family and of the provision of care and support within the community. The 2011 census found that Gypsies and Travellers are among the ethnic groups most likely to be providing unpaid care in England and Wales at 11%, and are the ethnic groups most likely to provide more than 50 hours of unpaid care per week, at 4% (ONS, 2011).

For neurodivergent Gypsies and Travellers who require care and support with activities of daily living, family members and peers may be providing this support, and previous research shows that Gypsy and Traveller communities report high levels of support within the community for care needs (FFT, 2018 (2)).

However, many Gypsies and Travellers may not perceive themselves as carers, viewing this instead as a family responsibility, and may therefore not be aware of relevant entitlements and support, including for autistic community members.

If you are working with someone from the communities who is, or who you think may be autistic, then some of the general strategies in this document will be useful in supporting them to access appropriate care. Specifically for people in Gypsy and Traveller communities, you may also want to think about linking in with local VCSE organisations and nurse-led services who have developed trusted relationships with communities and may be able to support with linking people into relevant services; Friends, Families and Travellers services directory is a good place to start.

It is also important to consider how you can make your communications accessible to those with low or no literacy or experiencing digital exclusion; offer videos and audio recordings of information wherever possible, offer telephone communication and WhatsApp voice-notes as opposed to written correspondence, and consider the use of audio tools such as Browsealoud, which adds speech, reading and translation to websites.

Many nomadic patients may be registered at a “care of address”, or with an address where they no longer live, so being flexible with your communication approach, contacting people by text or telephone, and asking patients about the best ways to keep in touch will help to ensure that you are reaching people. In addition, if a nomadic patient is awaiting assessment for autism, consider how you can advocate locally for a patient to retain their place on a waiting list if they are travelling.

Adjustments for working with autistic people in inclusion health

This section covers the kind of adjustments you could discuss with an autistic person you are working with. They may help to reduce overwhelm and allow for optimal processing and communication. This is not supposed to be a definitive list, but is rather to support professionals to understand the kind of things that may be agreed to be useful with an autsitic patient or client.

Sensory processing differences

Autistic people may be differentially sensitive to a range of sensory input including sound, light and physical sensation. This may be either hypersensitivity (finding things very intense) or hyposensitivity (not registering pain, for example, in a usual way). Autistic people can also experience problems with interoception, which means not being able to pick up on the signals of their own body in the same way as neurotypical people.

Ways that you could adjust for sensory processing differences include:

- Appointments at times when the service is less busy
- Quieter rooms
- Allowing people to wait outside rather than in waiting rooms if they prefer
- Adjusted lighting
- Giving options for communication such as email or text
- Giving plenty of personal space
- Ensuring a person feels comfortable using their own processing or self soothing methods such as repetitive movements, which are sometimes called ‘stimming’.
- Not expecting or demanding eye contact

Autistic people can find some settings, like noisy group sessions or activities outdoors overwhelming and unpleasant due to the sensory experiences they involve so this should be taken into account when planning support.

Communication

Autistic people may struggle with typical communication, and may have learned to mask how they are feeling, including not showing pain or distress. Some autistic people have non typical affect including unusual patterns of speech or physical expression, and can also be intermittently non verbal. Just because somebody is not speaking does not mean they cannot meaningfully communicate. Minimising assumptions about an autistic person's experiences and having open dialogue can help to work out what adjustments someone might require in order to establish and maintain communication.

Information processing differences

Autistic people often process information differently. Being stressed or overwhelmed may affect processing. They may also struggle to change topics quickly. There are a number of theories as to why this is, including the theory of monotropism (Murray, D. et al, 2005), which describes a high level of focus on a single topic and correspondingly finding it diffuclt to shift attention to something else.

Autisic people may have ‘spiky’ profiles whereby they are very fast and what would be considered typically effective when thinking about some things and much less so with others. This can make it difficult to discern where an autsitic person may find something very hard to think about, process or imagine and again minimising assumptions will help.

As well as communication measures that would help anybody, autistic people may also benefit from:

- Extra time to process information
- Checking that the client has understood information and repeating it if necessary
- Giving the client a written summary of keywork, plans and future dates in a preferred format
- Suggesting that they are accompanied by a friend or carer if they think this would help
- Giving documents suitable for dyslexic or visually impaired clients if necessary

Other considerations

While it may be useful to speak to a person who knows an autistic client well such as a parent, partner or friend, professionals should not assume that a person who is not autistic will understand an autistic person's needs better than the autistic person themselves.

Autism may make it harder for clients to change exsisting habits, and engage in new healthy habits, such as getting sufficient sleep, exercising, eating well, taking medication as prescribed and organising and planning. Autistic clients should be supported to build their wellbeing in a way which works for them as far as possible.

The 'double empathy problem' and autistic peers

An important consideration is whether you can find an autisic peer or staff member who may be able to work with an autistic patient or client alongside or instead of you. There is evidence that difficulty in understanding between autistic and neurotypical people goes in both directions, and that autistic people communicate more effectively with each other, in the same way that neurotypical people do. This is called the ‘double empathy problem’. The term was coined by Dr Damian Milton (2012), who is an autistic academic. Recent research has backed up this theory with evidence. (Crompton et. al, 2020).

Tips on advocating for 'priority need' under housing law and considerations for suitable accommodation

There are good reasons to predict why someone diagnosed with, or showing features of autism would be significantly vulnerable if they became homeless. The assessment the local authority should carry out must take into account all relevant facts and circumstances, and even if the applicant doesn't have a diagnosis, as the worker who maybe knows them best at that time, you can advocate for them as needing priority for accommodation.

'Demand Avoidance' may mean an autistic applicant uses strategies to resist and avoid the demands of the assessing local authority and support services; and the rules/expectations of the local authority's housing policies may conflict with the autistic applicant's difficulty understanding social behaviours or their own responses. It's important for you and the local authority worker to understand that this is likely to be motivated by anxiety and distress. As the worker who knows the applicant it's important you get their consent to share their difficulties with the local authority assessor, and negotiate an environment and time for appointments that the applicant thinks they can cope with.

Being autistic infers strengths as well as difficulties. This can include particular skills or ways of seeing the world that may distract from the significant difficulties an autistic person may have resolving their homelessness. It's important to remember that though the person may appear to have good social skills in some of your contacts, if there is a general pattern over a period of time of them not completing agreed tasks and the case is not progressing, they may be lacking the capacity to resolve their homelessness without more significant support and consideration for 'priority need'.

The local authority housing assessment may take into account other support the applicant has, but the difficulties autistic people have in maintaining supportive relationships mean they are likely to be socially isolated and this needs to be highlighted to the local authority assessor.

In modern services it's difficult to offer a consistent worker developing a good rapport over a period of time, but with autistic people this can be key to establishing ways of working that keep the person engaged in the housing application and this could also help inform what the most suitable temporary accommodation (TA) would be for them. There is a very broad spectrum within autism and each applicant is going to have a different set of criteria that make a TA suitable for them (e.g. self contained, on a quiet or busy road; structured support or infrequent check-ins), and the person may not know themselves what works best for them at the start of the process. But any unsuccessful viewing or rejection of accommodation can be learning about what might be more suitable next time.

Supporting a client to access and maintain accommodation

Examples of things you may need to consider in a housing context include:

• Communication differences, as highlighted elsewhere in this guidance

• If paperwork is a barrier, think how it could be reduced or done differently

• If you are able to support somebody into housing, think ahead about what could cause difficulties, particularly if the person has a history of evictions or abandonment.

• Clear guidance and support up front to accommodate special interests but prevent hoarding that could become a health and safety concern

• Adapting or dropping normal expectations such as welfare checks, conventional key work and support planning, based on the clients preferences and needs

• Special attention to sensory needs (noise, light, temperature) and support and space to accommodate interests and hobbies

It is important to recognise that even with your and your clients best efforts many hostels will be challenging environments for autistic people. They are likely to find it difficult being around other hostel residents and parts of the environment might be beyond control. Smaller, quieter, more self contained environments tend to work better but you may need to work with the options available.

In summary

As with any patient or client, care planning for an autistic person should be done with the autistic person, and should be person centred and holistic. Autism is varied, often accompanied by co-occuring conditions, and poorly understood by many professionals, and the public.

As professionals we should be seeking to understand our clients and their needs collaboratively, with creativity and curiosity, and being clear when we don't understand.

London Network of Nurses and Midwives

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