

# Informing Autism Service Improvement Through Lived Experience Insight

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NHSE/I Midlands Autism Workstream

EbE Focus Group Feedback Report v6

December 2021

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# Introduction

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*Informing Autism Service Improvement Through Lived Experience Insight* is a compendium of feedback from the NHSE/I Midlands Autism workstream Expert by Experience focus group to date. It details the priorities identified by the group, supported by feedback received in focus groups along with direct quotes from the group members themselves and other experts by experience (autistic people, or their parents/ families) who have fed back outside of the group.

The Expert by Experience focus group comprises autistic individuals, family members of autistic individuals and a small number of 'Experts by Profession'. Feedback from virtual meetings has been gathered via taking notes from discussion, and from the text chat section.

We have also taken feedback from emails following the meeting; this has proved to be a useful way to receive feedback as it allows individuals time to reflect and feed back in their own time

We have also incorporated some feedback from individuals who are not attending the focus group meetings, but who have been kept informed and encouraged to feed back their thoughts by members of the group.

We are extremely grateful to Expert by Experience participants for taking the time to share their experiences and valuable insight. This document would not exist without them.

This document is updated periodically to add new feedback. Each update is allowing us to clarify and reinforce priorities, and to gradually better organise the document into a coherent 'directory of priorities' so to speak.

The contents of this document will inform the development of the NHSE/I Midlands Autism Strategy, it will also be available as a resource which it is hoped will inform work occurring more widely across the region.

# About this document

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This document is arranged in sections based on common areas of priority identified in focus group discussion.

Each section begins by outlining key messages for quick reference, and then goes on to include the expanded feedback from the group.

The format of the feedback section is as follows:

- **Key points from discussion (in bold, blue text)**
  - 'Sub points' (marked with a round bullet point)
  - *Direct quotes (in speech marks, marked with an arrow bullet point, in italics)*
  - Material taken directly from notes taken by workstream members (in inverted commas, marked with an arrow bullet point, not in italics)

In note taking and translation of material into key points and sub points, great care has been taken to record, preserve and interpret views as comprehensively, accurately and sensitively as possible.

## Language

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Identity-first language is used throughout (i.e., 'autistic person' rather than 'person with autism') in this document, but some quotes may feature person-first language.

The term 'autism' has generally been used, as opposed to ASD, but again some quotes may use other language. Language and label use is an individual preference.

## Acronyms and Definitions

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Acronyms have been avoided, or expanded where appropriate, but some acronyms remain for the sake of brevity, where a term is used on multiple occasions.

EbE – Expert by Experience - an Expert by Experience is defined simply as a person who has become an expert in their own condition or experience of life. The term here is used to refer to autistic people, or parents of autistic people, who participated in the focus group.

NHS – National Health Service.

NT – neurotypical – those who do not have a neurodevelopmental difference, such as not being autistic, having ADHD or dyslexia etc.

# Informing Autism Service Improvement Through Lived Experience Insight

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# Key Principles

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This section covers universally applicable key principles which, when applied effectively, are likely to support autistic people to feel safe, supported and respected.

This includes respect, communication, considerate use of language and labels, how research and services can inclusively encompass the experiences and needs of the diverse autistic population, and how best to implement consistency of care to allow people to feel supported.

# Respect

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## Key messages

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- **Autistic people and their families must be treated with respect.**
- **It needs to be respected that autistic people and/ or their families or carers have often become 'experts' in autism (and potentially in co-occurring conditions) often through necessity due to not being able to access appropriate support.**
- **People's desire to seek a diagnosis (for themselves or their child) needs to be respectfully understood.**

## Respect Feedback

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- **A hugely important, non-negotiable point which comes up time and time again is the need for autistic people (and their families and carers) to be treated respectfully.**
  - *“My sons best service was the OT we've seen ... she was adaptable and treated both us and him with respect. she really tried to relate to him and us and I loved that. When he told her it was over and didn't want to carry on she respected that and we came back the following week to finish the assessment. She made sure his strengths were acknowledged, and ours as parents.”*
  - *“[A good service should be] strengthened by a balanced professional/ service user power dynamic. It doesn't perpetuate the 'them and us' neurotypical/ autistic divide, it nurtures inclusion.”*
  - *“If my voice and views are cast aside/ not respected, I'm less trusting/receptive in the future to services in general.”*
  - *“[A bad service makes me feel] worthless, which perpetuates low self-esteem/mental health struggles.”*
  - *“[Those working within services should treat] autistic people as equals, learning is 2 way between person and the professional. Shouldn't be a power role.”*
  - It needs to be respected that autistic people are not ‘broken’ in comparison to neurotypical people. *“Not subordinate individuals needing to be fixed [we should not be] viewed as inferior”*
- **It needs to be respected that autistic people and/ or their families or carers have often become ‘experts’ in autism (and potentially in other co-occurring conditions) often through necessity due to not being able to access appropriate support. Their knowledge and understanding of their own unique situation need to be taken into account and valued, rather than ‘shut down’ because it doesn't fit in with a professional's view of how things should be.**
  - *“Out of necessity I have done a lot of research about autism and my other conditions online. I once saw a mental health nurse who totally shut down all the things I was saying and told me to stop looking things up online. They also clearly had no awareness of the fact many autistic people have a propensity for knowledge gathering and researching things, I did point this out.”*
  - *“[Ideally] my voice is genuinely heard, as an expert of my own experiences.”*

- **People’s choice of language and use of ‘labels’ needs to be respected, and it needs to be understood that this might be different for different people (see language and labels)**
- **Professionals should have a compassionate understanding of people’s needs for diagnosis (or support) be this autistic people or their families.**
  - *“[I] overheard a professional referring to [one] parent’s pursuit of a diagnosis for their child as ‘...it’s just parents being fashionable...’”*
- **It goes without saying that those working within services need to have empathy and compassion.**
  - *“[There needs to be] understanding and empathy of the impact of anxiety experienced by autistic people... even where on the face of it, the person presents as confident.”*
  - A focus group participant gave an example of a receptionist (who had received training in autism) responding to a person’s worry of being late for a meeting that was already underway; this worker sensitively accompanied this person the meeting room. It was felt that this demonstrated that this person was making space for the person and saying ‘I value you’
  - A family carer shared an experience of her child requiring surgery and a community learning disability nurse ensuring that all the staff on the ward understood her autistic child’s needs. She felt this demonstrated compassion and empathy.
  - A focus group participant shared an example of their psychiatrist producing minutes of a meeting about her child which were so respectful and non-judgemental it made her weep, she was so moved.
  - *“[There is a] need to look at the types of people being employed; empathy can’t be taught”*

- It is frequently referenced in focus groups that professionals often talk down to autistic people, patronise them or don't believe them.
  - *"When I say that I am autistic, health professionals start to talk down to me."*
  - With reference to co-occurring chronic physical illness, a focus group participant remarked that they felt they had been treated as if it was 'all in their head' because they are autistic.
  - *"It seems we are often patronised when it comes to knowledge of things like our own health, as though we are not to be believed or listened to, which is so wrong."*

# Communication

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## Key messages

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- It is essential that people's individual stories and experiences are listened to and treated as important.
- People should not be communicated with in a condescending way and should be directly engaged in conversation about their care or support, not spoken for or excluded.
- Communication needs to be clear and consistent.
- There must be an understanding that some autistic people may have particular communication needs, such as needing to know a lot of detail.
- It is important to build trust and ensure people feel comfortable with those they are interacting with.
- Some autistic people may communicate their needs in ways other than speech, and there should be sufficient expertise within services to adaptably accommodate this.
- Individuals need to feel that they can raise concerns about the care of themselves or their loved ones should they have any, and these concerns need to be fully and respectfully addressed.

## Communication Feedback

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- **It is essential that people feel listened to, particularly with regards to listening to individual stories and experiences.**
  - *“Listening is also important we have had social workers who thought they knew best and never listened so my son - he just didn’t want to see them.”*
  - *“My sons psychiatrist is in neuropsychiatry previously with LD he totally gets my son and it is lovely to watch them converse (we always come away with a good feeling)”*
  - *“When I do meet a professional, they continue to ask questions, that I had already answered on their forms, that they hadn't read. I'm not sure, if I am stressed or annoyed at this point but, it gets worse when I get my session summaries, that left me wondering if I was in the same session.”*
  - *“The summary letter says that I have said things, that I have no memory of saying such as I have fleeting thoughts of self-harm and suicide, that I can now deflect, using strategies that I have learned, however, the reports read no thoughts of suicide or self-harm.”*
  - *“When I requested my diagnostic report following my assessment it contained several inaccuracies, which added to the stress I felt around the process. It should’ve been a respectful and meaningful report but upon reading it I felt like I hadn’t been listened to and treated like an individual. I was able to send a version over with some of my own notes on addressing the inaccuracies, but I didn’t ever feel that the issue had been satisfactorily resolved.”*
  - *“[I] have to fight for my needs to be listened to, they can’t get in my shoes. Some don’t want to listen, they don’t understand, I am either classed as rude or naughty, but I am trying to assert my needs, seen as aggressive instead”*
- **Style of knowledge presentation needs to be carefully considered.**
  - *“The style of knowledge presentation is important as any suggestion of patronising or condescending behaviour will immediately alienate and switch the focus of attention to feeling angry.”*
  - *“...we met this different psychiatrist who was very condescending.”*
  - *“I was once handed a leaflet by a mental health nurse about sleep which said ‘sleep tight, don’t let the bed bugs bite’ on the back. I felt like that was really condescending.”*

- **Communication needs to be clear, consistent and needs to allow people to feel safe, secure and reassured.**
  - *“Need to be given the right type of information in the right way.”*
- **Those communicating with autistic people need to have an understanding of the fact that they may think, understand and communicate in particular ways, or have particular communication needs, such as needing to know a lot of information in advance or needing to know a lot of detail.**
  - *“...the person who rang me didn't put me at ease and got into arguing with me instead (which does not work as, quite rightly, I will not accept anything without fully substantiated proof and am stubbornly resistant in maintaining my own position until they provide evidence showing that I am wrong - do not try to challenge what I am saying when I am right.”*
  - *“However, I don't even know yet whether any filling of forms will be needed because, unacceptably, they still have not gone through this detail - and, yes, as an autistic person I need every nth degree discussing and being made clear and set out fully”*
  - *“I always want to know all of the information, in great detail, and to have a deep understanding of things. I also do a lot of research so do go into situations with my own knowledge or at least with many informed questions to ask. I think this frustrates some professionals. I've had people say if I have any questions I can ask, then they don't respond, or I think of things I need to know after the appointment then often can't easily get in touch.”*
  - One participant spoke of how as neurodivergent people we often have our 'own language' i.e. a particular way of putting things across, and of how if this isn't understood, it can have a negative impact on a professionals perception of us or of our ability to put across important points about our own health *“Psychiatrists need to understand autism as a language... we can be champions of our own health but really it's perceived as something else [if those we are speaking to don't speak 'our language'] in our neurodiversity we have our own way of communicating.”*

- **Professionals should be mindful of the need to communicate directly with the autistic person, and not speak for them, or speak to a person they are with (such as a parent) as though they are not present, which implies an assumption that all autistic people lack capacity to engage.**
  - *“Professional speak on behalf of the supported person instead of asking them directly.”*
  - *“Problem with children’s services is there is a preconception about how much the child will understand. This may result in the child being discussed with parents without being directly addressed.”*
- **It would be ideal if people could have someone within services they can get to know, ‘gel’ with and who understand. If this doesn’t happen, difficulties can arise.**
  - *“[If they don’t gel] the person with autism can become agitated, aggressive, making them worse off than they were to begin with. They need trust.”*
- **If an individual raises concerns, these concerns need to be fully and respectfully addressed. Individuals also need to be made to feel like they can raise issues or concerns about their care or about the care of someone in their care if they need to.**
  - *“I raised a written complaint to PALS, who are yet to respond, more than a year later.”*
- **There should be provision within services to support those who communicate via AAC (Augmentative and Alternative Communication)**
- **There needs to be awareness around how when a person is exhibiting so called behaviour that challenges that they are trying to communicate something. How this can be identified and how they can best be supported?**
  - *‘A person making sounds such as growling is not exhibiting so called ‘challenging behaviour’. Judgements are focussed on whether it’s communication or not, or how it affects anyone but the person. The focus needs to be on why the person is doing it, what are they trying to communicate.’*
  - *“Understanding that people may use alternate language and/ or sounds to communicate - that is their norm.”*

# Language and Labels

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## Key messages

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- **The language used around autism is a personal choice, professionals need to be aware that individuals may have their own preference for language use.**
- **Person first language is generally preferred (i.e., 'autistic person' rather than 'person with autism')**
- **Functioning labels are generally considered unhelpful (i.e., 'high functioning' or 'low functioning')**
- **Positive, enabling language is generally preferred over impairment and disorder led language.**

## Language and Labels Feedback

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- The subject of language and labels is one which often comes up for discussion amongst autistic people. Language preference is individual and can evolve over time.
- There is generally a preference for using first person language, (i.e. 'autistic person' rather than 'person with autism')
- 'Functioning' labels are generally disliked (i.e. 'high functioning' or 'low functioning')
  - *"I significantly dislike functioning labels and most autistic people I know [do] too - I think they significantly ignore the fact that those of us who are 'high functioning' on the surface in one moment can struggle significantly with other tasks and still have meltdowns, shutdowns, non-verbal periods etc."*
  - *"...we all function differently day or hour by hour... or in different areas of life."*
  - *"The use of functioning labels reminds me of the demeaning old low/ medium/ high grade language and there's an assumption that if you are 'high functioning' you won't have any 'complex needs', so no one asks and you are left to struggle on your own."*
  - *"Functioning is a broad term for any individual. What is 'functioning'?"*
  - *"Sometimes I function sometimes I don't. Sometimes my brain does not function with me. It's such a broad thing. There are different areas of functioning in every single thing in life for the average person. I don't see how this can be put in boxes across a population of people."*
- **Generally, it is preferred that impairment and disorder led language is not used, with positive, enabling language used instead.**

*"Using neutral or positive language rather than impairment and disorder led thinking can create a good first impression."*

- **It is said that academic studies can often be 'label heavy', which is felt to be understandable but also alienating.**
  - *"Totally get that academic study means old language (as a student!) but it shouldn't - it's not accurate to our experiences and takes away from its validity and perpetuates inaccurate perception of us."*
  - *"...studies don't often include lived experience to inform the language. In many cases it could be viewed as interfering with the process. It should be viewed as a translation issue - as you would with any language - as it can affect the way it is interpreted."*
- **Language is a personal choice. Professionals need to be aware of individual language preference.**
- **It is also useful to be mindful that some may have been diagnosed with, or use the term, Asperger's.**

# Inclusion and Diversity

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## Key messages

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- We are conscious that there is a need to expand diversity in the focus group and look specifically at expanding this section, as BAME and LGBTQ+ individuals are underrepresented at present.
- Consideration needs to be given to adapting diagnostic assessments to be more considerate of specific gender based needs.
- There needs to be awareness around the fact that males can mask as well as females, or not present in a stereotypical way. Indeed, there needs to be awareness and understanding of autism encompassing the entire gender spectrum.
- More knowledge and understanding is needed around LGBTQ+ and autism.
- It would be beneficial for more research to be done into diagnosing autism, and providing autism support, in the BAME population.
- There is a need for more research, knowledge, and training around autism in women and girls.
- Late diagnosis can be a particular problem for women and girls, with many reaching crisis point before a diagnosis is considered.
- Provision of gender specific support is considered beneficial, including gender specific social groups.

## Inclusion and Diversity Feedback

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- **There needs to be awareness that males can mask as well as females, or not present in a stereotypical way. Indeed, services must recognise, be inclusive of and be able to respond needs across the gender spectrum.**
  - *“It's worth saying that there's a lot of research saying it is not about female autism and male autism, it's about socialisation and gender roles instead. autistic lads can mask and such too (and we also must be trans inclusive too when discussing terms like 'female autism', instead using assigned female at birth and such)”*
  - *“Male not fitting stereotype - when pressure builds up I can't cope and collapse and stop. Now recognise this but didn't as a child/ teenager. Missed diagnosis and not recognised as autism, was seen as depression and anxiety but then told this didn't fit. I don't understand the 'male'— I don't get blokey blokes, I don't understand 'bloke', I get and understand women – this can also cause difficulties. My interests don't 'fit' with men.”*
- **There is sometimes a concern around gender diversity in terms of staffing in services, with an example given of women not being understood if most professionals working within a service are male.**
- **A participant spoke of how it would be beneficial for more research to be done into diagnosing autism in non-white western cultures, and also especially into autism in people who live in very repressive culture, due to a 'multiple layer of mental health and social stress on them' which means that often when they come to see a psychiatrist or professional, they have additional needs that a lot of mental health professionals often don't understand, empathise with or take into account. It was agreed by other participants that ethnicity can be a barrier which can impact how professionals judge a person, and the professional's subsequent willingness to listen and understand.**
- **There may need to be staff within services with expertise in particular demographic areas. There is also a concern that experience is often from a limited range of socio-economic and cultural groups.**
- **There needs to be an awareness of autism in the LGBTQ+ community/ gender minority groups, and any specific support needs that may be present.**
  - *“So many get patronised about sexuality purely because [we are] autistic, it's assumed it's because autistic people don't experience emotions in the same way. Need work on how professionals interact about this.”*

## Women and Girls

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- **The area of autism in women and girls could benefit hugely from more research, knowledge and training. Awareness of this area does seem to be improving but more work is needed to improve understanding of how autism may present differently in women and girls, and particular struggles they may have.**
  - Research needs to be as inclusive as practice.
  - *“There appears to be a longstanding and pervasive ignorance about autistic women and girls, due to initial research by Kanner and Asperger done on males almost exclusively.”*
- **Consideration needs to be given to ‘picking up’ girls who may be autistic in order to best support them through adolescence. Early life may be well managed by some girls, particularly if there is a supportive family environment. At secondary school or college age life can become more challenging and autistic traits may become more evident and more difficulties may be encountered.**
  - ‘A participant, a parent, spoke of how her son was diagnosed early, but it was a very different situation for her daughter; the parent in question had said since her daughter was two that she needed to be seen for a possible autism diagnosis. Her daughter didn’t speak at school for three years, still wasn’t seen, and ultimately a referral was made so social services where the parent was accused of fabricating illness, before her daughter would be seen for assessment. Her daughter now has many diagnoses due to not receiving appropriate early support. Lack of early support is likely to lead to ongoing issues in adulthood.’
- **Late diagnosis can be a particular problem for women and girls. Autistic women and girls often end up at crisis point before a diagnosis is considered.**
- **Gender specific psychoeducation could be beneficial, to assist in supporting people in relation to gender specific expectations for example.**
- **Gender specific support in general may be needed, this is felt to be particularly relevant for females, due to particular challenges that autistic females may face.**
  - ‘E.g., autistic women and girls are often more vulnerable to sexual exploitation and abuse.’

- **Autistic women’s groups can be very valuable, as women may value being able to meet other autistic females, feel more comfortable talking and sharing amongst themselves, and may have gender specific issues they would like to discuss.**
  - *“I attend an autistic women’s discussion group and it has been absolutely invaluable for allowing me to meet people who experience life in a similar way to me. My self-esteem has improved hugely from taking part in the group and I have made new friends.”*
  - *“[I had] very little knowledge of autistic females, I had many male friends and this caused its own difficulty, sometimes it’s easier to get on with males. So many females mask that it is hard to find other females like me – is this part of the problem?”*
- **Consideration may need to be given to diagnostic assessment in relation to women and girls. It is suggested that diagnostic assessments aren’t built for females and non-binary individuals, e.g., they may not be sensitive to non-stereotypical special interests; an autistic girl might be obsessed with collecting soft toys which might not seem like a ‘typical’ autistic interest.**

# Consistency of Care

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## Key messages

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- Consistency of care is incredibly important.
- Named key workers for children, young people and ideally also adults can be beneficial in supporting consistency of care.
- An autism diagnosis should be clearly recorded on medical records, to make anyone involved with a person's care aware. Consent must be obtained ahead of doing this.
- Services need to work together synergistically to allow people to have a smooth journey through services.
- Ideally services should be co-located where possible to support collaborative working and prevent people having to go to lots of different places if they need to access more than one service.
- People should not have to tell their story over and over again to different professionals or services, as this is often tiring and traumatic.
- There is a need to focus on supporting smooth transitions between services.
- A care plan being put into place post diagnosis could support consistency of care and create a feeling of reassurance that a person wasn't going to be left to 'fend for themselves'
- Services need a system whereby they are able to flag things up to other services to build a picture of how a person is presenting and ensure that things are not missed.

## Consistency of Care Feedback

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- **There is a need to understand that consistency of care is incredibly important, to alleviate anxiety.**
  - *“trying to get me to go to a different children’s centre, time, person etc (as postcode changed). It was the change in routine, had melt-down and led to crisis, they didn’t understand this.”*
- **It has been suggested that autistic children and young people could have a named key worker; it is thought that this could be beneficial for some adults too. This may help to support autistic people or their parents/ carers by giving them a reliable consistent point of contact to receive guidance from or to help point them in the direction of appropriate services, and to support transition between services. This may help to ameliorate the feeling of having to fight alone to access certain support services, and the feeling of not knowing who to turn to, providing security and reassurance.**
  - It has been suggested that a ‘gateway professional’ could be helpful to assist those who need support in liaising with support services. This individual would know a person’s story to prevent being asked questions constantly.
- **When autism is diagnosed, it should be noted on medical notes to make anyone involved in care in future aware. This must, however, only be done with consent from the individual.**
- **Services need to work together synergistically, communicating well with one another and supporting movement of people between services in a smooth manner. It would be beneficial for autistic people to be more easily able to access support for different issues, as often when there are co-occurring conditions, the process of seeking support can be very fragmented. Any support service an autistic person is involved with should have the scope to work with any other area a person is engaging with; schools, higher education, physical healthcare etc. There should be excellent communication between these services.**
  - *“There needs to be good communication between services, things need to just fit together, there needs to be good contacts between services to take out stress.”*
  - *‘Working as a team - you go to it and the people cover different areas rather than try and act on areas they don't understand. This person understands this - so they are your guy - this person understands this - etc.’*

- ‘One body many parts’ is what a good autism team should aim for... people /professionals with different, broad skills... where people are met with compassion as well as constructive support.’
- ‘The system is siloed, fragmented... professionals don’t know about each other or what is happening in their own areas.’
- *“Services must work closer together to support individuals and with the various services they all provide not be in competition with each other, as they all have the same aim to support the individual yet there seems to be an ‘us and them’ attitude, instead of a we can provide this, what can you provide, and in what way will this help. For example, transitioning from childhood to adulthood and the journey the individual takes with things such as independent living, work and bereavement.”*
- *“[In an ideal world the service should have] strong links with any other services and professionals involved e.g., mental health services, or voluntary organisations. It can then provide skilled autism support to other services engaged with the individual around adjustments and knowledge which may help them to support the person better.”*
- *“... the service themselves [should be] well informed and up-to-date with the provision and accessibility of wider services that may benefit the individual and can help to support the person to access these.”*
- Different teams need to speak with each other and not be segmented. An example given was that mental health services might say a problem is best dealt with by eating disorder services, and eating disorder services might say it’s best dealt with by mental health services, so a person can end up not actually getting access to any support services.
- The process of needing support in different areas is so often too complex, and when needing to see someone who is for example specialist in a different area, the referral process can be complex (who can refer to who and when) and the wait can be very long.
- It is considered that a ‘user journey map’ may support this, making services aware of which services have previously been accessed/ utilised.
- **People should not have to tell their story over and over again (to different professionals within one service, or to different services)**
  - *“Consistency of faces/people would be so helpful, every time we go to appointments it is a different person, they only see what it is on last screen, you have to explain yourself over and over again and explain what you need. We have to educate, this is tiring.”*

- *“One point of contact; not having to tell your story over and over again. Overall support needs to be consistent.”*
- *“Good experience is not having to tell story over and over [it is] traumatic to keep going over it, never any communication [between services] It is detrimental.”*
- *‘A lot of locums can affect consistency of person seeing us.’*
- **Information held about people to assist with them not having to tell their story repeatedly must be coherently organised and accessible to those who need to see it.**
  - *“Much time is spent collating information that is often erroneous and never read. Perhaps, the worst issue was [when] my notes were transferred to the electronic system. As a management professional, I would have expected the migration to include key information such as care plans and existing diagnosis. At best, this migration was and remains incomplete with diagnosis omitted and care plan missing.”*
- **It has been suggested that it may be beneficial to house several services under one roof if possible. Although this would of course come with its challenges (such as finding suitable premises) it would allow an autistic person to access various services and support in one building, a ‘hub’ so to speak; this could provide consistency, familiarity and reassurance which in turn may reduce the anxiety which can often be present with having to frequently familiarise yourself with new places. It would also allow for an easier exchange of knowledge between services, and a supported handover between services when necessary. This would provide familiarity and reassurance.**
  - *“The dream would be for the councils to see sense and put empty buildings (e.g. old library and police station) into use by housing all services under one roof as a central hub [autism specific support services, mental health charities, a carer’s hub] so people in need can easily access this.”*
  - *“Going from one service to another service is a really difficult thing for a person to deal with.”*
  - *“There are risks in creating stand-alone specialist services ... universal services need to be developed to be responsive and effective for autistic people ... worried about the creation of ghettos.”*

- **There is a need to focus on transitions between services, perhaps most importantly the transition from child into adult services. There should be no ‘cliff edge’ transition from children’s into adult services. Continuity and support are needed through transitions. It was also noted in reference to this that there doesn’t seem to be enough consideration of service provision for adults, so often when children and young people adulthood there are often few or no services to move onto.**
  - *“Transition into adult services is problematic and often lacks professional guidance, leaving families to manage this by themselves.”*
  - *“Get to 25 and fall off a cliff edge, it’s assumed that by the time you get to 25 you’ve had ‘the service’ and somehow you’re not autistic anymore and [you don’t get any more support]”*
  - *“We were fortunate to have a psychiatrist and CAMHS worker very experienced in autism diagnose our son at 15 years old - but of course [there was] minimal support [available] post 16.”*
- **A care plan could be put into place post diagnosis, as often occurs when other conditions (the example given was physical health conditions) are diagnosed. Often people are diagnosed as autistic then simply left alone.**
  - From a focus group, in reference to a staff nurse who had been diagnosed as autistic ‘Nurses set out care plan [for other health conditions] why does no one with autism post diagnosis? They liaise with other teams to ensure health is looked over, with autism its diagnosis then the person is left alone.’
- **Services need a system whereby they are able to flag things up both to alert other services to issues, and also to build a solid picture of how a person is presenting to allow them access appropriate support (and an appropriate diagnosis, if they are not yet diagnosed and wish to be)**

# Service Planning and Provision

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Service planning is an incredibly important area, as 'getting it right early on' is crucial to successfully creating and providing an effective and sustainable service.

It needs to be ensured that once services are in place, they are monitored and always have a forward-thinking attitude of how they can adapt and improve to fit the needs of those accessing them.

## Key messages

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- Co-production and collaboration are vital, and Experts by Experience must be included.
- Services developed need to have the capacity to flexibly implement individualised adaptations.
- It is important to look at, and learn from, what is already working well.
- The scale of the problem (of lack of adequate support provision) must not be underestimated.
- It is important to obtain feedback from people using services to ascertain whether a service is working well, rather than just asking the services themselves, and it is important to look at qualitative outcomes before quantitative.
- There is a need for a greater consistency in availability of services across the country, there should be no postcode lottery.
- Consideration needs to be given to rural areas which may struggle to make funding stretch over a large area, or to attract adequate staff.
- Services always need to be focussed on how they can improve.
- Consideration needs to be given to employing 'the right type of people in the first place', and those working within services with the skills and ideas to improve things need to be supported in this, not 'shut down'
- It may be beneficial for autism services to be neurodevelopmental services, rather than autism only.
- All areas should have an autism partnership board.

## Service Provision and Planning Feedback

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- **Co-production and collaboration are vital.**
  - It is considered useful to have autism forums that a service works with, made up of EbEs, clinicians and other stakeholders.
  - ‘It is important for autism services to talk to and learn from each other.’
  - ‘Collaboration is really important yet there appear to be limited mechanisms to establish co-operation/ collaboration. It would be beneficial to look at how different individuals/ sectors/ organisations can collaborate effectively.’
- **Staff taken on by services need to be carefully recruited and vetted.**
  - An example was given of an existing autism support service who’s potential new employees are interviewed by EbEs. This service is grown through co-production.
- **The concept of ‘if you’ve met one autistic person, you’ve met one autistic person’ is important to pay heed to, but it is recognised that this can also make commissioning services challenging. It is felt there is a need to approach the establishment of autism services in a way that is accessible to commissioners, but it is crucial to ensure these services then have the capacity to consider individualised adaptations and deliver a personalised service. Common support needs can be grouped together to some extent, but the path through service needs to be individual and personalised.**
- **It is important to look at what is already working well.**
- **It is suggested that there is a need to look at the third sector, as this may provide examples of service provision which is already successfully meeting the needs of autistic people in a creative and flexible way. Charities are frequently mentioned as examples of services providing useful support, sometimes in situations where a person hasn’t been able to access support within the NHS. It is suggested that there could be collaboration between the NHS and voluntary sectors.**
  - *“Third sector can bring flexibility and creativity and governance frameworks can be developed. Often NHS focus is on making people fit their institutional framework.”*
  - *“Could we perhaps turn things around and, rather than make services change shape and what they do, just allow groups run by autistic people to do what they do but, enhanced and supported with proper funding?”*

- **It is felt that local autism services/ third sector organisations and smaller groups are often left out of planning, when if they were, they are likely to be able to provide useful input.**
  - *“I find that local autism organisations are mostly left out of planning and so not involved in co-production.”*
- **Groups and charities are often pushed to ‘fit into boxes’ if they want to engage, or if they need to access funding**
  - *“we couldn't have a lot of input [in planning discussions] or be funded without having to fit to very strict council funding criteria which would have gutted our effectiveness and effectively removed the autism relevant ways we were working. If we had taken funding, they would have changed us to a model that would have stripped away most reasons we were doing things in the first place - because they were for autistic people and worked! I.e. not the norm. Being funded by the council effectively meant being forced to adhere to requirements which were the opposite to autism appropriate. We chose to remain appropriate!”*
- **The scale of the problem must not be underestimated. Members of the group frequently report huge difficulties accessing services and getting the right support. Many report having had to fight for years. Of course, in an ideal world appropriate support would be readily available, and this should be the aim, but it has been suggested that provision of an easily accessible advocacy service may be beneficial in the meantime, to support those accessing services.**
  - *“I have been fighting for over 20 years to get a service that will support my son’s needs but it has been an uphill struggle.”*
  - *“...the only way I have obtained help for my son has been to make complaints. I must have done this at least 5 to 6 times over the past years. I was so annoyed that the main reply to my complaints were that they were not commissioned to provide services for people with autism.”*
- **Other models have been mentioned as being examples of good service and support, it may be beneficial to look to these.**
  - *“[Other models] should be looked at to inspire and guide services, e.g. MacMillan cancer nurses, Admiral dementia nurses, HMP Listener services, and, crucially, the Multiple and Complex Needs work.”*
- **The judgement of whether a service is fit for purpose must be firmly focussed on service user feedback, not the opinion of staff working in the service.**

- There is a need for greater consistency in availability of services across the country; to support equal opportunity for access to services, and to support professionals by making evident a clear potential path (or paths) for them to direct people along.
  - ‘a professional contributor felt there needed to be greater consistency in the availability of services across the country. They compared this to the pathways for cancer care and heart disease which are clearly articulated.’
  - There needs to be an awareness of local issues/ local needs (e.g., services might be great in one area but non-existent in another)
- There is said to often be differences within the same trust. There shouldn’t be a situation where some people in an area are being offered support, but others are not.
- Services in certain areas can end up fragmented, and a postcode lottery is created as some areas are under resourced or not ideally resourced.
- How far funding stretches and what it can achieve can vary massively depending on the location of a trust; the example of rural counties and the cost of delivering an effective service over a large but under populated area compared to urban areas was given.
- There can be difficulty attracting adequate staff to certain areas, such as rural areas.
- Services need to be adaptable and focussed on improvement.
  - *“[A service should always be] willing to consider what it could do better and be open minded to change, and adaptive to the changes in the outside world, this year being a huge example.”*
- It has been suggested that services need to look at employing people with the right attitude in the first place (ideally empathic, open minded, knowledgeable yet willing to learn and expand)
  - *“Need to look at the types of people being employed; empathy can’t be taught.”*
- Those working within services with useful skills and the right attitude should be encouraged to engage in service improvement. In focus groups we have heard from well-intentioned people within services frustrated at their limited remit to influence positive change.
- It is felt that services are often dependent on key individuals who may not be replaced (or be able to be replaced) if they leave.

- **The performance of a service should be judged on qualitative outcomes before quantitative.**
- **In service planning, it has been suggested that it is useful to look at a 'triangle of needs' format.**
  - 'The 'triangle of needs' should be considered, forming a solid base of things like kindness, acceptance, basic training and education, what's being communicated, environment, how we view other people, befriending and coming alongside, community engagement including social groups. The second tier would represent training of health workers, social care, education in issues relating to neurodevelopment, and an NHS focus on prevention of long term mental health issues. The top of the pyramid would equate to crisis point/ hospitalisations, and it is hoped that this point would be able to be made smaller with the building of a solid foundation to the triangle.'
- **It may be beneficial for autism services to be neurodevelopmental services, rather than autism only.**
  - "Need to see a service that is [neurodevelopment based] versus diagnosis specific, to see a whole person versus one part of person. [There are] so many with other neurodevelopmental difficulties e.g. dyspraxia/ ADHD. It's rarely 'just' autism."
- **All areas should have an autism partnership board to provide a forum for communication between various stakeholders and autistic people in the local population. Partnership board membership should include:**
  - Autistic people and their families
  - Local authority commissioner
  - Clinical commissioning group commissioner
  - Health care
  - Social care
  - Education
  - The criminal justice system (including police)
  - Housing
  - Employment, and the benefits system

- **Partnership boards need to be conscious of the importance of encompassing all ages and needs.**
  - One partnership board was mentioned as having a very heavy focus on children and young people. A focus group participant noted that he'd had to push to get them to look at anything relating to adult services, and that the focus they do have on adult services is limited to those who are experiencing obvious 'extreme difficulty', rather than anything relating to those who appear to be coping but may really be struggling. It was noted that in this particular partnership board, the focus appeared to be on fewer and fewer people (largely due to lack of funding)
- **It has been suggested that partnership boards may also do well to look broadly at neurodiversity rather than there being a narrow focus on autism.**
  - 'Re Autism strategies ... do areas need to be thinking about neuro-diversity[?] Should partnership boards mirror this?'

# EbE Engagement in Service Planning

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We held two focus groups to look specifically at Expert by Experience engagement in service planning and provision, and found that many felt opportunities for EbE engagement are often difficult to find out about and engage with. This is unfortunate, as Experts by Experience engaging directly to support service development can really make a difference, providing a wealth of expertise based on lived experience.

## Key messages

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- **Expert by Experience engagement is key in service planning and provision. Experts by Experience must be involved in:**
  - **Developing new services**
  - **Assessing and supporting improvement of existing services**
  - **Recruiting staff to new and existing services**
  - **Training/ mentoring staff**
  - **Recruiting staff to new and existing services**
- **People should be made aware of opportunities for Expert by Experience engagement (such as via partnership boards, and other systems concerned with service planning and provision) There is a need to 'reach out' into the community to ensure that no demographic is excluded.**
- **Engagement opportunities should be accessible, this may include things like offering diverse engagement options (face-to-face, phone, video call) and holding meetings at times which are considerate of people's other commitments (work, childcare etc)**
- **Opportunities must also be transparently accessible in terms of things like avoiding using acronyms, supporting people in understanding how best to engage, keeping people informed, allowing time to prepare for meetings etc.**
- **Expert by Experience engagement may need to be supported by training, and/ or a 'key worker' primarily concerned with supporting engagement.**
- **When Experts by Experience are engaged in service provision and planning, involvement should be meaningful, and not a tokenistic 'tick box' exercise. Their input needs to lead to positive change and evidence of this must be demonstrable. Care should be taken to ensure people are being asked the right questions and engaged in such a way that their words will influence positive change.**

- **Experts by Experience should be engaged from the start in service planning**
- **It is considered useful to engage those providing services directly with Expert by Experience groups, so that they can hear directly what is being spoken about and get a real idea of the reality of what it's like to live as an autistic person.**

## EbE Engagement in Service Planning Feedback

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- **It is thought to be crucial that in planning for new services or in making changes to existing services, Experts by Experience be thoroughly consulted. Ideally, the nature of their input would be forward thinking.**
  - *“If individuals are courageous enough and are still willing to have faith that the landscape of future services can look different and the faith to still want to work collaboratively and want to share these as a way of helping commissioners to truly understand the impact a good service would make, autistic voices should be heard first-hand to add to the focus group feedback. Autism services aren't just about improving people's quality of lives, it's often about saving them, and that's why I just feel it's so important that this is fully appreciated by commissioners. It was said in the meeting yesterday commissioners don't really understand autism, and I know that this work is all about helping them to understand what's needed to help our community, but maybe if they heard a collation of autistic voices and stories, this could help too?”*
  - *“[EbE engagement] shouldn't be focused on 'pointing the finger' or blaming, but ... [should] be more forward-focussed. Yes, it's really important to understand and acknowledge the mistakes and failings, and certainly to acknowledge the huge detriment and devastating impact it's had on individuals' lives, but it would be a shame to get lost in the past narrative.”*
  - *“The service [should be] regularly reviewed by both EbE's and professionals, through speaking with or obtaining feedback from individuals who access the service.”*
  - The importance of involving young EbEs in service planning and provision for children and young people, and allowing them to have their voices heard, is considered to be incredibly important.
- **It would be good if there were scope to create jobs for EbEs within services, both in a co-production and training capacity and a support/ mentor capacity, and it would be important to consider how to support them and to ensure they were properly remunerated.**
- **People often aren't aware of partnership boards or other organisations which are concerned with service planning and provision. It was noted by focus group members that even when they were involved with services in other ways, in steering groups etc, that partnership boards still seemed somewhat inaccessible and unfathomable. It would be good if people could be made more aware.**

- 'Autism Partnership Boards need to be clearly communicated as a right to people on the ground - not something you have to find out about or only up to a commissioner to communicate to you - it's your right to have this forum.'
- **It is felt that service systems are fragmented, difficult to engage with and somewhat unfathomable. It was suggested that partnership boards and those concerned with service planning and provision must 'reach out' to involve more experts by experience. It appears that quite often they are rather 'closed off' currently, when it would be good if they were able to involve more autistic people and their families.**
  - 'Right people and in right place – need to have the right people to influence the change, people need 'door to be opened for them''
  - 'Autism Strategies are supposed to be owned by the people! Therefore, Partnership Boards should be advertised and promoted.'
  - 'Partnership Boards in place are not always accessible ... how do people contact people who are able to help them without 'knowing the right person'?'
  - 'You can only define and comment on the services if you can comment, contact and engage those delivering the services.'
  - 'Services exist under a cloak of invisibility.'
  - 'System is so fragmented - like you need to hold a piece of string to know it is there when you know about it.'
- **It is felt that consultation is often simply a tokenistic 'tick box' exercise to enable services to simply tick a box to say that they have consulted with experts by experience, only for nothing new or different to be put into place based on the exchange.**
- **People feel frustrated at the lack of change they see 'on the ground' despite conversations taking place, it is felt things tend to get lost.**
- **Those concerned with service planning/ provision must take care to reach out into areas of society where there are likely to be many autistic people who would perhaps not ordinarily have the opportunity to engage in expert by experience work.**
  - *"we need the people who aren't on these types of things" (referring to the focus group)*
  - *"Making sure we reach the voices..."*

- ‘Reaching out to addiction groups etc was suggested, to ‘access people who have perhaps found dysfunctional coping strategies to deal with life, and to give them a voice with regards to how they could feel better supported in society’’
- ‘Local authorities should work working proactively to ‘reach into different areas of society’’
  - It was suggested that autism champions in local communities may be beneficial in recruiting EbEs.
  - Some may understandably be unwilling to engage due to prior bad experience.
- **Engagement opportunities need to be made clear and accessible, and widely advertised to make as broad a range of people as possible aware of them (posters in GP surgeries, hospitals, schools etc)**
- **There is a need for consideration of the fact that some people may struggle to engage within usual ‘office hours’ due to work or family commitments.**
  - ‘Shouldn’t partnership boards meet in the evenings as most parents and autistic people work?’
- **Some may need alternative methods of engagement to be made available to them, e.g., being able to join in virtually, being able to feed in by email or be able to be represented by someone else.**
  - Online meetings necessitated by Covid have transformed the potential for co-production. *“[There is a] whole new dimension to co-production that wasn’t there before”*
- **People need to be engaged from the start in service design and planning, so that they can positively influence it. Quite often, by the time EbEs are asked what they think of something, it’s too late to influence positive change.**
  - *“if you’re involved at the end, it’s usually too late.”*
- **Co-production must be carried out with an awareness of how passionate people are likely to be about getting things right and establishing a good support system.**
  - ‘If we are truly talking about co-production... shouldn’t the approach be ‘how can we help you, what is it what you need. Professionals just need to work compassionately and recognise this is like a hunger... we just have a need, a hunger to understand and have support to help ourselves where, when we need it.’

- **Care should be taken to make things transparent, as it is felt that the NHS and other systems often have ‘barriers’ of jargon and excessive use of acronyms.**
  - *“we have a massive organisation [the NHS] with your own language your own acronyms [and] culture etc, [this causes] massive barriers for the people you are trying to help especially autistic people who are outsiders and on the periphery.”*
  - An autistic workstream member, in reference to thoughtfully amending a presentation to be worded more accessibly, in ‘plain English’ *“People who have less exposure to the policies and systems can go ‘Oh I get this, all I need to do is go there and do that, OK bang!’”*
- **Systems set up to engage EbEs need to be transparent; their intentions need to be clear as does what they need from EbEs, to allow people to feel prepared. All the key principles referenced in this document around respect, allowing time to prepare, communication etc need to be applied.**
- **It appears to be very useful to engage those providing services with EbEs/ EbE groups, so they can hear directly what is being spoken about.**
  - *“I come from a different perspective as a professional from X council. I came for an hour with Y who is in this group too. We support people with learning disabilities and autism into paid work. We are finding out different people’s experiences and want to bring people along to the group and find out about it.”*
- **Care should be taken to ensure people are being asked the right questions and engaged with in such a way that their words will influence positive change. This applies to the EbE focus group itself, as well as other organisations. The example here relates to people feeling they were being asked the same sort of question again, so care must be taken to clearly put across what is being asked and why. EbEs must not feel as though they are being asked the same thing repeatedly and not being listened to. Those with capacity to make change must listen to EbEs and take visible action. Some EbEs speak of feeling that they have put the emotional energy into ‘opening up’ and speaking about their experiences and needs time and time again only to see nothing change.**
  - *“We have had 10 years of things getting lost in talking shops and individuals on the ground are not seeing what they need on the ground.”*
- **The concept of ‘tooling up’ and training EbEs was spoken of, to give them the tools they need to influence positive change.**

- Engagement needs to be supported, there may need to be a ‘key worker’ concerned primarily with supporting EbE engagement.
  - *“Having one person to be the 'key worker' would really help. This is not new, this is how it is done in industry where you have one business contact who would do it for you.”*
- It was suggested that it was important to think about how the voices of those going through diagnosis was captured by the NHS, given that there is a relatively short amount of face-to-face time during the diagnostic process.
- It must be made as clear as possible how long certain processes (implementation/improving existing services) may take.

# Training, Knowledge, Awareness and Understanding

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This section looks at issues relating to training, knowledge, awareness and understanding. It is apparent that there is often a lack of awareness and understanding about autism across health and social care, and this can lead to autistic people and their families being exposed to avoidable traumatic experiences. It is key that there are efforts made within services to raise awareness and improve understanding, through improved training (which should include direct Expert by Experience input) and improved efforts to really get people to 'see the bigger picture' of what it's like to live as an autistic person, going beyond impairment and disorder led thinking.

Also covered are some specific key areas identified by our focus group which it is essential are adequately understood by professionals, so that those within their care can be supported appropriately.

# Key Principles for Training, Knowledge, Awareness and Understanding

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## Key messages

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- There needs to be a greater understanding of autism within health and social care services; autism education should be an integral part of these services, not an afterthought.
- Professionals need to have their knowledge updated, monitored and refreshed with ongoing professional development.
- It would be beneficial for consideration to be given to how professionals, either in training or continued professional development, can engage with Experts by Experience to get a real understanding of what it's like to live as an autistic person, rather than just having a 'textbook' or clinical understanding.
- People with lived experience working within services should be supported to disclose diagnosis if they want to, not feel they will be penalised for doing so.
- It can be beneficial for there to be staff available within services with expertise in particular demographic areas.
- It should be clear to those working within services what pathways are available for autistic people to be referred for diagnosis or to receive support.
- Protocols need to be implemented for how clinicians/ staff can raise the possibility of autism with undiagnosed clients/ patients exhibiting autistic traits.
- It is important to recognise good work that is going on within services and look at how to expand upon this.
- Often people working within services could make a valuable contribution to improving autism awareness and understanding feel frustrated at their limited remit for creating change.

## Key Principles for Training, Knowledge, Awareness and Understanding Feedback

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- **Professionals need to have good knowledge and understanding of autism and autistic people (e.g., how they may experience life, not just a clinical understanding) but also need to have a willingness to learn and adapt.**
  - *“[Professionals] can’t meet the needs of autistic people unless [they] understand autistic people. Don’t [need to] have all the knowledge, but [need to have] the willingness to learn”*
  - *“[It is beneficial for] Professionals [to] understand what it is like to live with autism whether you are the person or the parent/ carer.”*
- **It is hard for professionals to become experts in autism due to the lack of specialisation within the services in which they work, and has been suggested that it can be valuable to engage those interested in ‘specialising’ with those with lived experience of autism.**
  - A contributor from an autism charity mentioned that they have medical students engaged with their service, listening to parents and people on the spectrum and appearing to really want to learn. It appears it would be beneficial to have medical students engaged with things such as autism charities and perhaps where appropriate social groups, to enhance their knowledge and understanding.
- **It would be beneficial to spread enthusiasm for autism education, making it an integral part of NHS services, not an afterthought.**
- **Professionals need to have their knowledge updated, monitored, and refreshed with ongoing professional development. There is a need to ensure all those being trained have full understanding.**
  - *“Staff should have the ‘core competencies’ but also be very well trained in autism and the presentation of autistic patients. They should be very well supported and supervised. Clinical mentors and sharing groups seem essential to me, as does regular input from organisations such as NAS etc.”*
  - *“[There should be] yearly mandatory training on [neurodivergence] amongst health professionals, education and social care.”*
  - It was noted that this need for updating and refreshing of knowledge is particularly important in professionals working within diagnostic services.
  - It is very important that EbEs might be engaged in this refreshing and monitoring of knowledge and understanding.

- **It is frequently suggested that stereotypical/ outdated views are often held by professionals.**
- **It is considered important that neurodivergence needs to feature in social services training.**
  - *“Social Services hold belief that autistic people are unable to understand any expressions of emotion. To this extent that they are presenting this to the court system as fact. Which is highly dangerous when you have ignorance within the court system, who are being led by Social Services.”*
- **Autistic people, parents or carers often end up having to be the ‘experts’ in order to be able to advocate for themselves or those in their care.**
  - *“His previous psychiatrist in the community mental health didn’t know about autism so I had to explain everything and although he was nice he wasn’t helping my son understand himself or his condition.”*
  - *“...things got no better and I spent all of my time reading books trying to make sense if my son had autism or a mental health condition or both.”*
- **Training must include EbE input. It is hoped that this might support those being trained to understand autism in reality and not just on paper.**
  - *“The problem with training is that it’s theoretical and can’t be easily applied to practice and the person in front of you”*
  - *“Absolutely autistic people have to be involved in a VERY meaningful way in designing and delivering training.”*
  - There is a need for more engagement with young EbEs.
- **It can be beneficial for those involved with healthcare and/ or support to have lived experience.**
  - *“There is a need to look at how we raise awareness in all services and how we get people to make reasonable adjustments, how can those in services who are autistic advocate or include those with experience in services to be there to support. How can people [working in services] feel more comfortable disclosing diagnosis?”*
  - *“Understanding is really important my son had a CPN for a short while whose own son was on the autistic spectrum it was such a relief having someone who understood and my son could trust and feel at ease.”*

- *“It would be helpful to have people in the team delivering the service who had personal experience and can offer empathy, who work alongside those who are professionals by experience. For instance, to have peer mentors on board, who are both well supported and trained. From personal experience of having therapy from a counsellor who has autism themselves, this had massive therapeutic benefit to me as I felt truly ‘heard’ and understood for the first time in my whole life.”*
- Though it can’t be assumed it will always be beneficial and it can in fact be the opposite. Appropriate training and an understanding of the complexities and nuances of autism is still required.
- *“Yes there are commonalities amongst autistic people, but just from personal experience, when I’ve received support from a person who has had knowledge of autism and so presumed I’ve fitted a certain stereotype or ticked all the boxes on a list without taking into account my individuality, it hasn’t been helpful.”*
- **There has been discussion around the challenge of being an autistic person working within health services and how people are often penalised, even losing their jobs, when they disclose their autism. If the response to autism diagnosis disclosure was more positive, it is thought likely that these people within services could support positive change.**
  - *“There are autistic psychiatrists ... Not that anyone is going to be open about it or they would lose their job, such is the stigma and misunderstanding around autism in the profession.”*
- **There may need to be staff with expertise in particular demographic areas.**
  - *“[There is a] concern also that experience is often from a limited range of socio-economic and cultural groups.”*
- **It should be clear to those working within services what pathways are available for autistic people to receive support. Clinicians need to have good knowledge of interventions, pathways and appropriate referrals.**
  - *“A member of the group talked of their experiences as a paid professional, acknowledging very limited knowledge and understanding in primary care about autism, and literally not knowing where to go for support if presented by one of his patients in need, who was autistic. He felt he needed support to understand how reasonable adjustments are made for autistic people (in primary care) He compared what was required to the national work that happened regarding dementia training and awareness; he thought this was a good model.”*

- *“If a clinician cannot see a clear pathway or means of supporting an autistic person (perhaps because they just don’t know) it effectively means that person gets no support at all.”*
- **There need to be protocols implemented to support professionals in raising the possibility of autism with undiagnosed clients/ patients.**
  - *“[There is a] lack of protocols for staff/ professionals who come across undiagnosed clients/ patients in treatment etc. How do we raise it in an acceptable way[?] Autistic people find relief in knowing [they are autistic] having [felt, prior to a diagnosis] that they are different but, not knowing why.”*
- **It would be beneficial to recognise the good work that is going on within services, and perhaps those who are working with autistic people in a knowledgeable and supportive way could be in a position to mentor those who are not doing this for whatever reason.**
- **Often well-intentioned people working within services feel frustrated at their limited remit for creating change.**
- **It has been suggested that NHS led initiatives to improve understanding around autism may be beneficial.**
  - *‘NHS have previously been instrumental in changing views of things like smoking [they are] well placed to start to change minds and educate, to reduce further damage being inflicted on [neurodivergent] people through lack of understanding in health and social care and within the community.’*
- **It is suggested that there are many people within services who have no training about autism yet are ending up supporting autistic people in crisis.**
- **Within training, the importance of making adaptations to suit individual should be emphasised, encouraging flexibility and not the attitude of doing things a certain way because that’s the way it’s always been done.**
  - *“[There should be] training to say ‘it may suit you, but is it suiting the person, does the person feel able to take part into the process?’ People should not feel they are having things imposed on them.”*
- **It is felt that there is a lack of quality information available to support understanding of autism.**
  - *“It is a very big problem for the general public and professionals alike regarding lack of good quality information that will help them understand autism.”*

# Training, Knowledge, Awareness and Understanding Content

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## Key messages

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Key areas in which there is a need for greater understanding include:

- The diverse and varied ways that autism may manifest.
- Neurotypical thinking vs neurodivergent thinking.
- Trauma – how autistic people are particularly prone to this, and the effects it can have.
- Increased suicide risk in the autistic population.
- Self-harm and self-medication.
- Restraint - how distressing this can be and how it is rarely conducive to de-escalating a situation.
- Sensory issues - the great impact that these can have on a person's life.
- Environmental factors - how environments can be made more 'autism friendly' to reduce distress.
- Behaviour that challenges – identifying the root cause and establishing what messages it may contain.
- 'Spiky profiles' – a person coping/ functioning well in one area, whilst struggling in another.
- Co-occurring conditions – the impact these may have, and how their symptoms may interact with autism.

# Training, Knowledge, Awareness and Understanding

## Content Feedback

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- There needs to be awareness in services (more likely to be a problem outside of autism specific services, SATs etc) that late diagnosis of autism doesn't mean that it is acquired later in life; just that it has been diagnosed later in life. One participant was asked how you 'catch autism' by an advocacy service who claimed to understand autism.
- It has been suggested that training is needed on how autistic people might think compared to neurotypical people, but it must also be understood that not all autistic people will think in the same way.
  - *"Professionals are primarily neurotypical and thus naturally have difficulties understanding or even empathising [with] what autistic people say or mean, there is training required on how neurotypicals think compared to how autistic people think."*
  - *"Professionals need (relatively) high level training on how neurotypical people think and how that differs from autistic thinking; both of which are equally valid."*
- There is a need for an awareness of the diverse and varied ways that autism can manifest.
  - *"Been pushed into a bracket of 'normal behaviours' for autism, no-one picks up on my own pattern – so weren't aware this might be autism."*
  - *'[Ideally] people would be much more aware of the different types of presentation of autism. This would help prevent institutional traumas/ mis-diagnosis.'*
- It is felt that trauma and the complexities of this is something that many services appear to know very little about. It is important that there is good understanding around this, as autistic people are often particularly prone to experiencing trauma.
  - *"Trauma most often isn't just one big trauma, it can be a build-up, chronic trauma so to speak, of big and small traumas over time, and things which people might not immediately recognise as trauma but are no less impactful."*
- There needs to be awareness of the increased suicide risk amongst autistic people.
- There needs to be understanding from professionals (in all areas) that autism isn't a medical problem that can be 'fixed' or that a GP can prescribe medication for.

- There needs to be a greater knowledge of how restraint can often be incredibly distressing, and it would be beneficial if there was awareness around the fact that there are often better ways to handle situations which have better outcomes for the autistic person. This could refer to a number of services, including the police.
  - *"[In relation to restraint] I know a young man who was handcuffed and bodily transported to the 136 suite last year when all he was doing was having a meltdown in his car on the car park where he works. The experience has left him practically unable to return to his job."*
- Some aspects of autism such as meltdowns can end up being criminalised; this seems to be a particular problem amongst children and young people, with their parents often being told to call the police when actually good mental health or autism specific support might help to alleviate issues. More training and understanding around this would be likely to be beneficial.
  - *"[There is a] high prevalence of meltdowns, due to pressures of environment, the response of professionals may criminalise this e.g., by suggesting calling the police. It does not take into account the needs of the individual at point of crisis and misses the point of the communication in the behaviour."*
- There needs to be good understanding around sensory issues, how they may cause difficulty for an individual, (in wider life but also in terms of engaging with services) and how that individual can be supported.
  - *"I needed health professionals to understand why I behaved how I did and accept that and that multiple stimuli was not conducive to me."*
- There needs to be an understanding that environmental factors can contribute to manifestations of behaviour that is so called 'difficult' or 'challenging', and that looking at and improving these factors to make them more 'autism friendly' and friendly towards that specific individual is likely to significantly improve situations and outcomes. Often so called 'difficult' behaviour is occurring because an autistic person is finding an environment difficult to deal with.
  - *"Many things that are labelled as 'autistic behaviours' are actually 'stressed human behaviour'. So it follows that if an autistic person feels safe and relaxed, they will naturally behave a lot less 'autisticly'."*
- When considering so called 'difficult' or 'challenging' behaviour, care needs to be taken to look at what the root cause of that might be, what is the autistic person trying to communicate?
  - *"Professionals who doesn't understand autism just see aggression and challenging behaviour, not the person."*

- Awareness and understanding are needed around 'spiky profiles', i.e., the concept of a person being very proficient in one area but struggling in another. It cannot be assumed that just because someone can, for example, work, that they are also going to be entirely capable of coping with other things in life without support.
- It is important for professionals working within services to understand the complexity and interrelated nature of things like sensory issues or struggles with change, and understand how these can cross conditions and be influenced by one another/ outside sources etc; to understand that traits aren't static so to speak.
  - *"...as well as the sensory assessment being for autism, it's part of accepting neurodiversity and potentially helping undiagnosed conditions to be identified. The recognition that sensory issues can cross conditions or impact on different conditions in different ways, is part of recognising that a person isn't just a bunch of conditions, but a person under different influences, existing in different environments, with different motivations which result in different responses. My issues with sudden change are much greater when under stress or distracted or tired and my ADHD really kicks in, so I have change constantly such as losing things or missing things and then I have to deal with that change and the anger with the process I put in place to ensure this didn't happen, such as losing my keys!"*
- The issue, and extent of, self-harm and self-medication needs to be better recognised and understood within neurodivergence.

# Accessing Services

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We are frequently told by Experts by Experience that accessing services can be extremely challenging. This section looks at two areas:

- Accessing services in the first place, either by being referred by a professional, or self-referring, and the challenges around this.
- Then, once a person is to be seen by a service, things a service needs to put into place to allow a person to feel that they can comfortably access and make use of the service in a way which will lead to a positive outcome.

# Referrals and Pathways

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## Key messages

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### People should:

- Not have to feel they have to fight to access the services they need.
- Not be denied access to services by non-specialist 'gatekeepers'.
- Not be denied access to services they need due to being 'under the care of' other services.
- Be able to access a service they need whatever their age; there should be no gaps in service provision.
- Have a say in the professional/ service they are seen by.
- Not feel as though they are being 'passed from pillar to post' between services.
- Not be penalised for having private diagnoses, and be able to access support if they are self-diagnosed.

### Services should:

- Have sufficient expertise to identify a person who may be autistic, so that person can get the help they need as early as possible.
- Consider how they can make connections with other services to best make themselves available to those who may need to access support.
- Not penalise people for missing appointments without taking into account difficulties they may have around attending appointments.
- Be available to people wherever they live – there should be no postcode lottery.

## Referrals and Pathways Feedback

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- **People should not have to feel that they have to fight to access services.**
  - *“I have been fighting for over 20 years to get a service that will support my son’s needs but it has been an uphill struggle.”*
  - *“...the only way I have obtained help for my son has been to make complaints. I must have done this at least 5 to 6 times over the past years. I was so annoyed that the main reply to my complaints were that they were not commissioned to provide services for people with autism.”*
  - *“Had to fight all the way through for support for an autistic teenager with mental health issues.”*
  - *“These are RIGHTS people shouldn’t have to be using advocacy organisations to get health, education and social care etc to meet their statutory duties.”*
  - *“I have had to fight for my now adult son since he was a child. I have had positive experience of advocacy services supporting my son to get the right support in hospital.”*
  - *‘Where families push, seek support they frequently get an inappropriate response, the risk is you then internalise a view that you are a problem which needs to be fixed!’*
  - *“I got my diagnosis in about 3 months, but I’m quite bullish and push people away with a bow wave until I get what I need.”*
- **Decisions regarding access to services and decisions about people’s care should not be allowed to be made or controlled by people who do not have a sufficient understanding of autism.**
  - *“[People should] not having to fight layers of ‘non specialist gatekeepers’ who deny referral to specialist service on their opinions.”*
  - *“He has had at least 2 awful social workers who thought they knew best and both argued with his psychiatrist one regarding his need of funding for a personal assistant to go out with and the other who decided my son didn’t need an advanced care plan. Both of these social workers resigned from my sons care.”*

- **There should be no barrier to accessing appropriate services due to being ‘under the care of’ other services. It is understood that this is often an issue relating to ‘double funding’ but ultimately it can often be detrimental to people’s health and wellbeing, not only meaning they are unable to access the services they need, but also potentially creating a lot of stress. support services.**
  - *“not being able to access the local autism service full stop because I have a cormorbid MH condition, so I was excluded as a result of stringent eligibility criteria.”*
  - *“[In an ideal world] The service [should widen] its eligibility criteria as much as is feasibly possible i.e., an individual with suspected autism is not excluded from accessing the autism service on the basis that they are under the care of secondary mental health services. It may be that somebody is under MH services as a result of undiagnosed autism, so that exclusion from accessing autism-specific services (in my opinion) does not seem logical.”*
  - *“I couldn’t access a local counselling service CBT course whilst under the care of a psychiatrist.”*
- **Restrictive criteria of services can make it impossible for people to access the support they need for themselves or their children.**
  - *“Why do autistic people come under only being supported by mental health services. Still in X don’t meet criteria for autism support if got no learning disability... Under CAMHS didn’t meet criteria for children with disabilities team as autistic and no learning disability and didn’t meet it for preparing for adulthood or now as an adult”* It was noted that this situation had also been reported in a coproduction group elsewhere and is likely to be a widespread issue.
  - A participant who works with a charity mentioned difficulties getting the people they help into services, saying it is either difficult or impossible as they don’t fit criteria (of the services)
- **People often experience years of trauma due to ‘invisible struggles’ before they are identified. Ideally people wouldn’t have to reach ‘breaking point’ before they were ‘spotted’ and referred for assessment or autism specific support.**
  - *“traits often aren’t picked up until there is trauma attached.”*

- It must be considered that people might miss out because they struggle to initiate engagement with services. To help with this, it may be beneficial to open up as many different forms of communication as possible for a person, and to also engage with their GP and/ or family, ‘putting tendrils out’ to initiate contact with those who may feel unable to initiate, or who ‘shut themselves off from the world’. Not to miss people who are ‘hidden’ One local charity for example makes itself known to community services, GP practices etc so they can approach them and refer people who otherwise wouldn’t have found organisations or support.
- People often feel that there is stigma attached to being diagnosed, or to being ‘under the care’ of services, which may mean they feel unable to engage and so do not get the support they need. Consideration needs to be given to how this could be addressed.
- Age thresholds can be an issue in accessing support.
- Consideration needs to be given around who might be the best professional for a person to be seen by, and ideally a person would have some say in this.
  - *“I’d been asked to be referred into secondary mental health services again but when I was eventually sent an appointment it was with a nurse with whom I’d had a bad experience in the past (not being listened to or respected) I had to push for an appointment with someone else who thus far has been and continues to be incredibly helpful. Had I not pushed for this I’d probably have just been seen, not listened to again and then discharged from the service again.”*
- It is reported that in mental health services people are commonly discharged from service if they miss two appointments. This doesn’t effectively take into account the fact autistic people may have particular struggles around feeling able to attend appointments and may need to be given more time.
  - Services should accept that sometimes autistic people won’t engage; it doesn’t mean they don’t still need help. Why people aren’t engaging or are struggling to engage fully should be looked at, e.g. due to sensory issues, or the fact the information isn’t being delivered in the right way. People should not simply be discharged from services.
- Consideration needs to be given to making sure people are seeing professionals who will be best placed to make a thorough assessment and then either provide support or refer them on for further assistance. People’s access to support should not be dependent on who they have seen and the remit they have for referral.
  - *“Often depends who you see as to what is diagnosed and what pathway you have access to, this can cause a block.”*

- Seeing a GP isn't always the best way to access support, there should be a different way of accessing overall support. It is often said that GPs don't have the scope or knowledge to make useful support referrals.
- The problem of people feeling 'passed from pillar to post' is something which is mentioned time and time again. Difficulties often arise if people don't 'fit' into a particular service. People are likely to feel much better reassured and supported if they are able to access a service which suits them and build familiarity with it and the professional(s) working within it, or at the very least be supported in moves between services.
  - *"Especially where there has been a theme of being passed from 'pillar to post' between services, the individual accessing the service should feel confident that it will be reliable. Also, to see the same set of healthcare professionals throughout the process would provide continuity and minimise the distress associated with change."*
- Access to support shouldn't be dependent on diagnosis.
- People sometimes end up having to pay for private assessments to get any help. We often hear from people who face problems with private diagnoses not being accepted. This can be a particular problem if they cannot access NHS services for a diagnosis, but then a private diagnosis is not accepted by, for example, support services, leaving people with nowhere to turn. If an individual has had a private diagnosis, this should not prevent them from accessing support.
  - *"I spoke to a Mum this morning who went for a private diagnosis for her son. Services will now not accept this because it's not NHS."*
  - *"... if an individual has been forced to access a private assessment, [a] service should [still] then allow the person to access any follow up support the service can offer."*
  - *'It was mentioned that sometimes a private company will provide an autism or ADHD service for an area where there is no service, and that more assessments are being done online by private organisations used by health boards to lower waiting lists, but if an individual seeks a private option themselves it is often not subsequently accepted.'*
- It is reported that there is presently a 'postcode lottery' when it comes to accessing services, with people in areas without adequate service provision or capacity often not being able to get the help they need. Ideally, there should be no postcode lottery.

# Making Services Adaptably Accessible

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## Key messages

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### Services should:

- **Consider how to provide as much information as possible ahead of an appointment, to allow people to feel prepared.**
- **Allow enough time for appointments that a person doesn't feel hurried**
- **Work to make their facilities as accessible as possible, considering, for example, sensory needs, and be able to flexibly adapt to accommodate individuals' access needs**
- **Consider provision of alternatives to face-to-face appointments as required**

## Making Services Adaptably Accessible Feedback

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- Preparation ahead of time when visiting services is important for many autistic people, in terms of feeling well informed and aware of what's going to happen (which can help to reduce anxiety) and to give services time to address needs and adjustments. Services should be reliable and consistent and aim to not make changes at the last minute, such as cancelling appointments or changing the practitioner who the person is seeing, people should be able to feel informed and prepared.
  - *“Unplanned change really affects me – if I have control in it and things are planned I can cope.”*
  - *“we need to be intercepted early on and things clearly explained to us, we need time to process info, be well prepared and then explained in a way that make sense and has relevance to us. This may require information to be given in different ways/right type of information... We need to be sure of the environment we are going into and who we are going to see. Our sensory problems and adjustments for these should be understood and taken into account.”*
  - In reference to not being given sufficient information ahead of a Covid vaccination *“Why they could not have told me [that there would only be four people present] when I told them I was concerned about long queues and lots of people being there (potentially increasing the risk of catching the virus at the vaccination centre), as this would have avoided much distress I have had from last week until today.”*
  - Things like videos, walk-arounds (like Google street view, but within buildings) and similar orientation material can be incredibly helpful for people to feel well prepared when accessing services, this is applicable to a huge variety of places including hospitals, GP surgeries etc but also in the wider community too. Some tourist attractions do this, presumably often as a promotional tool but can be incredibly helpful for people visiting who benefit from having an idea of what a place is like before visiting.
  - *“Video clips to help people prepare, orientation visits [are] really helpful for mental health, was a project in my hospital for cancer treatment but this was stopped because there were no observed change/improvements in the cancer treatment side effects and symptoms. There was no holistic patient centred approach in the decision to abandon the project. Services forget that mental health and physical health linked. It made a huge difference to our anxiety and we were much better prepared.”*

- **Orientation is important, and awareness that autistic people may need increased support with finding their way around a place, as particularly in stressful situations this can be a difficult thing to grasp.**
  - 'Meet and greet' on arrival may be helpful
  - *"I really struggle to find my way around places, medical places especially. It's okay if someone comes out to meet me but otherwise, I don't know how to work out where to go and often can't find my way back out! Feeling anxious which I always do when going to appointments makes this even more difficult for me."*
- **It is also important for people to feel that they have enough time in appointments, and it would be good if appointments could be longer, or flexible, to allow for preparation (getting into the room and feeling settled enough to begin interacting rather than being rushed into it) adequate understanding of the content of the appointment, and adequate time for 'wrapping up' at the end.**
  - *"Needing more time to read and understand paperwork that is shared with me."*
- **Consideration needs to be given to the fact that providing a range of access options may improve accessibility, e.g. allowing people to access the service face to face, by phone, online etc.**
  - These access options need to be set up to be as 'autism friendly' as possible, e.g. not having a long block of automated speech at the start of a call, or long wait times on the 'phone.
  - *"My main problems with accessing services are to use a phone, instead of e-mail or web-based alternatives, that overload callers with often, useless information. I rarely use a phone anymore because of this, which stresses me before I speak to someone. I usually now, rely on my wife to ring them."*
  - 'Need alternatives for communication, as face to face talking is not always the most appropriate – text and or writing down.'

- **Environments can create sensory overload and reasonable adjustments may need to be made. Places offering diagnosis (or indeed other autism services) need to be sensory friendly and not distracting, but there also needs to be an awareness of other needs, e.g. lit well enough for those with limited sight. There needs to be an awareness of diverse and varied sensory needs.**
  - Passports are felt to potentially be useful particularly in informing those involved with care of sensory needs, and they may help to reduce the trauma that can occur if needs aren't recognised.
  - 'It is suggested that 'clinical' environments should be calm and minimal. Particular reference was made to the context of diagnosis/ assessment, as environments can influence how people present.'
  - *"[A good service] ensures each individual accessing the service has all the knowledge, support and any reasonable adjustments that they need are made so they are able to access the service as easily as possible."*
  - *"[A good service] considers the physical environment of consultation rooms carefully, for example, just the removal of a ticking clock from a room could make a huge difference, and it considers any sensory equipment that may help to make the environment more comfortable."*
- **Assumptions should not be made about a person's capacity to attend appointments in person.**
  - *"When you've got psychiatrists that say because your child doesn't have a physical disability they can come to a clinic..." It would be beneficial for professionals to have more awareness around this and how people can be supported/ adaptations can be made.*
- **There should be provision within services to support those who communicate via AAC (Augmentative and Alternative Communication)**

# Diagnosis

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Many feel that going through a diagnostic assessment to receive an autism diagnosis is essential in allowing them to better understand themselves, and often an 'official' diagnosis is needed to allow access to certain support services. Ideally, access to a diagnostic assessment should be available to all those who need one. Some autistic people choose to self-diagnose; this is valid, however it can cause difficulties in accessing support if needed, and unfortunately is sometimes a decision made out of necessity as result of people being unable to access a diagnostic assessment.

It is clear that presently diagnostic process can vary across areas, with assessments being carried out by different clinicians, over different durations and using varied methods, and that diagnostic assessments aren't set up to be sympathetic to the diverse ways in which autism can present. We have had some really valuable feedback from Experts by Experience looking at what a meaningful diagnostic assessment would look like in an ideal world.

# Accessing Diagnosis

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## Key messages

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- **Wait times for diagnosis are, almost without exception, unacceptably long.**
- **Professionals (including GPs, those working within mental health services etc) need to have adequate knowledge of the complexities of autism and how it can manifest differently for everyone, to increase the likelihood of them being able to ‘pick up on’ a person’s autistic traits and refer them for assessment, if the person wants this to happen.**
- **The pathways for referring someone for assessment must be clear and professionals must be well aware of them.**
- **People must not feel that they are having to fight for a diagnostic assessment, and there must be empathy and compassion around a person’s desire to seek a diagnosis either for themselves or their child.**

## Accessing Diagnosis Feedback

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- **Almost without exception people report that wait times are unacceptably long between being referred and having a first assessment appointment. These need to be reduced, but in the meantime, people need to be kept updated about what is happening with their referral.**
  - *“[In an ideal world] because of extended waiting times, the service provides updates to individuals to help them to manage their expectations and concerns about when they may be able to access the service. The service is very transparent throughout the whole process about waiting times and expectations of the service and what is available, which builds trust.”*
  - *“[In an ideal world] the service provides early intervention and minimal wait times to access the service to help to reduce the likelihood of individuals getting stuck in a cycle of needing to access mental health services, and potentially hospitalisations which can be very traumatic. Where there are long wait times, could there be a dedicated part of the service that could provide a certain degree of support to the individual, like a dedicated helpline/ web chat that can provide signposting etc?”*
  - *“I was referred 23 months ago. The GP did not know where to refer me, I advised him after speaking to [a local charity]. 7 months later I filled out a huge booklet giving what felt like my life story. I called around April time this year and was told I was on the list but not a priority because [of where I am located.] Then had a brief letter around September to say I should be assessed around April next year.”*
- **Those with capacity to refer for diagnosis need to have adequate knowledge of the complexities of autism and how it can manifest differently for everyone. There needs to be greater awareness of autism so that there is a chance it can be ‘picked up’ and a referral for assessment made before people reach crisis point, which is something which often seems to happen (e.g., someone with longstanding mental health difficulties reaching the point of being admitted to inpatient services before autism is considered)**
  - *“I was denied an assessment as I was told I didn’t look autistic.”*
  - *“Healthcare professionals referring individuals such as GPs [should] have up-to-date knowledge of the autism service so they can refer an individual in an informed and timely way.”*

- *“I will always be grateful to the psychiatrist I saw who picked up on my autistic traits (even though they weren’t obvious/ stereotypical, often the case in late diagnosed females) and recommended that my GP refer me for assessment (this was also helpful, as I didn’t have to persuade my GP to refer me myself). I know if it hadn’t been for that I wouldn’t be in the position I am now of being able to understand myself and why I experience life in the way I do. Being able to be diagnosed was life changing for me and I know if I hadn’t been lucky to see someone who ‘spotted’ my autistic traits things would be very different for me today.”*
- *‘[Ideally] people would be much more aware of the different types of presentation of autism. This would help prevent institutional traumas/misdiagnosis.’*
- *“[I was] bounced around within mental health services and no-one picked up on it.”*
- *“Autism is not picked up on by GP’s, [counsellors], or any of the services I encountered.”*
- *“At outset of an individual experiencing difficulties in their life, it would be good if people asked questions and considered autism early on rather than waiting for crisis/admissions to inpatient services.”*
- **Consideration needs to be given to how autistic people might be ‘picked up’ earlier so that autistic people could potentially better understand themselves and receive support, if necessary, which may alleviate the possibility of reaching crisis point. It can often be difficult for those who have passed through life without ‘seeming autistic’ to get a diagnosis in later life. Consideration should be given to how these people might be able to be ‘picked up’ and supported in being assessed and supported if they wish to be.**
  - It is suggested that people often find places they fit in (it is said that they may be accepted as ‘eccentrics’ in these places) which ‘masks’ their autism. Sudden massive change or challenge brings problems to the fore sometimes leading to crisis, many people only find out that they are autistic at this point, then suddenly so much makes sense. Earlier identification could help with crisis avoidance.
  - One of the challenges is that people may not be presenting to services (including GP etc) so therefore not presenting to people who may be best placed to ‘pick up’ on the possibility of autism. There may need to be a creativity of approach, raising awareness of autism through different channels.

- **There is a need for greater compassion around understanding of people's desire to seek a diagnosis, and a need to understand that having a diagnosis of autism may be life changing in terms of allowing people to understand themselves.**
  - *"People are seeking a diagnosis for confirmation of difference not fault, diagnosis implies something to be cured."*
  - *"In autism groups I hear of so many people not being believed or even in a couple of cases being laughed at by their GP when they raise the subject of neurodevelopmental issues (ADHD or autism) and ask if they might be referred for assessment, it's heart-breaking."*
  - *'It was mentioned that there is often a common barrier of, as one participant put it "are you sure? Being treated a bit like a hypochondriac"'*
- **That said, there also needs to be consideration of what a person wants. There may be situations where a healthcare professional wants to refer for assessment, but this is not actually what a person wants.**
  - *"Took two years of reading before I decided I was going for assessment which is how I wanted to do it."*
- **GPs and other professionals with the capacity to refer must have adequate knowledge of available diagnostic services which they can refer to.**
  - *"...makes sure that the healthcare professionals referring individuals such as GPs have up-to-date knowledge of the autism service so they can refer an individual in an informed and timely way."*
- **People should not have to feel they are having to fight to access diagnosis (for themselves or someone in their care)**
- **It is noted that sometimes referrals for assessment are refused by diagnostic teams.**

# Diagnostic Process

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## Key messages

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- Ideally everyone should have access to assessment by a multidisciplinary team, though in some circumstances it may be appropriate for a diagnosis to be made by one professional, as a multi-disciplinary assessment for all may prolong waiting times.
- The diagnostic process is not standardised and can vary between areas.

The diagnostic assessment process should:

- Ideally be adaptable to suit different modes of communication and be able to provide support with specific communication needs if required.
- Be reliable, with people being kept fully informed about the process and appointments not being changed or cancelled at the last minute.
- Be broad enough that it might pick up on other neurodevelopmental conditions if they are present.
- Incorporate a sensory needs assessment.
- Consider throughout how best to support a meaningful outcome.
- Provide support with processing diagnosis.
- Conclude with supported progression into appropriate support services if desired.

## Diagnostic Process Feedback

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- It is generally accepted that everyone should have access to the option of a multidisciplinary team assessment, though in some circumstances it could be possible for a diagnosis to be made by one professional, as a multidisciplinary team assessment for all may prolong waiting times.
- The diagnostic process is not standardised, from feedback we have received, it appears to vary between areas. This includes things like some people's assessments being arranged differently (e.g., some people are assessed over the course of a day, some have two or three appointments) different diagnostic criteria being used (DISCO etc) and the fact that some people are sent a booklet of questions ahead of time and some are not.
- The assessment process should be considerate of people's unique presentations of autism, e.g., taking into account how autism may present differently across the gender spectrum, or between individuals.
  - It is important for the diagnostic process to be able to pick up on the diverse ways in which autistic traits can present, but also to be flexibly able to adapt when people are struggling to engage *"My ADOS was awful not only in how it didn't pick up my traits but I was so anxious I couldn't even engage with it. I was diagnosed by 3DI in the end but I only got one as I was inpatient. It does need changing."*
  - 'It was said that the ADOS is often quite focussed on a 'stereotypical male presentation' of autism, and that there needed to be 'clearer definitions' around autism in females.'
  - *"I think the process needs to be a lot more personal, with time observation if possible ... and plenty of time afterwards for questions and support, with ongoing support as you can't think of all your questions on the very first day."*
- Some consider it is helpful to be sent a booklet ahead of time to allow time to consider answers to questions and time to process.
  - *"Yes, I did find it helpful. It was very thorough and allowed me time to reflect back on my childhood experiences and to really process what the question was asking."*

- **A diagnostic assessment should be comprehensive and meaningful.**
  - *“[Ideally] making the assessment meaningful with a prescription of services and provisions needed, identified or completed analysis, so the person can move forward, have closure or [be] directed to the service/intervention they need next.”*
  - *“Diagnostic reports should help make adjustments that are meaningful for that person [in terms of] communication, sensory needs etc; a report to state needs (this would help with PIP, MH support etc, in employment)”*
- **There is a need to consider how the diagnostic process be flexible/ adapted to suit different access needs and communication methods (face to face, phone, Zoom etc)**
- **The SHAPE report identified that signposting post diagnosis doesn’t really work. Thus, at the end of the diagnostic assessment, any referrals for post diagnostic support need to be supported and managed. People shouldn’t be left on their own post diagnosis and should be appropriately guided into support (if they wish) but it is also important to be mindful that some may not immediately want to access support.**
  - *“Signposting has to be more than just pointing... you need to be supported along the way.”*
- **The diagnostic process should be reliable and try to avoid making changes (such as cancelling appointments, or changing the location of appointments) last minute, as this can be extremely unsettling in a process which is already stressful.**
  - *“I had four appointments cancelled/ postponed during the course of my assessment process, two (which were on one day) on the same day. I found this very distressing, as I don’t cope well with last minute changes and had spent a long time ‘building myself up’ to these appointments. I later found a friend who had been diagnosed by the same service had also had two cancelled on the same day.”*

- It is thought to be beneficial to ensure that people are well informed about the assessment process. It may be beneficial for people to be sent ahead of time a leaflet with clear information about how the assessment will play out, photographs of the location and if possible, photographs of and information about the clinicians too, to reduce feelings of uncertainty around the situation. It would also be good to use this as an opportunity to invite people to phone beforehand to ask questions, and provision should be made to accommodate this.
  - *“[In an ideal world] Professionals inform you in advance about what to expect at an appointment e.g., a little bit of basic information about who you are seeing, what will happen at the appointment, and what might help you to prepare. An individual is informed as soon as possible if there is going to be a change to any scheduled appointment or details.”*
- A diagnostic service should make themselves aware of a person’s unique situation and should consider early in the diagnostic process how best to support a meaningful outcome.
  - *“[In an ideal world] The service looks at why a person is seeking an autism assessment, not just because the individual recognises that they have certain traits so could be autistic, but they are asked why being assessed for a diagnosis is important to them and how they feel it will help them in their life moving forwards. A good service would then use this to help lead to a meaningful outcome post-diagnosis.”*
  - *“The service [should provide] practical and educational support to assist in making the diagnosis process meaningful and to help the individual to translate the information gleaned from diagnostic, sensory and occupational assessments into their everyday life, developing a toolkit of strategies and developing skills to assist in everyday life.”*
- The diagnostic service should be aware of a person’s need to process the outcome of an assessment, whether a diagnosis is given or not.
  - *“[In an ideal world] The service provides not just either confirmation, or not, of an autism diagnosis, but emotional support to come to terms with this, either way. This links with the point of autism-specific counselling, to process the potentially mixed emotions around this.”*
- People should not have to push for post diagnostic support or be solely responsible for seeking their own.
  - *“It’s great to go to [a local support charity] but [accessing that is] another hurdle in itself and it would be good to have support which is immediately and automatically accessible. When my son was diagnosed I was told about [a local support charity] and recommended a couple of books - not good enough, I felt like I was drowning!”*

- **People should be supported through the diagnostic process and not left alone to deal with what can be a difficult process.**
  - 'Assessment process is very lonely'
- **There should be staff based within assessment services to support specific communication needs.**
  - 'Skilled support staff within assessment centres – appropriate environments. Speech and language therapists and communication tools e.g. Makaton etc. to find out best way of communicating.'
- **It is felt that it would be beneficial for the assessment to be broader, to encompass the possibility of picking up on other neurodevelopmental conditions.**
- **A sensory needs assessment/ sensory profile should be part of an assessment.**
  - *"Everyone diagnosed should get a sensory profile, even if not having meltdowns etc sensory issues will always come in"*
  - *"Absolutely agree re the sensory problems. Can't be diagnosed as autistic without sensory issues. It's a red flag for me when I work with a client/patient that means that I then explore further, usually the autism becomes clear."*

# Autism Specific Support

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We have had some really valuable feedback from Experts by Experience around what autism specific support is considered to be beneficial, and how that is best delivered. This section looks at four areas:

- How support should be approached, and key principles for provision of support.
- The most effective ways support can be delivered.
- Specific support content which is felt to be beneficial.
- Support provision for those with specialist needs.

# Autism Specific Support - Approach and Principles

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## Key messages

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- There should be a focus on 'getting it right first time'
- Services should be aware of their remit, to ensure they are confident that they are best placed to offer support for a person.
- Support needs to be respectful, proactive and empowering. Forward focussed, but not ignoring or denying the challenges that living as an autistic person can bring.
- People should not be made to 'fit into boxes' – support must be person centred and personalised, and it must be understood that people will have very different support needs.
- Support must not be time limited and should be flexible to take into consideration the fact people's support needs will vary over time.
- Support services should be cautious not to teach people how to mask and 'fit in' and shouldn't try to make people 'less autistic'.
- Those who are self-diagnosed or have a private diagnosis should not be excluded from being able to access support.
- It is important that there is adequate provision of support for families of autistic people and that when they have a good idea of what may help those in their care, they are listened to.

# Autism Specific Support Approach and Principles

## Feedback

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- **There should be a focus on ‘getting it right first time.’**
  - Importantly, this would potentially reduce the risk of crisis, admissions and the traumatic results of that.
  - Getting it right first time could also save resources.
- **Support services should possess an awareness of their remit, and know how to guide an individual into another service appropriately and effectively when they realise they are not best placed to provide support with a specific issue.**
- **Support needs to be respectful, proactive and empowering.**
  - *“[In an ideal world] The service allows the individual to be in the driving seat as much as possible regarding their support, as the expert of their own experiences, leading to an empowering experience.”*
  - *“The service acknowledges an individual’s difficulties, treats them with dignity and respect, and does not just focus on these difficulties; an individual’s potential and strengths are equally recognised, whilst not undermining the struggles.”*
  - *“...positive engagement/ collaboration with a service also creates a mental template for any future interactions with other services.”*
  - *“We are always talking about the negatives which is demoralising, we need to focus on the positives and examples of where it is working really well, it gives you hope.”*
  - *‘Thought needs to be given to how people are effectively being disabled with attitudes and comments, and how attitudes and understanding/ knowledge could be improved to be enabling instead.’*
- **Support should be growth/ forward focussed (but must also not deny or ignore the challenges that living as an autistic person can bring.)**
  - *“a strong, holistic, consistent service allows me the opportunity to grow confidence in my abilities to manage day-to-day.”*
  - *“[In an ideal world support should make me feel] positive about my autistic traits and what I can bring to the world.”*
  - *“[in an ideal world support should make me feel] optimistic about my future living and engaging in society as an autistic person.”*

- *“The service acknowledges an individual’s difficulties, treats them with dignity and respect, and does not just focus on these difficulties; an individual’s potential and strengths are equally recognised, whilst not undermining the struggles.”*
- *“... the strengths and benefits should be known and shouted about! However, I do think the issues we face are ignored and not supported too - there has to be a balance.”*
- *“the support in the first place, and then promoting strengths when the support is there.”*
- *“Many autistic traits are a positive aspect in society, such as attention to detail”*
- **An approach which doesn’t require people to ‘fit into boxes’ is essential, either ‘boxes’ set up by the service themselves, or ‘boxes’ set up by the rigid ideas of a particular member of staff.**
  - *“[There should be] A willingness to be flexible and engage with patients”*
  - *“My son has had various support workers during his life - he had a good OT when he moved into supported living, she gave him time and listened. We tried recently to get another OT to work with him but she had a different approach her way or no way.”*
  - *“Lots of services that try to fit square peg (autistic) into round hole (NT methodologies not suitable for [autistic people])”*
  - *“Once in service – in a sausage factory and pushed along pathway whether appropriate or not.”*
- **Support must not be time limited. Autistic people should be fully engaged in any support process and should guide the pace. It can take time to build up trust to allow a person to feel they can engage. If they are not given this time, and a service is of the opinion that they cannot help if the person won’t engage, the person may be discharged from the service prematurely on unreasonable grounds. It is suggested this may be a particular problem with children’s services.**
  - *“[Support] should be sustainable, long term, nurturing, aiming for self-resilience and self-management. This means a long term budget and commitment.”*
  - *“My son [who is] 36 struggles and loses faith in people especially if what is offered is time limited. He needs to be regularly reminded of strategies of how to deal with life.”*
  - *“There’s no ongoing support for children where we are either. The diagnosis is last meeting.”*

- *“[There is a need to] acknowledge that people on the spectrum need time and don’t immediately settle into having a heart to heart.”*
- *“[Only] six sessions for people on the spectrum[?] they may need 6 sessions to start trusting the professional before they can start to interact.”*
- *“Too many services rush through things, set time limits, don't respect that people fit to them or can do so. Might mean a person comes for several months then starts to contribute. Time is a very important thing, decided by the person. Not prescribed.”*
- *“Contact with support is time limited and autistic people tend to need more time to build up trust and to feel supported [they] cannot be rushed and need to go at the pace that person needs, not pressured into employment or pressured to open up during treatment.”*
- *“[Support being time limited] can limit the building of trust and relationships. Adds pressure on the individual to comply. Can be very damaging.”*
- *“These things borne of time and trust...”*
- *“Services with time limits or confined inclusion criteria limit access to service.”*
- *“You get a [speech and language therapist] initially at time of diagnosis but then they disappear, leaving you to manage on your own.”*
- *‘If you are blind and you have a guide dog and you then stop bumping into things, you don’t say that’s fixed now and take the guide dog away! Some people will need to be able to access some help and support throughout or at different points in their lives.’*
- *It is beneficial if trust and familiarity can be established before expecting people to engage or ‘open up’. An EbE spoke about her good experience with a local organisation - “I knew my support worker before she was my support worker- I would’ve been too anxious to meet someone I didn’t know already”*

- It also needs to be understood that support needs may vary over time. For example, some autistic people may need support pre diagnosis, some may need it immediately afterwards, and some may need it months or years later (or any combination of these) Provision for this needs to be considered.
  - *“what people need in post diagnosis won’t necessarily be ongoing.”*
  - *“20 years down the line and I’m still learning about what autism is to me.”*
  - *“some people want social groups, some are diagnosed then need support five or six years later.”*
  - *“it can take 12 months for people to acknowledge what their diagnosis means.”*
  - *“People will likely feel they would benefit at different time points from support post diagnosis. Some may need that immediately, for others later, and for some it will need to be revisited on and off.”*
  - *“Ideal situation is to make [services] available for the person to come to when they are ready, they call the shots.”*
  - ‘The example given was of this person’s son and the work that she was doing to develop his independence, ability to self-manage and to empower him. Whilst she felt that transition was important, he might need more support at a later age and throughout his life’
  - It has been suggested that an ‘open door’ policy may be good, allowing people to ‘hop in and out’ of a service once they are diagnosed. There were concerns about how this would work in terms of capacity raised, so this would need to be considered, but one EbE noted that in the service she is familiar with, because people’s needs are so diverse (support needed and when) things tended to ‘level out’.
  - There may be critical points at which specific support is required such as transition, employment, bereavement.
  - With this in mind, it must be considered that then people might miss out if they don’t access support immediately post diagnosis, because they cannot initiate engagement with services. To help with this, it may be beneficial to open up as many different forms of communication as possible for a person, and to also engage with their GP and/ or family, ‘putting tendrils out’ to initiate contact with those who may feel unable to initiate or who ‘shut themselves off from the world’. Not to miss people who are ‘hidden’.

- It goes without saying that there needs to also be awareness around people's individual support needs, which will of course vary enormously. Some may need substantial support input, others may just require a brief drop in for advice about employment for example, and as previously mentioned support needs are likely to vary over time. Support needs to be adaptable to accommodate this. A personalised, person-centred approach is essential.
  - A passport to services is considered to be something which may be beneficial in supporting this. This would include information about an individual's specific autistic traits, the needs arising from these and potentially information about support previously accessed. This would allow anyone working with an autistic person to quickly familiarise themselves with key points and thus allow them to provide a personalised service.
  - 'One participant who runs a charity mentioned how they profile their clients so that they best know what they need and how they can be helped.'
  - *"[A support service] needs to be flexible to take into account the diverse and varied needs of an autistic person - a holistic approach to the person, not the pathology, meaning a variety of tools, therapies and services would be offered, not just a 'one size fits all' nor 'single method' service."*
  - *"[An ideal support service] sees each individual as a unique person; it does not adopt a 'textbook' approach. The service asks the question, 'What do you as an individual want to achieve from accessing the service and in wider life?' The service is then able to incorporate these goals into personalised care planning."*
  - *"[An ideal support service] is able to acknowledge that whilst an autistic person may be able to engage in some form of work and certain everyday activities/ tasks well, this does not cloud the areas they may still face significant challenges, or vice versa."*
  - *"[An ideal support service] looks at the individual as a whole person, not just at one portion of their life. It addresses all areas of their life, whether it be communication difficulties, sensory difficulties, isolation, work, education etc. linking with other services and organisations where necessary."*
  - *"[An ideal support service] is able to assess and provide a clear pathway and care plan that can be adapted along the way if needed, to help the person to reach towards their own personal goals and to thrive."*
  - *"A good integrated pathway, a life pathway which adapts."*

- *“People being prepared to listen about what support is needed; not being so prescriptive. Being person centred, changing needs.”*
  - *“Acknowledging that autistic people may not fall into acceptable routines.”*
  - *“... the responses to people [have] to be individualised and people have to have the skills to be able to flex and nuance their support and advice to people according to their needs and personality.”*
  - It is essential to be aware that the content of support needed will vary enormously. Some autistic people may need support with understanding empathy for example, but some would not. Being aware of this will avoid approaching situations with a stereotypical view and allow each person to be worked with as an individual.
- **The best way to present knowledge needs to be considered.**
    - *“The style of knowledge presentation is important as any suggestion of patronising or condescending behaviour will immediately alienate and switch the focus of attention to feeling angry. Coaching is probably better than teaching.”*
    - When considering support and information delivery, there needs to be awareness around the fact that some autistic people may understand things differently to those who aren't autistic, e.g., taking things literally.
    - *“There is a need to teach in a ‘language which people on the spectrum understand’, have responsibility of acting as translator”*
  - **Support services should be cautious not to teach people how to mask and ‘fit in’ and shouldn’t try to make people ‘less autistic’.**
    - *“there is skill to supporting someone to be more independent and helping someone towards more confident social engagement, without doing it in a way that just tries to make them ‘fit in’, or tries to make them into something they aren’t.”*
    - *‘[We should not be] trying to impose neurotypical behaviour onto autistic people.’*
  - **Support shouldn’t be ‘fully immersed in a medical model’**
    - *“The NHS model is you get ill and you get fixed... but autism is not an illness. So access to low level support always is so helpful. Having someone to check in with me if I don’t arrange an appointment or make contact.”*
  - **It also needs to be considered that some people who are autistic may not want to be, or may not have been, diagnosed, and their support needs should not be disregarded because they don’t have an ‘official’ diagnosis.**

- Lack of or poor support in any area can make people feel excluded from wider society.
- It is important that families feel supported. Support should be available to families of autistic people (particularly autistic children) to help them feel they are not having to 'go it alone'
  - *"[Ideally] the service provides education and support to family members, not just to help them to process their loved one's diagnosis, but proactive support to assist them in helping and living with their family member."*
- It is felt that when parents/ carers who may have a good idea of what would help those in their care, they are often not listened to.
  - *"Costs NHS £5k a week to keep daughter in inpatients yet can't get them to fund £100 a week for a therapist in the community"*

# Autism Specific Support - Provision and Delivery

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## Key messages

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- **It is considered useful for support to be provided in the following ways:**
  - **One to one advice and guidance sessions**
  - **Drop-in advice services**
  - **Advocacy services**
  - **Support groups**
  - **Supported self-help**
- **Ideally, support services would be accessible in diverse ways, e.g. face-to-face, video calls, phone, websites etc.**
- **Delivery of support via peer support is considered beneficial.**
- **There may be a need for help to access support, or helping a person to work out what support they might need.**
- **It is important to consider the support needs of those who are not accessing health, social or support services; how can these people be identified and provided with support if needed?**

# Autism Specific Support Provision and Delivery

## Feedback

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- **One to one advice and guidance sessions are often considered helpful, and can support guiding an autistic person into other areas of a support service (e.g., suggesting a social group)**
- **Drop-in advice services have frequently been mentioned as being useful, allowing an autistic person to quickly access a service and get the help or advice they need (or be directed to a service which could provide this).**
  - *Consideration needs to be given to 'out of hours' support "almost 24/7 support [is] needed. Some put a text up at 1am, if they need that they need that"*
- **Advocacy services may be beneficial to some autistic people to help them with seeking support or helping with the 'admin side' of dealing with services (phone calls etc)**
  - *"I have had to fight for my now adult son since he was a child. I have had positive experience of advocacy services supporting my son to get the right support in hospital."*
- **Although the involvement of mental health services is of course appropriate in some situations, such as where there is a co-occurring condition present, it is generally considered that autism support doesn't need to come from mental health services, particularly as the focus of these often seems to be on 'fixing' rather than supporting.**
  - *"Culture in MH is addressing symptoms and fixing. Approach for ASD needs to be about enabling, living a good life."*
- **A focus on providing ways for autistic people to build social networks (e.g., well managed support groups) is something which is broadly considered to be beneficial, as there is said to be a strong relationship between social networks and positive mental health outcomes. It is also pertinent to keep in mind that specific support groups can often be particularly beneficial, e.g. support groups for autistic women.**
  - *"I am part of an autistic women's discussion group through [a local charity] and have found it invaluable to be able to share experiences with others who have an innate knowledge of what it's like to experience life as an autistic women. It has helped me with self-esteem, self-acceptance and confidence and helped me to feel less isolated."*

- *“People seem to assume we're not sociable, rather than that we socialise differently.”*
- *“[it is good to] provide therapeutic peer support groups.”*
- ‘Human interaction has to be present in the life of neurodivergent people... we know the impact on people’s lives, where they are deprived of human contact.’
- ‘Some people just want to be around other people who understand the world as they do. Special Interest Groups available for autistic/ [neurodivergent] people to connect to [are a good idea]... opportunities for having social interactions that have relevance for autistic people.’
- Autism ‘cafes’ are often mentioned as being helpful *“the power of the cafe [should not be underestimated], the safe haven where people will unmask and feel at home.”*
- Support groups set up by autistic people themselves exist, it has been suggested that funding these could be considered. User led groups/ hubs are often considered beneficial.
- There needs to be an awareness that support groups will not suit everyone, so they should not be the only support offered *“I personally saw no follow-up post-diagnosis other than the group session that were offered... group sessions for the socially awkward?”*
- **Support groups/ charity group type situations can also potentially be very supportive for an autistic person’s family and be an excellent resource if well set up/ well run.**
  - *“I also became part of [a local autism charity] who were like a large family all of us either being on the spectrum or being a parent of someone on the spectrum.”*
  - ‘Connecting families to each other, just informally can be so powerful. Other families who have an autistic family member understand.’
  - *“Eventually I became part of local autism charities... who had a library which I could borrow books from.”*

- **It would be beneficial to be aware of the need for flexible ways to access support services.**
  - Video calls for example can be very helpful for some autistic people, as they can feel often more accessible than in person meet-ups. The COVID situation making such communication more common may have provided an opportunity to keep more online things up to reach those who perhaps wouldn't feel able to access services in person. That said, there must also be awareness around the fact video calls can feel inaccessible for others.
  - Video calling can also be good for social groups for those who may find it difficult to leave the house or socialise in person. It would be good if there could be the possibility for mixed meetings.
  - *“One of the bonuses of going online is that as many people as possible can join. When we go back into physical meetings the plan is to have a mixed meeting with some people using Zoom to attend if they want.”*
  - *“Linking to accessibility, can the service provide post-diagnostic support digitally via video calls if this is easier for an individual?”*
  - *“Also, virtual resources and a platform which could be tailored to each individual could be helpful. It can often be hard to absorb all information from appointments, and if there was a platform that a person could log onto and see relevant information such as identified strategies or resources all in one place, this could potentially help with encouraging self-help and independence, and maximising how much someone can take away from the face-to-face support.”*
  - *“Taking it a step further, in the future could a service provide an app with the facility for it to be tailored to each individual, to include things like executive functioning prompts and resources, appointment reminders, and anything relevant to their individual experience of autism to assist them with living a more independent life.”*
- **Services need to be mindful of the support needs of those living in the community who appear to be ‘coping’ but may need support. How to pick these people up may need to be considered.**
- **The concept of ‘self-help’ can be considered, but it is important that this is not in isolation (i.e., not someone simply saying “go and read this/ look at these websites” with no other offer of help) it would be good for it to be supported, e.g. one person noted that a list of websites had been suggested but perhaps not the best ones, so perhaps supporting people in seeking out other ways to find sources of knowledge (books, websites, online courses etc) may be beneficial. One participant spoke of how valuable reading books could be, with ‘things jumping out at you’**

- *“once I had a diagnosis I went to the library and got out books. [I did a] free OU course about understanding autism and LA evening courses about psychology, neurology... knowledge is a way of getting around anxiety, the more you know the more it helps you to calm down.”*
- A participant spoke of the need for information to be out there and accessible for people who weren't accessing services, or perhaps didn't need to access services as such but still wanted to find out information to support their own self-discovery. They spoke of being able to access information outside of services/ health services which wasn't impairment led and related to 'what is wrong with a person' How can people be supported to find peace with themselves but who may be outside of accessing services? Could people being able to find out more, earlier, and in a positive way, potentially improve outcomes and link to reduced need to engage with services?
- **It is felt that it would be beneficial to have autistic people employed as mentors for peer support within support services, and it would be important to consider how to support them and ensure they were properly employed/ remunerated. Peer support is broadly considered to be beneficial, but it has been suggested that those delivering peer support must be carefully chosen and also trained, as it can't be assumed that all autistic people will have the skills.**
- **It would be beneficial to make it easy to find out what support is available, there may be a need for support in accessing support (links in with advocacy).**
  - *“From my own experience with health and social care, I feel there is a lack of understanding and a failure to listen. I am undergoing an application for support via the council and the process is hard to understand as I am not fully aware of what support is offered.”*
- **Sometimes it is difficult for people to know what support they need. They may need to be supported in working out what kind of support would benefit them.**
  - *“This is quite a difficult question to answer [the question of, what help/ support do you need?] because there is something about adjusting to things being difficult... you don't know what you don't know.”*
- **It has been suggested that it may be good to explore the role of Artificial Intelligence/ technology to help people manage their daily functioning.**
- **Sometimes, when someone is receiving support for a specific issue, it may become apparent that they have support needs in other areas too. It would be beneficial for services to be set up to be able to encompass those support needs too, or to have good knowledge of who to refer a person on to, who may be able to help.**

- One non autistic focus group participant (who was involved in providing support services) spoke about providing person centred employment related support and finding that when people came to them for that, it often became apparent that they needed support in other areas, too. This quote also references the benefit of having a situation where a service is able to get to know a person over time, building familiarity so that they can be better supported *“We are only a small team in our team we work as person centred as we can we have one person per district to support people with work interviews applications. We try and be person centred, and people often have other things in life that are not work related that they need support with, because we know them well from working with them for a long time, we work with them for those issue too.”*
- **It has been said that “funding should not necessarily be ‘per head’, as complexities and durations will vary considerably.”**
- **Support provision should be adequate so that spot purchasing in exceptional circumstances should not be needed.**

# Autism Specific Support – Content

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## Key messages

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**Suggested autism specific support available would ideally include:**

- **Sensory support**
- **Psychoeducation**
- **Help with becoming as ‘self-sufficient’ as possible**
- **Support for parents/ families**
- **Emotional understanding and management**
- **Skill finding and interest finding**
- **Life skills**
- **Support with challenging life events, such as bereavement**
- **Support around making needs known**
- **Practical help with executive functioning**
- **Practical advice for neurotypical family members in understanding how an autistic relative may communicate differently**
- **Specific support around late diagnosis**
- **Financial/ benefits support**
- **Ongoing crisis avoidance**
- **Creative support options (e.g., engagement with nature)**
- **Speech and language therapy**
- **Pre-diagnostic support**

## Autism Specific Support Content Feedback

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- **Sensory support is incredibly important, and an area in which it is felt small adjustments can often create big positive changes.**
  - Support around how to cope with stressful environments (loud, bright etc) is beneficial.
  - *“If diagnosed people should be able to see an [occupational therapist] at least once. This would help with sensory issues, introduce things to support (wearing ear defenders, Powerpoint presentations looking a certain way (at university) [people] shouldn’t be actively struggling to access that service.”*
  - *“...access to a sensory room designed for all ages, as a form of therapy to help a person to decompress, benefit mental health and prevent sensory overload and crises. Tools at home such as fiddle toys, weighted blankets, noise cancelling headphones.”*
  - *“[In an ideal world] The service is able to provide access to thorough sensory assessments and occupational therapy assessments, translating the outcome of these in an accessible, informative and meaningful way as opposed to just providing a written report of information.”*
  - Sensory issues also need to be understood and supported beyond autism services, such as in workplaces *“certain impairments would not be an impairment to me if there was more understanding of sensory issues. is it a huge problem if i need to wear shaded glasses. is it a huge problem that i have to wear noise cancelling headphones. is it a huge problem that i like to wear a hat. to the workplace that is a huge problem.”*
  - *“If someone is so distressed that they are seen by people in a hospital setting, sensory issues should be the basic starting point for any conversations going forward.”*
- **A low arousal approach is generally accepted as being ideal.**
- **There is a need for good psychoeducation to be available. It is broadly agreed that understanding ourselves more, how our minds work, is incredibly helpful and perhaps it should even form the cornerstone of support.**
  - *“What is autism? What do you do with that? Where [do I] go from there? Lots will need coping strategies, quality of life assurances. Where do I go if I don’t understand? What do I do if I’m [feeling] hypersensitive? What strategies do I have there?”*

- It has been suggested it may be beneficial to help autistic people understand their 'limits' (or rather current limits, it's not to say they can't vary with time) in order to best judge whether to put self into situations which may be anxiety inducing or hard to cope with. It would be important to at the same time emphasise that said 'limits' could be expanded with time/ support.
  - *"There is something about understanding the tram lines you exist in and also understand the warning signs when you might be in danger of leaving those tram lines. Being helped to understand the parameters of your life which help keep you well and safe."*
  - Though as with all support strategies, it must be understood that this won't be ideal for all *"For some people this isn't a strategy which works... not all people cope well with boundaries! Some of us have a very resistant streak!! Interoceptive signal is poor in some people. This can only be managed through sheer brute force, but this is so tiring and can lead me to being ill."*
- It has been suggested that an area of emphasis in support might be on supporting people to become as 'self-sufficient' as possible, if they are not already and are able to be.
  - *"[This would] Help reduce the need for long term support from the state both directly and indirectly and hence reduce costs to the individual, their families and the taxpayer."*
  - *"Provide support pathway for amongst others – understanding empathy, planning for the future, eventually becoming self-sufficient."*
  - *"support people in getting to a point where they can help themselves."*
  - *"A good service makes me feel more independent, resilient and resourceful, less reliant on others - it fosters autonomy."*
  - *"[A bad service makes me feel] more dependent/ like a burden, where support needs are not met and fewer skills to manage independently are gained, it increases long-term dependency and a sense of being a burden on others/society."*
- There needs to be awareness around the importance of supporting/ educating parents in how to support, perhaps via the medium of peer support from other parents already engaged in and knowledgeable about this. Positive reference was made to a mother's work to support her son *"[the] work that she was doing to develop his independence, ability to self manage and to empower him."*

## Other suggested support content includes:

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- **Understanding emotions and empathy.**
- **Ability to think strategically in real time, how to ‘think on feet’, e.g., responding to unexpected questions or requests.**
- **Management of emotional reflexes; anger management etc.**
- **Specific support around late diagnosis.**
  - *“understanding what autism is and how it affects me and the people around me, putting into context life experiences, unpacking the past.”*
  - *“Adults diagnosed later in life [are often] left to ‘fend for themselves’”*
    - It is felt that there is a particular deficit of services for late diagnosis.
- **Skill finding/ creating skill profiles (useful for employment)**
- **Life skills (linking back into the idea of helping people to become as self-sufficient as possible)**
- **Practical advice about how to deal with things such as phone conversations.**
- **Support and advice around making needs and preferences known (e.g., if you don’t like to be hugged/ touched)**
- **Practical advice for partners and families around communicating with autistic family members.**
  - *“...giving advice to those individuals about how to react or respond if an autistic person appears to be tactless e.g. honesty is what people say they want but in reality neurotypicals actually use tactful honesty.”*
- **Encouragement/ support in finding interests and not feeling pressured to do/ enjoy things which may be hard to cope with.**
  - E.g., from a focus group ‘if you find parties difficult that is ok, but enjoy museums as much as you like’
- **Practical help with executive functioning**
  - *“Some practical help where executive functioning might be difficult for a person... I had a good social worker to support me with this.”*

- **Support and information around finances and management of them.**
  - The benefit system can be particularly hard for autistic people to navigate. Advocacy and support services that can help with this can be beneficial both in terms of helping people to understand the system and what might be available to them and helping with practical tasks like filling in forms.
  - *“Accessing the benefit system is so hard for some people... just facing the process is too overwhelming.”*
- **Help with food provision/ cooking**
  - *“In an ideal world I wouldn’t have to think about cooking food... a café project that is available all day has really helped some people with this.”*
- **Ongoing crisis avoidance/ support, this can be strengthened by communication and building a rapport, creating a ‘go to’ service or person who a person can access.**
- **Creativity of support is important and considered beneficial, e.g. something like contact with animals/ nature could be as beneficial for someone as an hour of therapy. Finding activities relating to interest and supporting engagement can be beneficial, and ‘thinking outside of the box’, particularly as some may find conventional therapy challenging to engage with. Social prescribing is highly relevant here, as this is something which may provide access to creative forms of engagement and support (e.g., a gardening club, canal walks)**
- **Speech and language therapies should be available to support all age points if required and shouldn’t be limited to children and young people.**
- **Diagnosis is important but getting a diagnosis can take so much time, waiting lists are getting longer in many areas, and waiting for that diagnosis can end up being damaging. It was suggested that support being available as soon as something was noticed would be beneficial, with a diagnosis not being a prerequisite for being able to access any support at all. It was suggested that “Individual components can be supported in mean time” Diet, sleep and managing anxiety were given as examples, and from other areas of discussion it is evident that providing some form of sensory assessment and support in the meantime could be extremely beneficial too.**

# Autism Specific Support - Specific Needs

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## Key messages

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- **There is a need for there to be professionals with an understanding of specific needs within autism services, and a need for professionals with an understanding of autism within specialist needs services. Specialist needs referenced by the focus group include:**
  - **Eating disorders**
  - **Addiction**
  - **Selective mutism**

## Autism Specific Support Specific Needs Feedback

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- **It would be beneficial for there to be people with specialist understanding of specific needs within autism services, or people with knowledge of autism within other services (e.g., eating disorder services)**
  - *“eating disorder, gender dysphoria; making sure there are ‘champions’ of these areas in teams to allow people to access ‘the gold standard’ [of specific support] in a way which is meaningful”*
  - There needs to be sufficient awareness of, and support for, eating disorders (such as anorexia, ARFID) in autistic people.
  - *“I do think that there are several other specialist areas like sensory or food that also need to be considered as part of coming up with any care plan. Not even asking about them [in the context of service planning] creates an unnecessary gap.”*
- **The importance of having services for or inclusive of selective mutism has been mentioned, or at the very least those working within services should have good understanding of this and how to work with those who experience it.**
- **Addiction needs to be understood and addressed in relation to autism, how addictions may’ve developed as coping mechanisms due to difficulties and often a person feeling like they don’t fit in in the world.**
  - *“...using meds and alcohol to manage anxiety and the permanent sense of otherness.”*
  - *“Addiction is a coping mechanism to not understanding the whole world around you.”*
  - *“I am currently promoting autism addiction support in [my local area]. Prevalence is much higher than might be expected.”*
  - *‘It needs to be understood that people can often have ‘functioning addictions’*
  - Addictions such as gambling and gaming need to be acknowledged as well as alcohol and drug addiction.

# Mental Health Services and Support

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A subject frequently raised in focus groups is people's experience of mental health services. Autism is a neurodevelopmental condition, not a mental health condition, but many autistic people will have co-occurring conditions which will mean they will have contact with mental health services. Unfortunately, it is felt that there is a pervasive lack of understanding of autism within said services, and this lack of understanding is rarely conducive to provision of suitable, effective support.

We also frequently hear from Experts by Experience who, when accessing mental health services before an autism diagnosis is in place, are often initially misdiagnosed with other conditions, when actually the 'core issue' is that they are autistic. This can mean that they often experience prolonged and unnecessary distress which could be ameliorated by an autism diagnosis being made earlier. This in turn would potentially allow them to access appropriate support in a timely manner which is likely to improve outcomes.

Conversely, where an autism diagnosis is in place, it is often the case that any mental health difficulties a person may experience are 'explained away' as being related to autism. This is called diagnostic overshadowing, and fails to take into account that people can be autistic yet also have accompanying mental health diagnoses such as depression, anxiety and OCD. Indeed, mental health conditions are unfortunately particularly prevalent in the autistic population.

## Key messages

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- There needs to be a significantly improved understanding of autism in mental health services.
- It is crucial that those working within services are knowledgeable enough that they can understand and support people's autistic needs appropriately, and do not resort to over-medicating.
- Mental health services need to be more easily accessible to autistic people, ideally available to 'dip into'
- It would be beneficial for adaptable, 'autism friendly' counselling to be available.

### Co-Occurring Conditions and Diagnostic Overshadowing

- Misdiagnosis is common, and this needs addressing. People are often diagnosed with conditions such as depression, anxiety, bipolar disorder and, very commonly, personality disorders when actually the 'core issue' is that they are autistic. It is not to say that autistic people cannot also experience mental health problems, they are common in the autistic population, but it is important that autism is not 'missed' and a different, incorrect diagnosis made instead.
- Frequently autism is only identified after someone has entered a crisis situation, often largely as a result of autism not being 'picked up on' earlier.
- Diagnostic overshadowing is a common problem; attributing all of people's difficulties to the fact they are autistic, rather than being willing to look at the complex picture and consider that there may be co-occurring conditions which if identified, could allow the person to receive more targeted and effective support. Autistic people experiencing mental health difficulties are sometimes unable to access the services they need, due to all of their difficulties being 'blamed on' autism.
- Autism commonly occurs with other neurodevelopmental conditions such as ADHD and dyslexia. It has been suggested that it may be beneficial for autism services to be neurodevelopmental services, rather than autism only.

## Mental Health Services and Support Feedback

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- **There needs to be a significantly improved understanding of autism in mental health services, as lack of understanding and subsequent poor treatment which can result from this can be traumatic.**
  - *“The psychiatrist admitted every time we met him, he knew nothing of autism and although pleasant person was not really helpful.”*
  - *“The voices of autistic people are missing from so much in mental health services.”*
  - *“...have had terrible experiences with mental health teams and social services who are terribly ignorant, and it's traumatised them. I wonder how many autistic people are carrying trauma from the mistreatment caused by people who are supposed to be helping people.”*
  - *“I don't think trauma from being misunderstood by services is taken onboard enough at all.”*
  - *“...I want to talk about when an autistic person needs mental health services. This junction is very poor – mental health services don't understand. Or say you need to go to autism services... but they don't exist.”*
  - One participant noted that they felt the attitude of a psychiatrist they had encountered had been *“appalling and abusive”* that this attitude risked *“re- traumatising autistic people in acute services”* and that *“people [are] getting more sick as a result of lack of understanding and dare I say ‘neglect’”*
  - One participant spoke of how she felt that psychiatrists don't go into the profession wanting to do bad jobs, but they are often negatively influenced by the culture of large trusts *“the culture almost teaches people that autism is a one criteria, there is no understanding of the spectrum, they don't understand the spectrum.”*
  - One attendee spoke of an experience with her daughter which was extremely negative. She was not communicated with clearly and was told a phone appointment was just a discussion, she was later told it was in fact a diagnosis. The next appointment she was given happened at short notice, which didn't give her time to get an advocate to support her. She reported that the psychiatrist talked over her, implied they knew lots about autism and that self harm was a trait of EUPD, not autism, as, they said *“most autistic people don't self harm”*

- One participant spoke of a friend who'd visited a psychiatrist some years ago; said friend mentioned that it was on her notes that she was autistic, and the response of the psychiatrist was *"you can't be autistic, you can speak"* another participant spoke of a 57 year old woman who had been told *"[you] couldn't possibly be autistic, you've got married and had children."*
- 'One participant said that there is 'myth and nonsense in mental health services at many levels' and gave an example of someone being told *"you can't be autistic because you can make eye contact"*
- **It is crucial that those working within services are knowledgeable enough that they can understand and support people's autistic needs enough that they do not resort to over medicating (see STOMP-STAMP, and this needless to say is crucial in adult as well as CYP services)**
  - *"we nearly lost our daughter many times. Just keep upping anti psychotics even though [it] was autism needs not being met causing ideation."*
- **It would be beneficial to be able to 'dip into' mental health services. It seems that mental health services are challenging to access, with referrals often taking a very long time and a feeling of 'doors being closed' after discharge.**
  - *"I was grateful that a psychiatrist I saw picked up on the fact I may be autistic and suggested a referral. Unfortunately following this I was discharged from the service and was left with a feeling of doors having closed when I felt I still needed support around my mental health in ways which weren't simply solved by having an autism assessment. The only way 'back in' would've been to try to persuade my GP to refer me again, which had already been a traumatic experience."*
- **Autism specific counselling, with counsellors who understand how they might select and adapt modalities to 'fit' with the way someone's mind works would be beneficial. Consideration also needs to be given to the fact that certain therapy approaches won't work for everyone (can't be a one size fits all approach) for example, CBT may help some, but is frequently referenced in focus group discussions as being not particularly 'set up' for the autistic brain unless it can be adapted. The other issue with CBT is that it's often very time limited (e.g. six sessions) It has been suggested that there needs to be a fundamental rethink of why some approaches don't work in some cases, and what might work better.**
  - *"[In an ideal world there are services which can provide] counselling tailored to the needs of an autistic person, that may be more appropriate than accessing IAPT. E.g., a counselling model that allows extra processing time."*

- *“It was suggested I do a CBT course with a local counselling service whilst I waited for my assessment, but I just didn’t understand how to apply it to my situation and the service seemed to be determinedly intent on getting people to fit into boxes. I had to choose whether I wanted to work on my OCD or depression.”*
- *“My personal thought is that CBT just goes completely against the grain of the autistic brain. Doesn’t get to the detail, and was completely illogical!!...”*
- *“I much preferred counselling where facts were discussed - the counsellor [discussing how I was likely to have been affected by my past] ‘so this caused that, and that caused this, so now we can crack on with healthy acceptance now that you know the detail!’”*
- *“CBT that does not acknowledge the different-ness of autistic people is just another form of ‘normalisation’ which can harm.”*
- **There is felt to be a need to look at opening up pathways for appointments with psychiatrists to be accessible. Quite often it is difficult to get to see one, and people must be very unwell or presenting in a particular way to access an appointment with one, where it may be beneficial for them to see one sooner (providing the experience they subsequently have is a positive one).**

## Co-Occurring Conditions and Diagnostic Overshadowing

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- **Misdiagnosis (people being diagnosed with conditions such as depression, anxiety when actually the core 'issue' is that they are autistic) is common, and this needs addressing.**
  - *"[mental health] issues in autistic people are made worse due to trauma because they're not diagnosed or supported - many of us are likely to have mental illnesses as co-morbidities but it's arguable it could be far less with proper support."*
  - *"I believe the lack of knowledge [of autism] within mental health services has really affected his whole life."*
  - *"From personal experience, the breakdowns I have had (and reactions by services to these) could have been avoided though if autism had been recognized at an earlier stage. Poor [mental health] and [mental health] services would not have been present if there had been understanding in place. For example, a meltdown at work has now been avoided since diagnosis, as my employer has been able to adapt."*
  - *"... bouncing around mental health diagnosis from teenage hood before I met a psychiatrist in 2017 who listened to me and said, 'You're autistic and I'm sending you for diagnosis'"*
  - Another participant spoke of how damaging it had been for their son to be 'passed from pillar to post' without receiving a diagnosis or appropriate support *"my son was diagnosed with traits of autism as a teenager, entered mental health system psychiatrist didn't understand him and sent him to the best (a local service) had, he was then diagnosed with anaclastic personality disorder, later seeing a third psychiatrist he was diagnosed with Asperger's - this has affected his whole mental wellbeing"*
  - 'The difficulty of labels/ diagnoses 'sticking' was mentioned (i.e., if a misdiagnosis is made, it's hard for it not to 'stick' even if subsequently a more appropriate diagnosis is made)'
- **It is frequently mentioned that autism is only identified after people have entered a crisis situation.**
  - *"so so many of us who are picked up as teenagers are only picked up because we go into mental health crisis"*
  - *"Don't get [a diagnosis] until meet crisis then sent hundreds of miles away to non-autism trained [Assessment and Treatment Units] which do untold damage. Early help needed."*

- **There is a need for greater understanding around the diagnosis/ misdiagnosis of personality disorders in relation to autism.**

- ‘There increasingly, seems to be a pattern within psychiatry of people, particularly young girls, entering adult services from CAMHS being diagnosed with EUPD on top of autism (and sometimes ADHD)... it was suggested that the EUPD diagnosis is used as it allows people to be sectioned. It was said that there is a worrying trend of young people particularly being diagnosed with personality disorders. Another participant noted that this has been reported elsewhere, too. Concerns were raised in relation to this around how the mental health act is being applied.’
- ‘Another participant spoke of how she was diagnosed with EUPD, then eventually PTSD, which they felt was more accurate (than EUPD) as PTSD is common in autistic people. It is so important to get a diagnosis right, and can be extremely damaging if this doesn’t happen.’
- ‘The psychiatrist talked over her, implied they knew lots about autism and that self harm was a trait of EUPD, not autism, as, they said *“most autistic people don’t self harm”*
- ‘Some autistic people may end up with the label of EUPD as a result of trauma, possibly experienced as a result of being autistic particularly if undiagnosed.’
- One participant spoke of the harm of essentially being told ‘your personality is disordered’ by being given a personality disorder diagnosis, and how traumatic this felt.
- One participant mentioned having been told that she was an ‘enigma to psychiatry’ She was diagnosed with borderline personality disorder prior to her autism and ADHD diagnosis, and now feels that BPD diagnosis is a misdiagnosis.’
- It is felt that misdiagnosis can often be somewhat gender/ societal specific *“Women tend to get the EUPD diagnosis, whereas men used to get schizophrenia and bi-polar diagnosis. There is a gendered thing, but it’s shaped by societal expectations. Saying nothing about the imbalance of numbers of PoC (far too many % wise) caught up in the MH system.”*
- “[there are] plenty of women being diagnosed with personality disorder who are clearly autistic, it takes one autistic to know another.”

- **Diagnostic overshadowing is a common problem; attributing all of people's difficulties to the fact they are autistic, rather than being willing to look at the complex picture and consider that there may be co-occurring conditions which if identified, could allow the person to receive more targeted and effective support. This includes mental health conditions (e.g., OCD, BPD) and other neurodevelopmental conditions (such as ADHD, dyspraxia etc)**
  - *"There's a major lack of knowledge about co-morbid issues and how they interact with autism. The summary is that everything is blamed on autism."*
  - *"Mental health services always blame autism for [all of the difficulties the service user] might have."*
  - *"autism support workers struggle to refer to or enlist other services, they refuse the referral saying the difficulties are due to autism."*
- **Mental health services must not exclude people on the basis they are autistic, effectively 'blaming' a person's difficulties on being autistic.**
  - *'A participant spoke about parents taking their autistic children to CAMHS and getting turned away, often being told "all autistic people have anxiety it's just autism it's not mental health [problems]" They spoke of the likelihood of young people growing up with mental health problems if services will not see them to support at an early age.'*
- **There needs to be an awareness that autism can frequently co-occur with other neurodevelopmental conditions such as ADHD, dyspraxia, dysgraphia, and also with mental health conditions.**
- **ADHD commonly occurs with autism. Services having knowledge of this condition specifically (both in isolation and in how it might coexist with autism) is likely to lead to improved outcomes in terms of people receiving a diagnosis and receiving adequate support.**
- **It has been suggested that it may be beneficial for autism services to be neurodevelopmental services, rather than autism only.**
  - *"Need to see a service that is [neurodevelopment based] versus diagnosis specific, to see a whole person versus one part of person. [There are] so many with other neurodevelopmental difficulties e.g. dyspraxia/ ADHD. It's rarely 'just' autism."*

# Healthcare

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This section looks at barriers frequently faced by autistic people when it comes to accessing healthcare, adaptations which could be made to make access easier, and areas in which a greater understanding of autism is particularly needed in relation to physical healthcare.

Also covered are hospital visits, and how these can be particularly challenging for autistic people. It is likely that with greater understanding amongst staff working in healthcare settings, and small adaptations being made, that these experiences could be made much more manageable for many.

## Key messages

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- Autistic people should feel they are fully informed about and involved in their care.
- There needs to be a better understanding of autism amongst GPs. They are presently often the only 'gateway' to referral for assessment, and this is considered to not be ideal.
- More understanding around how best to communicate with autistic people in healthcare settings is needed.
- Annual health checks may be useful for autistic people.
- An autism flag in people's medical records to let professionals involved with their care know they are autistic would be beneficial, but this should only be recorded with their permission.
- There is a need for a greater awareness of conditions which may interact with autism, e.g. chronic illness/ chronic pain, or be more common in autistic people, such as Ehlers-Danlos syndromes.
- There must be awareness around how stressful things like medical appointments, hospital stays and pregnancy and childbirth can be for autistic people.
- The environment in healthcare settings often isn't very 'autism friendly', with hospital environments referenced as being particularly difficult to cope with. Consideration should be given to how people can be supported with this in as many ways as possible.
- Autistic people may need more time at medical appointments to allow them to feel comfortable and to allow for processing time. Time to prepare and process is felt to be particularly important for things like hospital stays.

- Those communicating with autistic people at medical appointments should be aware of the need to keep people informed, communicate clearly and patiently, and be adaptable to support specific communication needs.
- Experts by Experience embedded in healthcare settings could support those working in the service to gain increased understanding, and also potentially support autistic patients.
- Consideration should be given to making healthcare related appointments accessible. This could include things like enabling autistic people to attend for appointments during quieter periods.
- Healthcare passports, or having the ability ahead of time to write some things down, are suggested as being useful to make needs known.

## Healthcare Feedback

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- **Autistic people should be fully involved in and kept informed about their care.**
  - *"I often get stressed with medical appointments ... [I feel that] my care is done to and not with me."*
- **It is broadly agreed that GPs and those working in primary healthcare (and also in other healthcare settings, including places like hospitals) need to have a much greater understanding of autism, or at least to begin with an understanding of the complexities of it and a willingness to learn.**
  - *"GPs have a perception they know more than people with autism."*
- **It should be considered that perhaps GPs are not the most appropriate people to screen or act as gatekeepers, as they often lack the skills to identify autism. What would be a more effective route into diagnostic and support services?**
- **More knowledge and understanding is also needed with regards to communicating with autistic people, e.g., some autistic people may want to know information in detail.**
  - *"The one part of the NHS service I have great experience of is how the needs of autistic people are catered for in general clinical treatment. Or rather, how they're not. In the past 2 years I have been diagnosed and treated (successfully) for prostate cancer. Of all the many consultants and nurses I have spoken to I have only met 1 doctor and two nurses who had a clue about how I need to be given information and the kind of detailed information that I need for my mental well-being."*
  - *"[I've] been bounced along from expert and expert and I have to make sure they know what I am [like] and what I do/how I cope, e.g. in physical healthcare, oncologist for example e.g. they don't understand my reactions to their comments."*
  - In relation to this, it would also be beneficial for medical professionals to realise that autistic people might come to them with their own information/ knowledge about their condition, and it would be good if this could be engaged with rather than disregarded.
- **Annual health checks may be useful to pick up and 'check up on' those not presenting to services. It is suggested that this check could not only cover general health but also 'social health'/ social situation.**
- **It is felt that it will be beneficial to have an 'autism flag' in people's records to make those involved with their care aware that they are autistic, and to make them aware that reasonable adjustments may need to be made.**

- There is a need for an awareness of conditions which may interact with autism, e.g. chronic illness/ chronic pain, or be more common in autistic people. It is important that these be treated as important in their own right, and not simply explained away by ‘blaming them on autism’ It is felt there is a lack of understanding around complex chronic health conditions co-occurring with neurodivergence, including autoimmune conditions for example.
  - It was suggested that autistic people often suffer chronic health conditions possibly as a result of masking for years.
- There is a great need to consider the environment in healthcare settings, particularly in hospitals and particularly in terms of sensory difficulties (sound, bright lights, smells etc)
  - As well as causing distress, not addressing this could lead to clinical issues; an example given by a focus group participant was the fact that taking blood pressure reading from someone in sensory overload may lead to an overly high reading.
- Some autistic people may need to have more time in medical appointments to give more time for communication and understanding.
  - *“With health care, I have struggled to access services as my autism advocate has battled the local GP's to provide me with extra time but this was never provided.”*
- It has been suggested that having an expert by experience present within, or working with a GP practice, could enhance understanding amongst professionals and be involved in peer support to support people who may be/ are autistic.
  - *“Perhaps if it's difficult for all GPs to understand all aspects of [autism] they could at least have someone in each surgery that does and can help the person, parent and practitioners understand what is needed.”*
- Consideration needs to be given to the fact that if ‘traits of autism’ are picked up on by a GP (or within a non-autism specific healthcare setting) people should be able to access an assessment if they want to, and should not be turned away because they ‘just’ have traits of autism, or don’t obviously need to be referred to a specific service.
- Appointments such as GP appointments or hospital appointments may need to be flexible or available at specific times to accommodate particular needs (e.g., needing to visit the surgery when it is quieter)

- **There needs to be an improved understanding of autism and autistic people’s needs in maternity services, as pregnancy can be a challenging time with lots of sensory implications etc.**
  - *“[I was] impacted most when I became pregnant the first time, massive sensory overload – no midwife, GP, psych services picked up on autism, I raised as a possible issue the year before but people ignored me.”*
  - *“When I quizzed the medical team in Maternity services around areas I didn’t understand/didn’t make sense to me and needed these answering [I] was seen as challenging and not caring about child. [This] hugely affected me and my trust. I wasn’t listened to – no-one respected my views including in labour. [This had a] negative impact on my birth.”*
- **Autistic people often find it challenging to accurately convey pain or discomfort they are experiencing; this can lead to challenges in providing appropriate care.**

## Hospitals

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- **It is often referenced by EbEs how ‘autism unfriendly’ hospital environments are.**
- **Autistic people need support around procedures and hospital visits; time to prepare mentally and be aware what is happening and how to deal with it.**
  - *“Children’s hospital had [a] procedural anxieties group and a number of those attending had autism. It was helpful. We assume that children will struggle but adults won’t.”*
  - *“In physical acute hospital – preparation is key, lots of prep, I get anxious, support needs to be there for me, to help me.”*
- **It needs to be understood that hospitals may be very difficult for autistic people to deal with on a sensory level, as well as the experience being stressful due to illness or injury.**
  - *“... there were a few very loud and sudden noises on the ward. At this point I was lying in bed feeling very ill. A fire alarm suddenly went off and I had no idea that it was only a drill. It frightened the life out of me and I had to get out of bed to be able to look across to reception to see if it was a test or not. It was extremely loud and unsettling when I was already distressed... there was also a door that kept slamming very loudly every so often for around half an hour or so, and every time it slammed, it made me jump... it felt like a very unnecessary thing that caused me to feel more frazzled.”*
- **Communication needs to be considered and time needs to be given for processing.**

- *“One positive experience I had was one healthcare assistant ... She saw my sunflower lanyard which has a badge on saying 'I'm autistic, I can't always wear a mask' ... She spoke to me with a calm and gentle manner.”*
- *“Being able to talk to a receptionist in a small quiet room away from the rest of the waiting room, or even just in a quieter corner of the room away from the cafe area, would have been less overwhelming for me and I would not have had so much trouble in following what she was saying. More patience and understanding from the reception staff would have helped as well.”*
- *“Generally, staff talked to me extremely fast and I found it really hard to keep up with what they were saying. This was particularly difficult on the first day I was there, as that day was very overwhelming, I was very upset and I found it hard to process everything.”*
- *It can often be helpful for information to be written down, particularly if it involves instructions or directions about things like times of procedures, times when people can eat, and directions for getting around the hospital. An EbE who mentioned how beneficial this could be had faced some problems with staff being impatient about writing things down for her “I think staff need to be more aware that autistic people often process information better when it's written down and we aren't bombarded with too much spoken information at once. Less judgment and more patience from some of the staff is needed.”*
- **It is felt there needs to be more understanding of autism and adaptations which can be made to help people amongst staff working in hospitals.**
  - *“I told a couple of nurses/assistants that came to see me on the ward throughout my stay that I'm autistic and none of them seem to know how to react. One of them just nodded and said 'yes', then continued to fire questions at me. There was no effort on their part to ask me how they could accommodate me.”*

*“I got a choice of bed so I was able to choose the bed on the ward that suited my needs.... if I had been put in the middle of the room, I would have found it difficult having lots of people walking to and fro all the time as that would have been very disorienting and distressing ... I think that this is something that should be taken into account by medical care staff when an autistic person arrives on a ward, particularly, if an autistic patient is booked to stay overnight.”*

- **Keeping people informed can be really helpful, especially if there are going to be any changes to planned procedures.**

- *“...I was crying and I was not able to say much but just said I was feeling overwhelmed ... the assistant who took my blood pressure and temperature said 'oh don't worry about it' in a patronising and impatient tone as if I was crying about nothing and then she just left ... I was upset because my surgery was delayed and I had no idea what time it would be. The sudden change had thrown me ... they didn't seem to have any understanding.”*
- *An EbE spoke of having plans for anaesthesia for an operation changed multiple times, and how distressing this had been “Sticking with the original plan and not expecting me to change my mind last-minute [would've helped me] I think that staff need to be aware of how autistic people can struggle with last-minute changes of plan. I had mentally prepared for a general and had been 'nil by mouth' for hours in preparation for a general, so turning around and saying last minute that they could do it differently caused me a great deal of unnecessary stress.”*
- **It has been suggested that if possible, it would be beneficial for autistic people or someone attending hospital to support them to have opportunity to convey or write down a few essential things that staff need to know about them, like any sensory issues or communication issues.**
- **It would be beneficial for consideration to be given around hospital food provision, taking into account that some autistic people may feel uncomfortable with certain foods and may struggle to find something they can eat.**
  - *“...The food choices are very limited so for some autistic people, it might be good to remind them that they might need to take their own food to eat after an operation. I know some autistic people would really struggle with such a limited choice.”*

# Children and Young People

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We frequently hear from Experts by Experience exhausted by having to fight and advocate for their children, and often not feeling believed. Early identification of autism in children is crucial to allow the right support to be put into place; appropriate support provision early on in life and throughout the crucial period of childhood and adolescence is likely to lead to improved self-esteem and resilience, and support improved mental health outcomes.

## Key messages

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- Early identification of autism is considered crucial.
- Families should not feel like they are being left to cope on their own unsupported.
- CAMHS must have suitable resources and knowledge to be able to support autistic children and young people.
- Services providing support to autistic children and young people should be located in sensory friendly, child friendly environments.
- Parents of autistic children and young people should be listened to and respected.
- Parents should not feel like they have to fight for support for their children, or be unable to access any support services at all due to restrictive criteria or due to their child not having an 'official' diagnosis.
- The transition between child and adult services is often felt to be very difficult and traumatic.
- Attempts should be made to work out what message the behaviour contains when a child is exhibiting so called 'difficult' behaviour, to best ascertain how to support them.
- Autistic children and young people should be included and have a say in their care as far as possible.

# Children and Young People Feedback

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- **Early identification and intervention is considered crucial.**
  - ‘Early years approach first – health visitors at the very beginning, need to be proactive and well trained and aware – autism can be detected in babies by professionals with the right skill set.’
  - ‘Another parent’s experience – their child was diagnosed late at 16, was missed in earlier life.’
  - There should be very early interventions from health visitors who are sufficiently knowledgeable, to allow family to feel prepared and get them on a pathway of learning.
  - It has been suggested that as soon as autism is identified, it may be beneficial for an expert by experience to be linked up with the family, perhaps via the medium of accompanying a health visitor, to provide support and increase understanding of autism.
  - Communication issues should be picked up as early as possible to allow support to be put into place.
- **Things often don’t move forward efficiently enough to provide children and young people with the help they need, leaving them and their families stuck without support.**
  - ‘School advised access for diagnosis but son waiting for 7 years (and had to see various professionals to see same story) and had nothing – now going to university and had NO DIAGNOSIS and NO SERVICE’
- **CAMHS should have suitable resources and knowledge to be able to support autistic young people to help to prevent avoidable situations.**
  - *“CAMHS underfunded so people end up in crisis and don’t get support quickly enough, people end up in inpatient, no need, causes unnecessary trauma.”*
  - ‘Cognitively able children may be overlooked. Intellectually able children are often difficult to place within services.’
- **If services say they are child centred, it must be the case that they are actually making appropriate adaptations.**
  - *“Contradiction between saying it is a person centred experience, but service being unable to flexibly adapt to specific needs of child.”*

- Buildings (where services are located) are often said to be not child friendly, and rather business like. It would be beneficial for these places to consider how they might make themselves more child friendly.
- There is a need to listen to families to hear about their unique experiences, identify where they family is in their pathway, and how they can best be supported going forwards.
- It is suggested that there is a need for a service or helpline for parents under strain. Families are often put under pressure to cope and there is often not sufficient understanding from services that families can't keep taking on additional stress.
- Parents often feel like their parenting skills are being judged negatively, care needs to be taken to work with parents in a non-judgemental and supportive way.
  - *"...their experience was that they were being held responsible as parents for the difficulties their children were contending with."*
- The problem of parental blame has been spoken of extensively, and how much of a negative impact this can have on both parents and children. More than one participant spoke of the issue of parents not being believed and then being *"thrown to social services"* It is felt there is a culture of not believing parents, or indeed autistic people themselves, and not having the training to recognise themselves what the parents are telling them.
  - Parents speak of ending up being sent on parenting courses (one participant had been sent on 3) or even being put on child protection plans, accused of fabricating illness or abuse for advocating for child. It is said there needs to be a *"level of understanding, not this consistent blaming of the parent"*
  - One parent spoke of being involved in a tribunal in which a psychiatrist who had never met her child disagreed with their private diagnosis of autism and instead said they had attachment disorder.
  - A parent spoke of being asked *"why do you feel so confident?"* by a psychiatrist in relation to a child's autism.
  - 'One focus group participant shared that a safeguarding policy had been used by a school to stop parents pursuing/ asking for help. Unfortunately it appears that some schools often see parents as disruptive when they are fighting for support for their children.'
- It is thought that it may be beneficial for there to be a non-medical point of contact for parents when they first become aware that their child is not developing as they expected, to avoid instantly 'medicalising' issues.

- **Parents are often pushed towards a medical model of autism.**
  - *“My experience as a parent of an autistic child, [he] had a breakdown due to bullying by peers as he approached his GCSEs. Pushed down the medical model route. His needs were conflated with learning disability (although he was an A star student). He was caught between children’s and adult services and offered no support by the statutory sector.”*
  - ‘GPs don’t know how to respond to parent’s stress... BUT the response to that shouldn’t automatically be to medicalise/ adopt a medical model approach’
- **Often children are not seen to ‘fit in’ to any services offered, or the services required simply are not available locally, which leaves parents not knowing where to turn and issues not being addressed.**
  - *“no post diagnosis support, no help with strategies... only support from [an autism charity]... but nothing available in my local area”*
  - ‘Local CAMHS don’t appear to have any autism services or specialist.’
  - Parents with nowhere else to turn when struggling with ‘behaviour which challenges’ are often told to phone the police *“He has autism, phone the police if you need to.”*
- **Parents (and possibly wider family) should be supported and educated in how to support autistic children (covering issues such as anxiety, sensory issues etc) Providing a resource for them to know how to best support a young person.**
  - ‘Earlybird’ is referenced as being helpful for training and ‘upskilling’ parents to give them ideas and strategies.
- **Considering appropriate and smooth transition between child and adult services is crucial.**
  - *“Chronological age is not always reflected in emotional developmental age, and therefore this may not result in environments that are supportive of individuals going through transition to adult services.”*
- **Behaviour is always a form of communication and attempts should be made to work out what a child is trying to communicate when they are exhibiting so called ‘difficult’ behaviour.**
  - *“It is frustrating for [autistic] children to communicate their ‘idiosyncratic’ view of life, whilst trying to be processed through a ‘factory’ system.”*

- Access to support for a child displaying autistic traits should not be dependent on them having a full autism diagnosis (e.g., if they don't have an autism diagnosis but are exhibiting evidence of needing something like sensory support)
- The prevalence of gut disorders in autistic people was referenced in connection with colic in babies, it is considered that it would be beneficial for health visitors and other professionals to be able to educate and support parents in understanding this.
- The importance of peer support for parents was referenced, being able to share stories with others, pass on knowledge and feel supported.
  - 'Peer Support – parents in same position sharing their experiences and also parents/ autistic/ neurodiverse individuals who have experienced the journey and can pass on their knowledge. Hosted by others – outside the NHS.'
- Children and young people must be fully included as far as possible with discussions and decisions about their life and any support they may need.
  - *"Problem with children's services is there is a preconception about how much the child will understand. This may result in the child being discussed with parents without being directly addressed."*
- Obtaining a diagnosis for a young person later (after 'early years') appears to be challenging.
  - 'Later diagnosis was harder to manage in terms of services – nothing seemed to be available. Assumptions [were] made about young adult, that [autistic traits were] down to behaviour/ adolescence.'

# Education

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Education settings can be particularly challenging for autistic children, and it is felt by Experts by Experience that schools are often not well equipped to be able to best to support autistic children and young people. This section looks at key areas in which it is felt greater understanding is needed, and ways which children and young people could be better supported in education.

## Key messages

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- There is a great need for a better understanding of autism within schools.
- It is common for parents to make the decision to home-school their autistic children due to difficulties faced at school.
- Parents should not have to fight to access support for their children in education, and young people should not have to fight for support for themselves. Education establishments should work with parents/ young people to provide support, as not having this in place can negatively impact on a child or young person's mental health and education.
- The transition between schools can be particularly challenging for autistic children
- Education about neurodiversity should begin early to increase awareness
- There is a need for a better understanding of, and improved response to, 'behaviour that challenges' within education settings.
- It is felt that it's necessary to reassess the way children are taught and assessed, looking at how different children learn best, in varied ways, and finding ways to accommodate that, and considering alternatives to traditional exams which may be particularly challenging for autistic children.
- Bullying at school can be a particular problem for autistic children.
- Education establishments should be able to implement sensory adaptations to support creation of a more 'autism friendly' environment.

## Education Feedback

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- **Those working in schools need to have a greater understanding of autism and how they can best support young people.**
  - *“Schools not understanding fight/ flight/ freeze, and being able to respond if the child shows distress in a way that they don’t understand.”*
  - *“Schools, social services don’t understand autistic behaviours and discriminate, and the impact is huge (when I was younger)”*
  - ‘It is important for staff in higher education settings to have staff who understand autism and take time to listen to and understand specific support that people may need without making assumptions about what will help.’
  - ‘We need to provide more support to teachers and teachers and help them to recognise and understand the needs of autistic/ neurodiverse children.’
  - ‘Schools need understanding of entire spectrum. Can’t be one size fits all.’
  - Schools are said to struggle to ‘get their head around’ supporting students. Autistic children who struggle or are bullied at school often need parents or the student themselves to push or take their own initiative to get the support needed.
  - It has been suggested that it may be beneficial to embed EbEs in schools to increase understanding, particularly understanding of specialist areas like autism in women and girls.
- **Some parents end up choosing to or having to home school to take pressure away from having to deal with the school system, and this may also create a more agreeable environment for a child to learn in. Ideally children and their families would be supported in such a way that this wouldn’t be something which was done in desperation as a last resort.**
- **It is suggested that there are many autistic children in mainstream education without adequate support, and their education can be badly impacted.**
- **Parents should not have to fight to access support for their children in schools, and young people should not have to fight to get support in higher education.**

- It's said to be difficult to get linked up support with schools and hard to get things across to them. E.g., it's hard to get them to fill in necessary forms, and hard to get medical services/ other services to communicate with schools etc. This means constant chasing is needed, which can take over a parent's life and take up so much time, puts a lot of pressure on them. This is also applicable to young people in higher education who are having to self-advocate.
  - This is also relevant in terms of accessing diagnosis for children; to access diagnosis and support, parents need co-operation from schools from the moment that autism is suspected.
  - *"[when at university I] spent more time advocating than studying."*
  - *"[There needs to be] much greater involvement between CAMHS and education – things have moved on and services need to reflect this."*
- It is said that the transition between schools, either things like moving from junior to secondary or moving to different school is challenging and takes a long time to organise.
- Sometimes it's hard to find the right school, so children may need to move to a school which suits them better (but then the transition is difficult)
- It has been suggested that education about neurodiversity should begin in early education, to increase awareness.
  - 'This could include teaching children and families about 'differences' in human behaviour, and about acceptance from an early age, starting from nursery education. PHSE often comes too late, as it doesn't start until secondary school. Education should be celebrating differences.'
- It is said that education services need to consider their response to so called 'inappropriate behaviour' which they see to be impacting on the school setting.
  - 'They need to change their ideas and consider behaviour as a communication, what is the autistic child trying to say? Schools need to be flexible and not about control and conflict.'
  - 'Schools are very often stubborn in how they think about behaviour.'
- Children not engaging or refusing school may lead to schools not offering the support needed, when it may be the case that it is these children (and their families) who most need support.

- **It has been suggested that changing the approach of education to have a focus on creatively engaging children would be beneficial. Looking at how different children learn in different ways.**
  - Interest led learning has been mentioned as being positive, allowing children to discover, focus on and learn about subject matter which engages them.
  - ‘...children picking what they are doing, doing things when they are ready rather than being dictated by the national curriculum. Keeping children engaged may help with behaviour and stopping them ‘shutting down’ It’s the child’s education, not the MP who is in charge of the education system’s education.’
- **There is a need to look at different ways of assessing children, as very often they can struggle with pressure of exams, and things like sensory issues can also be a problem in an exam setting (bright lights, noise from others etc)**
- **The possibility of a child being autistic needs to be brought to a parent’s attention as soon as anything becomes evident, teachers and anyone else involved with the child need to feel they can say something as soon as something is noticed. Action then needs to occur (eg referral for assessment, access to support)**
  - ‘Autism needs to somehow be identified before ‘wheels come off’ and warning signs should not be ignored in school. Schools often see it makes sense when hearing people are diagnosed with autism but didn’t pick up on it.’
  - *“[In an ideal world] School listens, notes down evidence that something has been flagged up, then systems roll in and from that moment advice on behaviour, language etc starts.”*
- **The ICAN network (Australia) was referenced as a good example of support and mentoring in schools, providing mentoring and an inclusive system in Australian schools, running summer camps and support groups for children and supporting transition into adulthood <https://icannetwork.online/>**
- **There is a great need to address the issue of bullying at school and how it can affect people (this is relevant to later life too, i.e. how having been bullied at school can affect people in later life, but also how bullying in adult life can affect people, and how they can be supported)**

- There needs to be awareness of the fact children can often seem to be ‘coping’ at school then ‘fall apart’ at home, how this can be a symptom of autism (if a child is not diagnosed) how they can be supported with this (e.g., improving school environment/ situation) and also in encouraging schools to be aware of the fact this can happen, or it risks schools being unsupportive to parents trying to seek support or diagnosis, as a school may say the child is fine when they are there.
- There should be consideration of helpful sensory adaptations that schools may be able to make to support autistic children.
  - ‘Sensory differences and adaptation for these, easement on clothing allowed in school – so what if the child wants to wear Wellington boots to school on a daily basis?’
  - *“I heard of a child in a school who had a box of fidget toys to help him cope, but the school didn’t give it to him when he appeared to need it as “he didn’t ask for it” – the child in question is only five!”*

# Employment

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This section looks at why employment is often a particularly challenging area for autistic people to navigate, and adaptations which could be put in place to best support them.

## Key messages

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- There is a need to look at adaptations to support autistic people to access work and remain in work, if they want to and are able to.
- Discrimination and ingrained attitudes of potential employers can be a barrier to autistic people gaining employment.
- Some industries are considered to be more 'autism friendly' than others; how can these industries be learned from?

## Employment Feedback

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- **There is a need to look at adaptations for autistic people to work/ access work, which may not only make life better and easier to cope with for them, but also allow people to work who would otherwise not be able to e.g. someone who could not cope with an office environment being able to work from home, or someone who couldn't cope with set hours being able to work in a flexible way. Reasonable adjustments are crucial and should be flexible to work to find a mid-place which is beneficial for both employees and employers.**
  - A good example of how creative people can be with reasonable adjustments was given in the form of a video: Gareth Ford Williams, Head of User Experience Design at the BBC spoke about the adjustments he makes as a manager to enable his autistic staff, including Jamie and Lion, to do their job: <https://www.youtube.com/watch?v=08cXX5NHnsk> – Jamie and Lion created the BBC iPlayer radio app.
- **Employment opportunities for neurodiverse people in areas which have some influence over improving services are important.**
  - *“[It is a problem that] autistic people/ neuroatypical people are not getting to those employment positions in services to be able to influence and improve services. For some, [this is] a barrier due to their traumas which prevented access to education/breaks in employment. [They have often] not had the same opportunities.”*
- **Discrimination and ingrained attitudes of potential employers can be a barrier to gaining employment.**
- **Some industries are more ‘autism friendly’ and it may be beneficial to look to these for examples of good employment practice.**
  - *“In the IT world things are different, neurotypical staff are not as good at this role. I am good at processes, I see them everywhere. This could be roles we could take up.”*
- **Employers need to have understanding of the fact that people may have sensory issues, and may need to put things in place to help with this, e.g. allowing an employee to wear noise cancelling headphones.**
  - *“certain impairments would not be an impairment to me if there was more understanding of sensory issues. is it a huge problem if i need to wear shaded glasses. is it a huge problem that i have to wear noise cancelling headphones. is it a huge problem that i like to wear a hat. to the workplace that is a huge problem.”*

- **Mentoring and provision of other support around accessing and maintaining employment has been referenced as being helpful.**
  - '[A local council service], supporting individuals looking for paid work, CV and application support, offering support whilst in work in the environment, may be support holistically too – e.g. PIP access, mentoring was discussed and seen as very helpful.'

# Other Services/ Community Knowledge and Understanding

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It is felt by Experts by Experience to be crucial that there is a better understanding of autism in society. This section looks at understanding in society in general, and specific organisations where there is a need for better understanding of how to support autistic people, and to support the development of a more inclusive society.

## Key messages

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- It is necessary for Experts by Experience to work with organisations to increase knowledge and understanding.
- Raising awareness of autism in the community is important, which could include educating about hidden disabilities/ conditions, sunflower lanyards and autism alert cards and encouraging a more inclusive society.
- Reference has been made to a particular need for a greater understanding of autism within police services, the criminal justice system and housing associations.
- It is crucial that autistic people have access to affordable housing which is safe and comfortably habitable.

## Other Services/ Community Knowledge and Understanding Feedback

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- **It is suggested that it would be beneficial for Experts by Experience to work with organisations to increase knowledge and understanding. It is felt this would be beneficial as it is so much more valuable to learn from people with lived experience, learning about autism in reality rather than only in theory.**
  - ‘We need to get out and educate people in the ‘systems’ (Criminal Justice System, employers, health, education, social care) ... where it is fragmented as autistic people we need to try and pull those strings together as people with lived experience.’
- **It is considered that it would be beneficial for there to be increased societal awareness and understanding of ‘hidden disabilities/ conditions’ such as autism.**
  - It is considered that it would be beneficial for there to be more widespread knowledge of sunflower lanyards and autism alert cards.
- **It would be beneficial for there to be a greater understanding of autism generally across services and within society.**
  - *“I do find that autism is still regarded as a mental health issue and was once asked if my issues with noise was provoked by voices in my head!”*
- **There needs to be more knowledge of autism within the police service.**
  - One police service was mentioned as an example of good practice. Their officers have been issued with an autism card and are given training sessions in how to best help autistic people who may find situations involving the police very stressful and challenging to cope with.
- **It is evident that there is likely to be ignorance around autism in some part of the legal system which needs addressing.**
  - *“...court system have ordered me to get my medication to ‘cure’ my autism”*
  - It was noted in a focus group that the Ministry of Justice recognise the gap in training in neurodiversity.
- **There is a need for good access to legal support for autistic people when needed.**

- Ideally services and society in general wouldn't create an idea of 'other' when making adaptations or working to be inclusive; ideally the neurotypical world could adapt to be more inclusive, and autistic people should be able to be part of society without feeling segregated. An example of a social cafe was given; autistic people meet there, but it is not specifically an 'autism cafe'
- Society not being 'autism friendly' or even accepting of autism can be traumatic.
  - *"someone told me that society doesn't produce untraumatized autistic people due to ableism, the [nature of] healthcare and education sectors etc..."*

## Housing

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- It is crucial that autistic people have access to affordable housing which is safe and comfortably habitable.
  - *"Having somewhere to live where you can feel safe and which is affordable is crucial. (dilapidated, intolerable neighbours, poor) Not having this can destroy lives. If you are unwaged this is so very hard."*
- Sensory issues can be a particular issue in relation to housing. Sensitivity to noise for example can make it difficult to live in close proximity to others. This needs to be considered when an autistic person is moving into a home, and there may need to be support provided around noisy neighbours/ outside noise and how to cope with this, that is if it cannot be avoided entirely.
- There needs to be greater knowledge and understanding of autism amongst those working within housing associations.

# Looking Ahead

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The NHSE/I Midlands Autism Workstream Expert by Experience focus group commenced in 2020, in response to a key priority set out by the NHSE/I Midlands Autism Workstream to improve engagement of people with lived experience of autism across service development and delivery. This began a journey which has thus far provided an abundance of valuable feedback.

As a compendium of feedback, this document should be seen as a valuable resource to support service improvement, and to continually remind us of the importance of embedding and utilising Expert by Experience input to improve autism services.

The *Informing Autism Service Improvement Through Lived Experience Insight* document is live and will underpin the regional set of priorities emerging in response to the national Autism Strategy. The EbE focus group will be exploring further areas where gaps exist in our insight and representation, and will be guided by regional workstream priorities. Additional views will be incorporated into this live document over the next year to strengthen our commitment to ensuring we truly demonstrate a co-produced approach both at regional and system levels in taking this forward.

There is a wealth of insight brought together in this resource. Systems should consider how they will use this to influence and inform local change whether this be from a commissioning, provider or local partnership board perspective. Recognising that systems will have differing immediate needs and service priorities, there is an opportunity to use this document in an agile way, aligned to local planning.

The NHSE/I Midlands Autism Workstream will be collaborating with other regional teams and workstreams to ensure we utilise the cross-cutting set of lived experience themes identified in this document to inform plans such as those specific to quality improvement, health inequalities and Children and Young People services.