Assenti Research

Access to Mental Health Services for Autistic Adults
Lived Experience Research Report
November 2021

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1. Background and Objectives

In March this year, Scottish Government published the autism and learning/intellectual disability transformation plan 'Towards Transformation'. This plan sets out to address the inequalities and ensure that progress is made in transforming Scotland for autistic people and people with learning/intellectual disabilities.

Scottish Government and COSLA (Convention of Scottish Local Authorities) acknowledge there is more to do to ensure that autistic people and people with a learning/intellectual disability can live their lives to the full and be a rightly valued and integrated part of our communities. As a result they have introduced a collaborative and innovative leadership and engagement plan. People with lived experience will be at the centre of this work to ensure that change and improvement is led by the people who will see the benefit in their daily lives. This process looks to empower autistic people and people with learning/intellectual disabilities to be the leaders in transforming Scotland and to engage people with the ability to make the changes needed by those with lived experience.

It is envisaged that a series of topics will be addressed through this process. Access to mental health services was previously identified in the Towards Transformation Plan as being of critical importance. As part of the first stage in this process Assenti Research were commissioned to carry out primary research about access to mental health services with Autistic adults via Inspiring Scotland's Autism Advisory Forum. Separate research has been carried out with parents and carers of Autistic adults and/or Adults with Learning Disabilities.

The objectives of the research were:

- To understand how easy or difficult is to identify mental health issues and how Autistic adults can be supported in identifying mental health issues if they arise
- To establish if there are any barriers to seeking mental health support and how those barriers can be addressed
- To evaluate experience of accessing mental health services in the past, to help understand what has worked well and any difficulties or challenges that have been encountered
- To establish priorities for improving mental health services

2. Research Approach

The research included three elements: a quantitative online survey, qualitative focus groups and individual depth interviews. The online survey element was important to ensure that the wider community had an opportunity to take part in the research and have their say. The findings from this stage were important in helping us to refine our objectives and information requirements for the next stage of focus groups and individual depth interviews. The focus group / depth interview approach was important to help us understand the respondents' perceptions in detail.

This report presents the quantitative data gathered from the online survey, supported with qualitative evidence from the groups and depths. NB The qualitative research focused on key areas where more in-depth understanding was required.

All of the research has been carried out anonymously and confidentially.

2.1 Online Survey Approach

A short questionnaire was drafted in conjunction with Scottish Government and COSLA (see Appendix). As far as possible the questionnaire consisted of closed, tick box style questions. However, as the objectives were primarily qualitative it was necessary to use some open-ended questions where respondents could write in their answers. During analysis likeminded responses were grouped together and coded for analysis as well as being provided in list format (see Open Ended Comments in the Appendix).

Once approved we provided a survey link for Inspiring Scotland to share with the Autism Advisory Forum members. The survey was live for a three-week period from 27th September to 17th October 2021. A total of 113 questionnaires were completed. Data tables comparing sub-groups have been provided under separate cover. Care should be taken in analysing these data tables as the base numbers for some sub-groups are very small. Any notable differences between sub-groups are detailed in the narrative of this report.

2.2 Focus Group / Depth Interview Approach

The qualitative research sought to provide a more detailed understanding of positive and negative experiences of accessing mental health services and how they could be improved. Focus groups work best where they are as homogenous as possible. Five focus groups were carried out with Advisory Forum members. We aimed to have 6-8 respondents participating in each group and they were well attended. The focus groups each lasted about 1 hour. The groups were moderated/facilitated by Autistic facilitators with support from the researcher. The groups followed a pre-agreed topic guide (see Appendix). Groups were held online on a mix of daytimes and evenings.

A further 9 individual depth interviews were carried with members of the Advisory Forum who requested a one-to-one interview either because they couldn't make a group session, or just preferred to be interviewed this way. These interviews followed the same topic guide and took 30-60 minutes, some were carried out by phone and some by Zoom.

The qualitative research was carried out between 25th October and 12th November. Each respondent received a £30 Love to Shop voucher from Assenti Research as a thank you for their time.

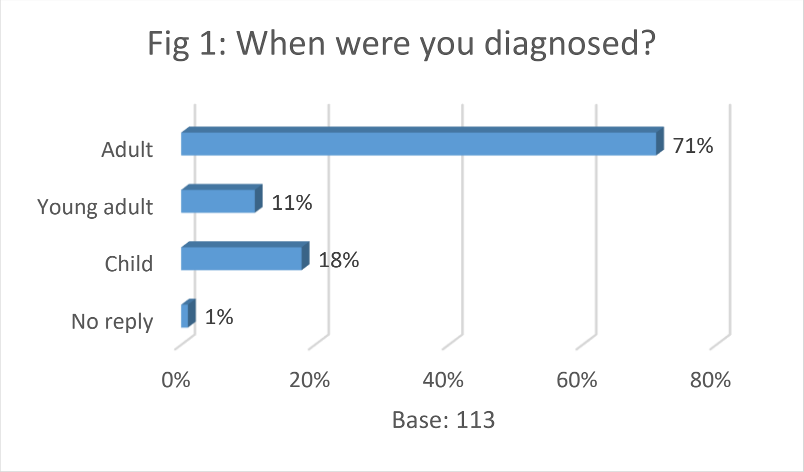
3. Research Findings

3.1 Profile of the Sample

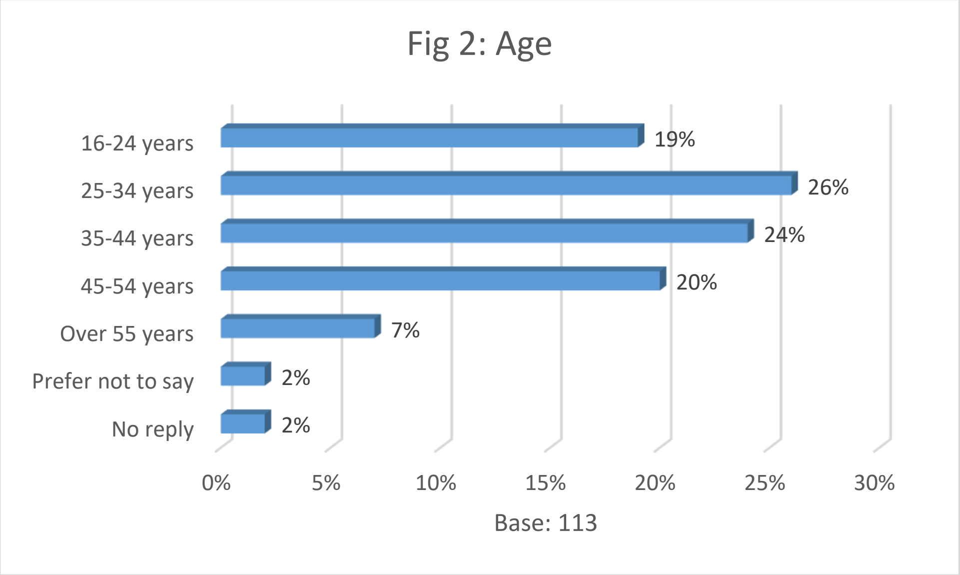
Online Survey

The respondents were all asked when they were diagnosed as Autistic. The vast majority were diagnosed as adults (71%), with much smaller proportions being diagnosed during childhood (18% under the age of 16 years) or as young adults (11% aged 16-20 years).

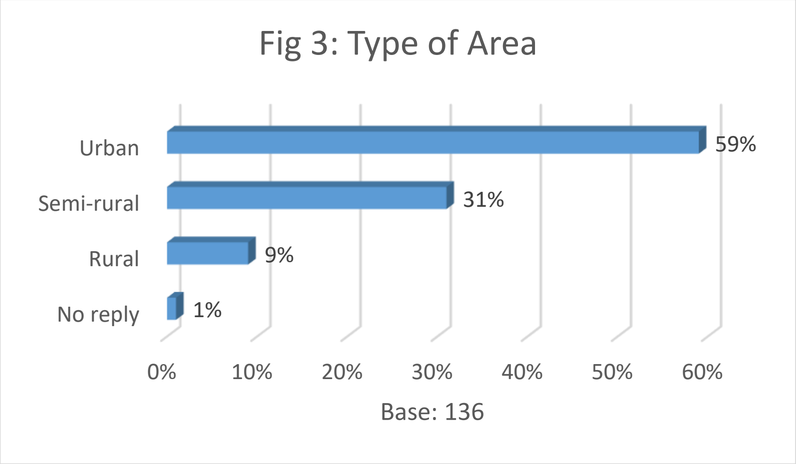
Those who were diagnosed as adults were much more likely to have also had a previous or current mental health issue diagnosed.

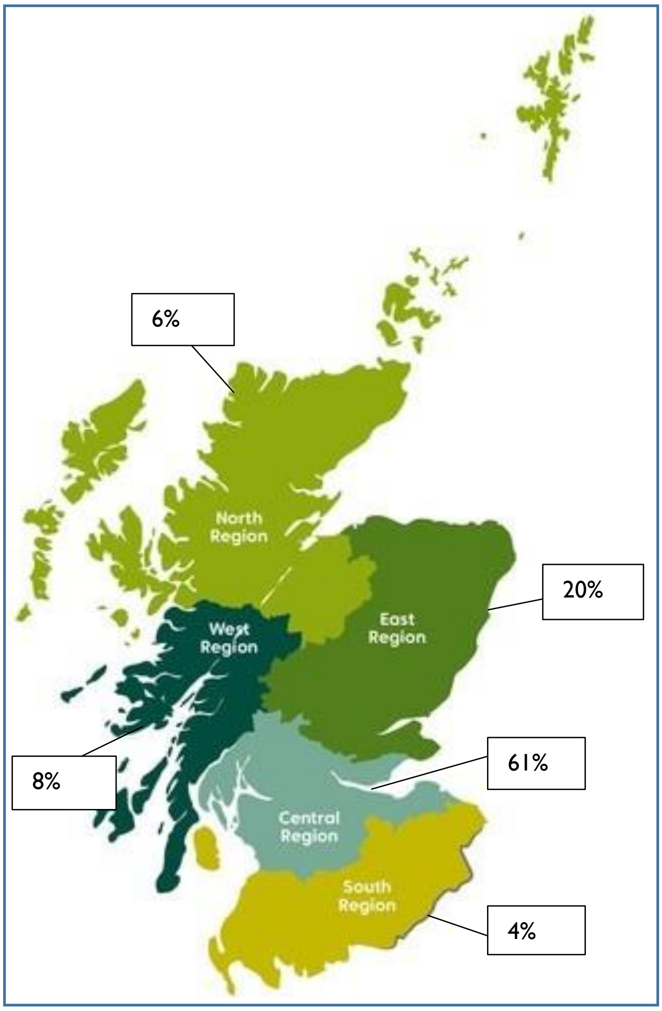


The age profile of the respondents is obviously largely dictated by the profile of Forum members. There is a good spread of respondents across the 4 youngest age groups (16-54 years), but a smaller proportion of older respondents.



The respondents included a mix of people living in urban (59%), semi-rural (31%), or rural (9%) areas.

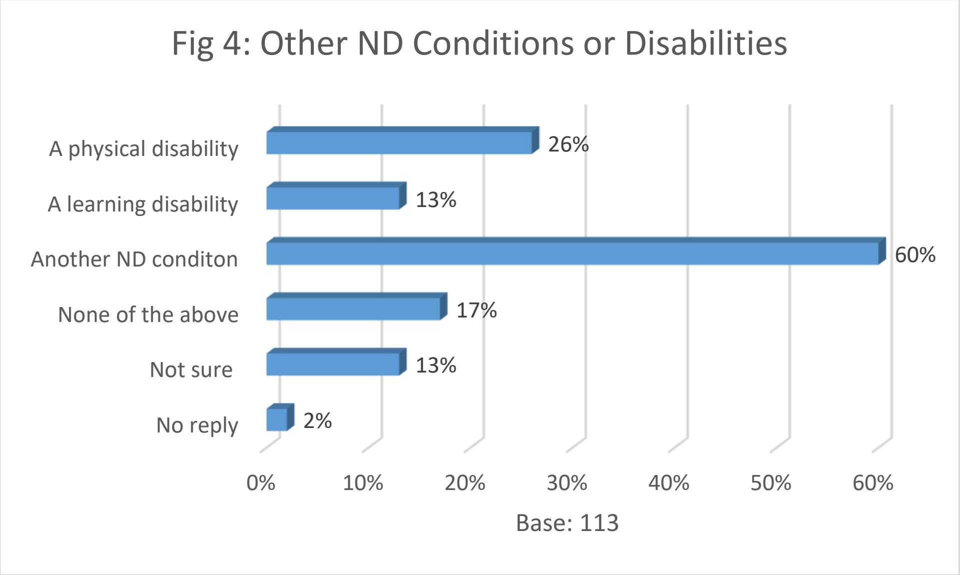




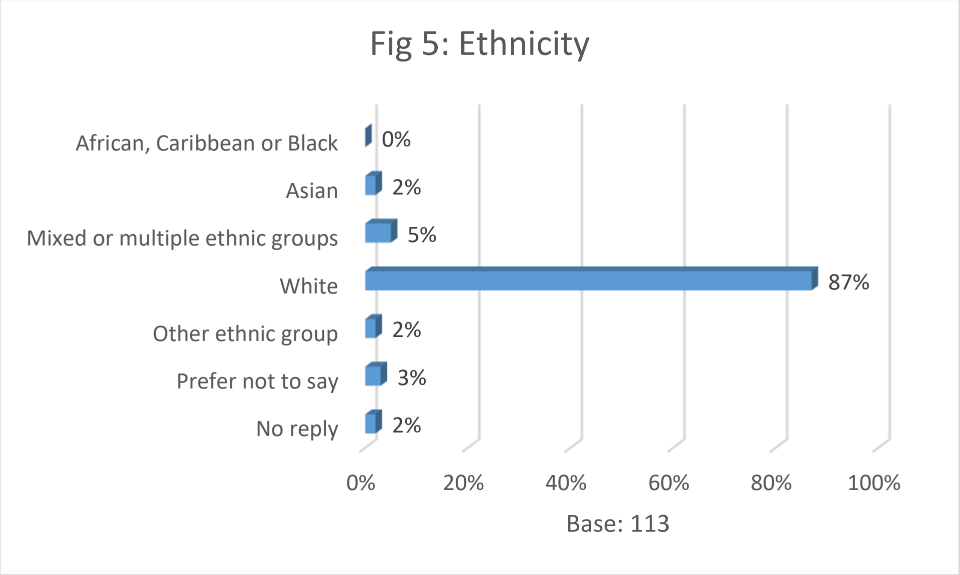
This image shows the location where respondents live. The largest proportion were from the Central belt (61%) and there was good representation from the East (20%). Input from other areas was more limited.

Most respondents (60%) had another neurodevelopmental condition in addition to Autism (60%). These respondents were much more likely to have had a diagnosed mental health condition than those who had no co-occurring difference or physical disability.

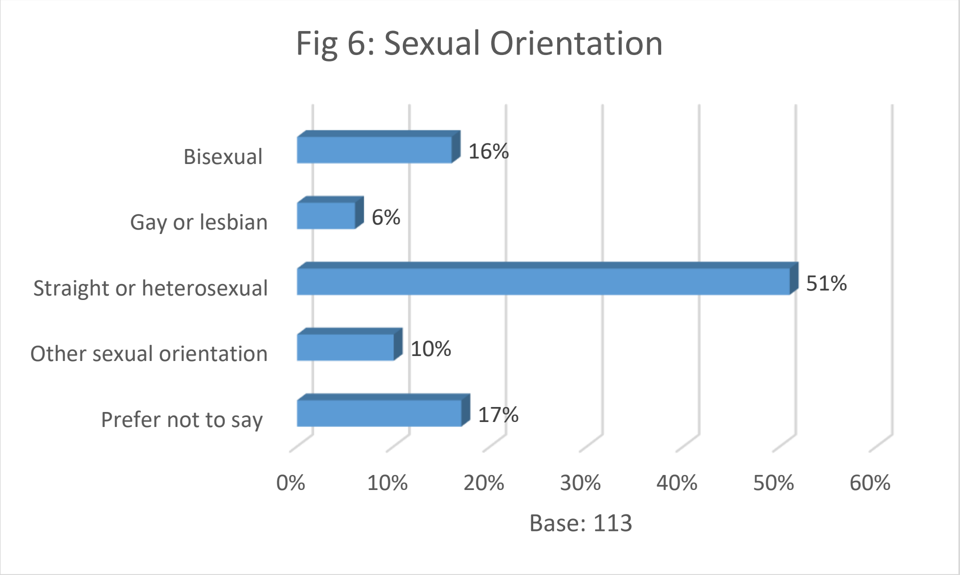
There were also 26% who had a physical disability and 13% who had a learning disability.



The following chart details the respondent's ethnicity, 9% were from an ethnic group other than white.



The sample includes respondents with a range of different sexual orientations.



82% of respondents identified with the same gender as assigned at birth, 10% did not and a further 7% said they would prefer not to say.

Groups / Depth Interviews

There were 41 respondents from all over Scotland (including urban and rural areas) who took part in a focus group or depth interview. A wide range of ages were represented, although very few respondents were aged over 60 years.

3.2 Good Mental Health (Online Survey Only)

The respondents were asked about what helps them to have good mental health. A wide range of factors were identified by the respondents. Most notable were Autism appropriate environments (86%), having a daily routine (81%) or having someone to talk to if I have a problem (81%).

There was little variation among different types of respondent. Respondents who had a Learning Disability were more likely to mention having a daily routine, doing a job they enjoy or support from family / friends.

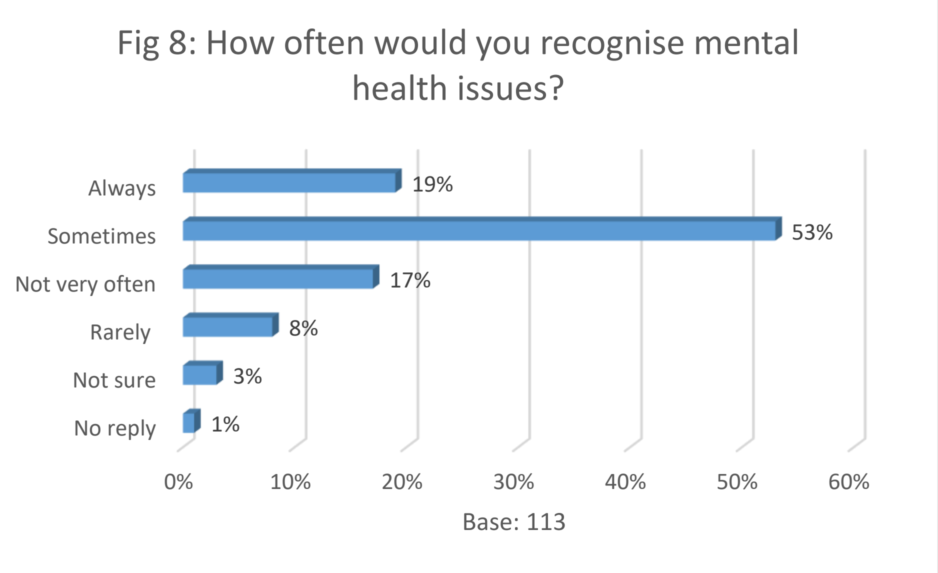
Fig 7: What helps you to have good mental health?

	%
Autism appropriate environments (avoiding sensory overload)	86
Having a daily routine	81
Having someone to talk to if I have a problem	81
Special interests or hobbies	78
Support from friends or family	78
Doing a job I enjoy	75
Feeling supported in work / education	71
Being part of a community	56
Exercise	55
Other	19
Base: 113	

3.3 Recognising Mental Health Issues (Online Survey Only)

The respondents were asked how often they would be able to recognise if they have mental health issues e.g. anxiety, depression, OCD, low mood, eating disorder etc. Almost a fifth said they would always be able to recognise mental health issues, 53% said they sometimes would, and a quarter said they would not very often or rarely be able to.

Respondents who had never had a diagnosed mental health condition and those who had never experienced an ongoing low mood, or had an undiagnosed mental health issue were more likely to say they would always or sometimes be able to recognise a mental health issue. Younger respondents (under 25 years) were less likely to think they would recognise a mental health issue and it appears that as respondents get older, they are more confident in being able to identify mental health issues. Respondents who did not have a Learning Disability were also more likely to think they would be able to recognise mental health issues.



Those who felt able to recognise mental health issues rarely or not very often, were asked what they thought made it difficult to recognise changes in their own mental health. Difficulties recognising emotions were common (87%). Spending a lot of time alone or being isolated (81%) or changes in mental health happening slowly (78%) were also seen as contributing factors by a large proportion. A small number of respondents suggested other factors which are listed in the Appendix under Q3.

Fig 9: What makes it difficult to recognise changes in mental health? (Those who would not very often or rarely recognise mental health issues)

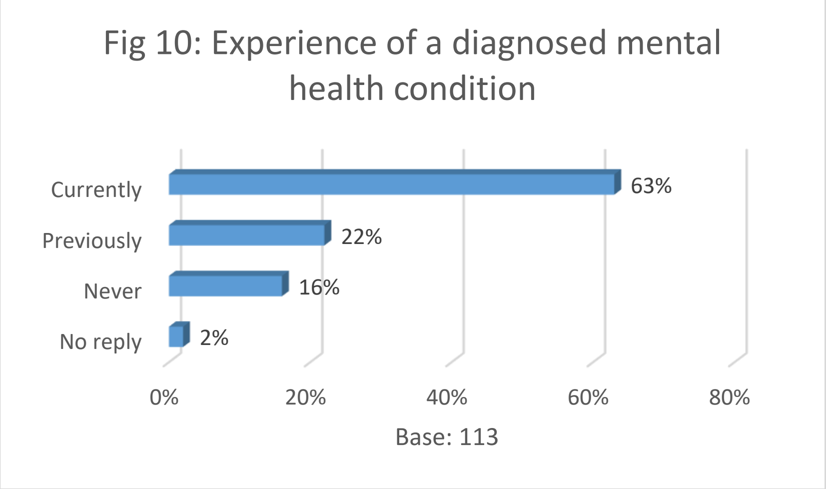
	%
Difficulties recognising emotions	87
Spending a lot of time alone / being isolated	81
Changes in mental health can happen slowly over time	77
Other	16
No reply	3
Base: 31	

3.4 Experience of Mental Health Issues

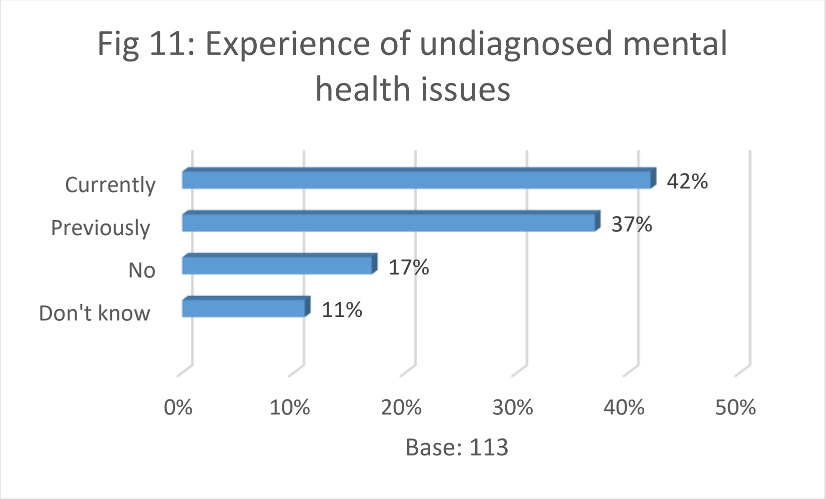
Online Survey

The respondents were asked if they had currently or previously had a diagnosed mental health condition. Almost two thirds had a currently diagnosed mental health conditions and a further 22% had previously had one.

Respondents who were diagnosed as Autistic in childhood appear more likely to have never had a diagnosed mental health condition, 30% compared with 17% diagnosed as Autistic as young adults and 13% of those diagnosed as Autistic after age 20. Those who also had a Learning Disability were also more likely to say they had never had a diagnosed mental health condition, 40% compared with 9% of those who had another ND condition in addition to being Autistic (e.g. ADHD, OCD etc).



Respondents were then asked if they had experienced an ongoing low mood or other undiagnosed mental health condition. The vast majority (79%) had either currently or previously had an undiagnosed mental health issue. In fact only 2 respondents from the total sample had never had either a diagnosed mental health condition or an ongoing undiagnosed mental health issue.



Groups / Depth Interviews

Experience of mental health issues within the groups and depth interviews was broadly consistent with the online survey, however very few had never experienced any mental health issues (diagnosed or otherwise).

It is important to note that some of the respondents we spoke to during the research were currently or had previously experienced very serious mental health crises. There was a real hope that as a result of participating in this process they would be able to change the way mental health services are provided for Autistic people in Scotland. It is fundamentally important that Scottish Government and COSLA now take concrete action to effect real change with urgency. If this is not seen to happen then the trust which has been built up with the community via the Advisory Forum will be broken and we may find to harder to engage with the Autistic community in the future.

3.5 Sources of support for mental health difficulties

Online Survey

There were 110 respondents who had (or previously had) a diagnosed mental health condition or ongoing mental health difficulties that weren't diagnosed. They were asked about where they sought support from. Most commonly, 80% had approached their GP or Practice Nurse. More than half approached friends or family and 37% had sought a private therapist. A range of other sources of support are detailed in the table below, it is apparent that most respondents had tried more than one route to access support. Some additional comments from respondents are listed in the Appendix under Q7.

Fig 12: Where did you go for support (current or previous mental health issues)

	%
GP/Nurse	80
Friends/family	55
Private therapist	37
Charity / third sector	29
School/college/university	26
Other mental health website	25
Employer	16
Breathing Space website	11
Social Care staff	9
Community based support e.g. Social Prescribers, Local Area Co-Ordinator	9
I did not look for support	8
Other	12
Base: 110	

Groups / Depth Interviews

The findings from the qualitative research broadly reflected the online survey with most respondents initially seeking support from their GP and then looking for support from a wide range of sources. Notably, many of the respondents' only positive experience of mental health support had been from accessing private therapy or a third sector organisation.

The survey findings suggest that almost 1 in 10 had not looked for support, however we know from the focus group and depth research that this may not be the whole picture. Indeed, we found that almost all individuals had, at some point in the past, approached various services, however, negative experiences often meant that they did not continue to seek support. It was commonplace for respondents to have one poor experience with a given service which then put them off attempting to re-engage. First experiences with a service were, for many, key to engendering trust and confidence.

"Unfortunately I have a bit of a defeatist attitude and if it doesn't go well then I just won't put myself through it again."

Furthermore, seeking mental health support was very often cyclical. Respondents would experience a period of relatively good mental health, but then more mental health issues would surface. This left many people constantly trying to re-engage with services (or at least wanting to re-engage with services), but often finding that they did not meet certain criteria or that there were no appropriate services.

3.6 Barriers to support for mental health difficulties

Online survey – Reasons for not seeking support

There were 9 respondents who had not sought mental health support and they gave the following reasons:

- I didn't feel confident enough to ask for help (7)
- I didn't know what services were available (5)
- I've tried before and waiting lists were too long (4)
- I tried before and there was no help available (3)
- I tried before and the support didn't help (3)
- I didn't think services would understand my needs (3)
- I didn't think I would be taken seriously (2)
- I wasn't sure if I needed help (1)
- "Felt it was just and appropriate that I suffer because I am not normal" (1)

Groups / Depth Interviews – Reasons for not seeking support

The findings from the online survey were very much echoed in the groups and depth interviews. Usually, the qualitative respondents had sought mental health support at some stage in the past, and a negative experience or multiple negative experiences meant that they were unwilling to try again. Indeed, some had found the process of engaging with mental health services traumatic in and of itself. They often felt that the 'support' had made them feel worse and that they were better off trying to find ways to cope themselves. The most extreme examples of these included respondents who had been mis-diagnosed e.g. Borderline Personality Disorder and had spent years being inappropriately medicated, spending extended periods as an in-patient or even being sectioned.

"In the past I've had to battle with my GP to get referred and then wait ages for the referral to happen. Then the actual support has been really disappointing and upsetting, trying to push me through CBT (Cognitive Behavioural Therapy) and make me keep up with their agenda and then getting angry with me when I'm not keeping up and accusing me of not engaging. I decided I'm better off just trying to cope by myself."

It was also commonplace for respondents to highlight that there were multiple barriers to seeking help which were compounded for Autistic people in mental health crisis. These are explored more in the next section. The most important issue that put people off seeking support were concerns around being able to effectively communicate to a health professional about their mental health when they are already in crisis. This was often worsened as there was an expectation (based on previous experience) that their mental health issues would be trivialised, that they would not be believed or that anxiety/depression would be viewed as a symptom of being Autistic.

"Communicating how I'm feeling is difficult anyway but when you add onto that being essentially in crisis, I don't think I could make myself understood. The last time I did try my GP told me I didn't look depressed and gave me some breathing exercises."

A perceived lack of mental health services in general and more specifically for Autistic adults was also an off-putting factor. For some, this view was based on previous experience of waiting lists or being offered 4-6 counselling/CBT sessions (seen as inadequate/inappropriate). Many others had been advised that because they were Autistic there simply was no mental health service provision available to them.

A very small number of respondents had never sought support for their mental health from statutory services and had instead gone directly to private practitioners in order to avoid waiting lists and/or sought help from specialists with knowledge and experience of Autism.

"It hasn't even occurred to me to ask my GP; I just wouldn't expect there to be anything useful and I know I'd have to build a case to get a referral and then probably wait ages – it's easier just to pay for it."

Online survey – Difficulties accessing support

Those who had a current or previous mental health issue (whether diagnosed or not) were asked what difficulties they had experienced while accessing mental health services. A wide range of issues had been experienced by significant majorities of the sample. Only 1 person reported that they had not experienced any difficulties – most had experienced multiple challenges in seeking mental health support.

The vast majority said they had experienced difficulties with health professionals not understanding Autism (82%). Related to this, 70% said services did not understand their needs, 59% had difficulties communicating with health professionals and 45% said health professionals attributed issues to Autism not to mental health.

There were also related issues with how they had been engaged with, 52% felt they weren't 'believed' or 'listened' to and 56% said they were rejected because they weren't 'unwell' enough. Linked to this is the two thirds of respondents who said there was a lack of ongoing support.

Most had experienced difficulties with waiting lists (70%) but it was also common to find a lack of local services (55% overall but much higher in rural areas and the West) or not to know what services were available (50%).

A large proportion were also anxious about accessing a new service (56%) or said they lacked confidence or were unwilling to ask for help (45%).

There were 13% who made a comment under the 'Other' category, and these are detailed under Q14 in the Appendix. Most of them illustrate the points raised in the following table very clearly.

Fig 13: Difficulties experienced accessing mental health services

	%		%
Health professionals not understanding Autism	82	Not being 'believed' or listened to	52
Waiting lists	70	Not knowing what services were available or where to go for help	50
Services not understanding my needs	70	Health professionals attributed issues to Autism not mental health	45
Lack of ongoing support	66	Lack of confidence / unwilling to ask for help	45
Difficulties communicating with health professionals	59	Not being diagnosed with a mental health condition	25
Being rejected because I wasn't 'unwell' enough	56	I haven't had any difficulties	1
Anxiety about accessing a new service	56	No reply	1
Lack of local services	55	Other	13
Base: 110			

Groups / Depth Interviews – Difficulties accessing support

There were a number of key areas where respondents in the groups and depth interviews reported difficulties accessing support. These difficulties were commonly and extensively experienced.

- Lack of training, understanding and experience of working effectively with Autistic people from health and social care professionals
- Delays in receiving treatment
- Lack of Autism informed / aware / specific services
- Difficulties navigating the 'system'
- Lack of flexibility

Each of these areas is complex and very often they are related and inter-connected. Individual respondents often experience each of these broad difficulties in different ways depending on their own presentation of Autistic traits and the specific services they have accessed or tried to access.

Lack of training, understanding and experience among health and social care professionals

All of the respondents had experienced this to a greater or lesser extent. This criticism was levied across the board from frontline healthcare workers (GP's, Practice Nurses, Receptionists) to mental health specialists and included Social Work. We know that most commonly respondents sought mental health support from their GP in the first instance. GPs were seen as gatekeepers and so a lack of training, experience and understanding around the needs of Autistic people left many feeling that this in itself was a barrier to them receiving appropriate mental healthcare. Whilst some had positive experiences with individual professionals, this usually came from the professional being open minded, flexible and willing to learn from the respondent rather than as a result of their training/experience.

"It starts with the receptionist when you phone up and have to tell them why you need a doctor. Then you get an appointment with the GP, and you have to tell them again. But then half the time I end up going back several times about the same problem because they haven't understood."

"When I'm low I struggle to vocalise what I'm feeling so asking for support can be quite challenging, I'm not providing the correct communication to get to it. A lot of people don't have time to sit and listen to someone who is taking longer to process things."

As an absolute minimum the respondents wanted to be listened to, believed and respected. Many perceived this kind of attitude to be fundamentally missing from their experience. It was commonplace for them to feel they had been misunderstood, dismissed, or their concerns trivialised.

"My experience is when you can articulate your differences and externally control your emotional response and present as capable then the people who are supposed to listen stop listening."

"I need to perform when I access healthcare."

"It's quite upsetting when it has taken quite a lot for you to get there, and I would have to be quite desperate before I'd even ask for help. Then they tell you how you are feeling is normal, everyone feels a bit fed up or they just offer medication."

Most had experienced stereotypical perceptions of an Autistic person. At best this was a source of irritation and frustration, at worst this led to misdiagnosis (e.g. Bi-polar or Borderline Personality Disorder rather than Autism).

"Not getting the right diagnosis triggered years and years of bad and inappropriate treatment. Because my Autism was not diagnosed, I had years and years of being medicated and institutionalised inappropriately. It affected my mental health, my education, my relationships…it was really traumatic and then just being left with a diagnosis of Autism to deal with that, but I also had to deal with the years and years I was in hospital."

Stereotypical perceptions were particularly highlighted by late diagnosed women, BAME and Trans respondents. Lack of understanding around different Autism presentations and the complexities of different cultures was damaging to the respondents.

"Racism is a big issue – I couldn't relate to where she was coming from, but I did get more from CBT with an Asian woman who I understood culturally."

"I had a GP who actually said, 'you don't seem very Autistic'. What do you say to that? They are expecting Autistic people to be white, males who are obsessed with numbers or trains or something."

The respondents gave a host of other examples of where a lack of training, understanding and experience had a significant and negative impact on them including:

- Lack of understanding around the high level of trauma that Autistic adults have usually experienced – compounded by late diagnosis.
- Not understanding that masking may mean an Autistic person does not present as expected.
- Misdiagnosis of Autistic burnout as depression.
- Perceiving anxiety/depression is part of being Autistic and is not treatable so refusing referral.
- Not automatically testing for co-occurring differences when testing adults for Autism which leaves individuals with an incomplete picture and often results in ongoing mental health issues and having to re-engage with services for further testing.
- Using medication as a quick fix (without understanding the impact of medication such as SSRIs on the Autistic brain – lack of research evidence).

"How I present may not be how I am because I'm masking….being told I'm not distressed enough, not believing I am suicidal, understanding I can't express what I'm feeling – when I'm most stoic and quiet it probably means I've shut down because of how intense the emotions are."

"There was limited understanding of Autism, and when they say things like 'it's not your fault you're Autistic' – it just makes me feel more guarded which is counterproductive."

Delays in receiving treatment

It was observed that many Autistic people would only seek mental health support at crisis point. There were several reasons for this including: difficulties recognising there was a mental health issue, anxiety about navigating the system/asking for help or previous negative experiences of seeking help. Long waiting lists were very commonplace which meant that even minor mental health issues had the potential to get to crisis point before any support was made available.

"There have been times in the past when I think I've had depression, but I was concerned they (GP) would be quick to prescribe a pill rather than therapy or psychiatric help. Even if they did refer you then I'd worry about the low grade of care."

"You're in desperate need but then it takes months to get referred and that's when things go horribly wrong. At that critical point there just isn't anyone available."

Those who could afford it often didn't even try to engage with the NHS for this very reason and would try to find support privately.

Some respondents also described being stuck in a referral loop, essentially being bounced from one service to another. Others observed that their mental health was a continuous roller coaster with periods of good mental health often followed by periods of poor mental health. They described a cycle of being referred by their GP, waiting a long time for support, receiving time limited support, feeling ok for a period of time and then having a dip in mental health and so going back to the GP to start the whole process again.

"You get taken off the books and you're in no man's land with no way to contact someone if you're struggling. It's a continuum of life. You know there will be something round the corner because there always is, and I'll have to get back in touch with the GP and start again. It's degrading."

"I go from nothing to something very quickly and it takes my husband to see I'm not ok."

It was seen as potentially dangerous for some very ill respondents to be left on a waiting list where there was no mechanism to check in with them and make sure they were still coping.

The lack of feedback whilst on the waiting list was very challenging for some respondents to cope with and was a source of anxiety in itself. Some respondents who experienced a lack of executive functioning (often worsened by poor mental health) may face barriers such as not understanding a requirement for them to opt in again once they reached the top of the list, or missing a first appointment which meant they went back to the end of the list.

Lack of Autism informed / aware / specific services

Many respondents observed that mental health services for the whole population were in crisis. Outside of private practice and the third sector, it was rare for respondents to feel that they had ever experienced a service which was Autism informed (a service informed by Autistic input). This was seen as a baseline requirement.

Many respondents went further to say that there was a need for Autism specific services, that Autism in and of itself was not a mental health condition but that there was a need for services that recognised and could respond to their needs as Autistic individuals.

"We need Autism specific support. I've been told before that I'm too Autistic for CBT! They don't know how to conceptualise Autism."

"It is insulting and distressing to be told by a neurotypical (NT) counsellor how I am feeling – how could they possibly know?"

Some respondents had been told by primary and/or secondary health services that there was no mental health support for Autistic people. In some cases, this meant that they were not referred on by GPs at all and in others it meant that they were pushed to participate in CBT or group therapy which was clearly not working and on occasion was further negatively impacting mental health. Some of the respondents had raised complaints or expressed their dissatisfaction and were viewed as not co-operating or being difficult – sometimes resulting in their therapy being stopped. This was even the case for some respondents who had tried to engage with the process but were prevented. For example, a woman who became non-verbal during therapy as a result of vague questions she didn't know how to answer e.g. 'how are you today?' Another woman who could not complete the CBT booklet during a therapy session and asked to be able to complete the booklet at home in her own time. In both of these cases the women's therapy was stopped,

"There are no services for Autism, plenty for mental health but nothing that fits us. I get the impression my GP doesn't know what to do with me so it's a case of 'ok we've tried psychotherapy and that didn't work, we tried the counselling so let's try psychiatry'"

It was very common for respondents to have experienced difficulties because they did not present 'as expected' for someone in a mental health crisis. Although this was true across the board it was a particular issue for people who were perceived by health professionals to be 'coping' e.g. those who were working, in a relationship, or who had friends. This was a significant barrier as they were often dismissed, and their difficulties trivialised. They reported being told that they were not 'unwell' enough to qualify for referral. Some of these respondents attempted to persevere and described trying to 'perform' for appointments or to try and build a case for referral.

There were also some specific examples of where Autism specific services were lacking:

- Post-diagnosis support (especially late diagnosis and where support needs were low)
- Transitioning to adult services
- OT input for sensory issues
- Gap in service provision for Complex PTSD (not recognised)
- Lack of Autistic practitioners (suggestion that Autistic practitioners were not valued/listened to/seen as experts within the NHS)
- Big third sector organisations geared up to support children and adolescents – not adults

Difficulties navigating the 'system'

This was a huge barrier to access and engagement. All of the challenges discussed in this section were compounded by poor mental health and often also executive functioning difficulties.

"I need emotional regulation to get through the systems."

"Just the impact of daily living as an Autist makes it hard to access the NHS."

In the first instance there was a lack of awareness of what (if any) services were available to them. There was a perception that even where services did exist there was a lack of awareness/sharing across all stakeholders. Respondents reported this was a particular challenge for some GP's who were reported to acknowledge the need for mental health support but did not know which services they could refer clients to.

"My GP is actually really understanding and is trying to help but just struggling to find me a service."

"Services are effectively hidden by being provided by different random charities and services that don't know about each other."

There was a perception that in order to be able to access support individuals had to be able to self-advocate which was a critical barrier for many. Even making an appointment with a GP often required an explanation to a receptionist. As mentioned earlier, many people felt dismissed and be-littled by their GP, and getting a referral often involved 'performing' or repeat visits to make a case for referral. Even once respondents had been seen by a mental health professional many found there was a significant communication barrier and found it difficult to express themselves. A small proportion noted that they would have wanted to be able to take someone with them to appointments e.g. parent, friend, key worker – to help them explain their challenges and advocate on their behalf. Indeed, this frustration was commonly expressed in the research carried out with parents of Autistic adults.

"I'd feel more confident about going if I could take someone with me – someone who knew me well and could pick up and answer if I couldn't or could tell them what I'm like if my words weren't there."

Challenges with self-advocating were further compounded by the lack of communication routes into referral. It was frequently highlighted that they had to use the phone to make appointments (and sometimes for the appointments themselves in the COVID-19 Pandemic) and for many this was a barrier. Some respondents had tried to get their GPs to allow them to email for an appointment. This 'gatekeeping' at every stage in the process was a cause of distress and frustration.

"You have to be able to advocate for yourself. A lot of people can't, and they shouldn't be discriminated against for that."

Not being able to self-refer to mental health services was a barrier.

Some respondents spoke about the unnecessary distress caused to them, as a result of having to repeat their history (specifically traumatic events) over and over again to different professionals. For these respondents repeating their 'story' felt like re-living events and compounded the trauma.

Inability to engage in support in the 'expected' way has already been highlighted as a difficulty. Respondents felt they were unfairly labelled as 'difficult' or 'not trying' where, in reality, support was simply not tailored to their needs. This could result in support being withdrawn or denied.

Respondents also mentioned that there was no tolerance for missed appointments, lateness, inability to complete 'homework' tasks, forgetting to complete paperwork etc. Given that many Autistic people have difficulties with executive functioning (compounded by mental health issues), this was perceived to deny them a reasonable adaptation to service delivery.

Lack of flexibility

There were a number of issues raised related to a lack of flexibility in approach / reasonable adaptations. It was seen as fundamentally important that support offered was tailored to individual needs as far as possible. A huge range of issues were highlighted:

- Not being to make appointments online or via email.
- Time limited support – often 4-6 sessions, not enough time to build a relationship and develop trust or explore the complexity of issues.
- Emphasis on talking – being unwilling to take on board written communication brought to appointments or to enable people to communicate during sessions in writing.
- Not understanding the stress of travelling to a new place, meeting new people and experiencing a new environment – whilst being expected to be verbal and concise in describing their mental health challenges.
- Offering only group support.
- Sensory environment – medicalised, issues with lighting / smells / seating etc, confrontational seating face to face, formal.
- Vague approach to asking questions which leads to confusion, distress.

"At one point I was asked if I could hear sounds in my head and I said yes, because I have tinnitus but the end result of that was me being sectioned."

"Therapy is all talk based but when I'm very low then I can be non-verbal. It would be good if there was something more activity based so you are doing the activity and talking at the same time which is easier."

"Usually what you get offered is a short course of counselling, maybe 6 sessions or something and then it just ends and maybe you haven't got to resolving anything, but it doesn't matter because you are out."

Impact of difficulties

All of the respondents had experienced a combination of the difficulties outlined here. The impact of those difficulties included:

- Only seeking help when they had reached a crisis situation.
- Giving up on seeking formal support and trying to ignore mental health issues or resolve them alone.
- Significant mistrust and very low expectations or what help might be available to them – therefore less likely to seek future support.
- Exasperating feelings of being different or 'othered' and being excluded from society.
- Lack of mental health support was seen as a life limiting factor e.g., not being able to maintain employment/studies, problems with relationships, not always being able to live independently.
- For some respondents their experience of 'support' only served to further traumatise them and make their mental health worse with several reporting contemplating suicide.

Online Survey – What would encourage them to seek support

All of the respondents were asked what might encourage them to seek help if they were experiencing mental health issues. The vast majority (92%) said they would be more likely to seek support if there was a service available that understood their needs. The need for long term support was highlighted by 79% and a further 63% wanted to know they would be taken seriously (especially if they were diagnosed in adulthood). Over half raised the issue of waiting lists.

Support from friends/family and a whole range of other organisations where there may be a relationship was important to smaller proportions of the sample. Younger respondents under 35 years (but especially those under 25 years) were more likely to value this kind of support from employers, colleges/universities and third sector organisations.

Almost a fifth gave an open-ended comment, and these are detailed under Q9 in the Appendix. Most provide further context and detail for the main points raised below.

Fig 14: Factors that might encourage you to seek support

	%		%
Services being available that understand my needs	92	Support from an organisation I already have a relationship with	30
If I knew there was long term support available	79	Support from a charity	27
If I thought I would be taken seriously	63	Support from school/college/university	23
No waiting lists	56	Support from my employer	23
Support from friends/family	34	Other	18
Base: 113			

3.7 Mental Health Support Received

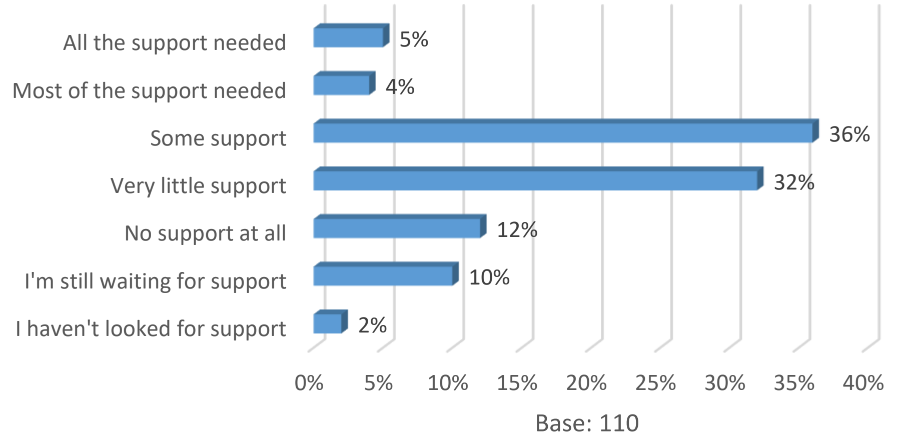
Online Survey – Accessing support needed

There were 110 respondents who previously/currently had experienced a mental health issue (whether diagnosed or not). They were asked if they had been able to access the support they were looking for.

Only 11% said they had got most or all of the support they needed. Just over a third (36%) got some support but the largest proportion got very little (32%) or no support (12%). 1 in 10 were still waiting for support.

People living in rural areas were more likely to have received very little or no support. Respondents from outside the central belt were typically slightly less likely to have received the support needed. People who had a physical disability, Learning Disability or another ND diagnosis were also less likely to have been able to access support.

Fig 15: Were you able to access support?

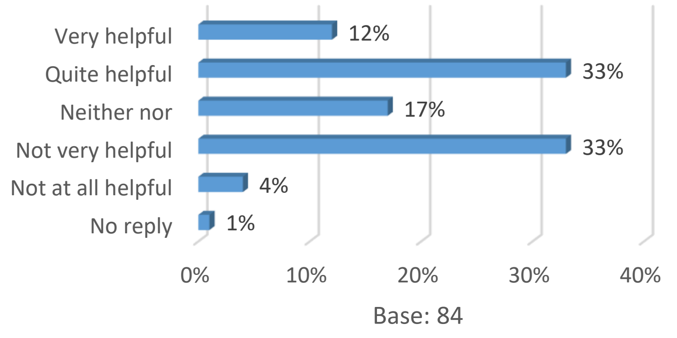


Online Survey – How helpful was support

There were 84 respondents who had received some form of support and they were asked how helpful it had been. Less than half said it had been quite or very helpful (45%). Overall, 37% said the support was not very or not at all helpful. Respondents who were diagnosed as children were more likely to say the support was helpful. Those who had another ND diagnosis were less likely to find the support helpful.

The most helpful support was received from universities/colleges or private therapists.

Fig 16: How helpful was support?



Online Survey – Ways support was helpful

The 38 respondents who said that the support received was helpful were asked why. Over three quarters said they were able to speak to the same person each time. A further 6 in 10 liked the regular support they received, and a similar proportion said that their needs were understood.

Having an appropriate environment was mentioned by a quarter. A smaller proportion highlighted supports around the logistics of the appointments, such as giving written information about what to expect (21%) or clear instructions about where to go (21%).

Almost a fifth mentioned something else, and a full list of these comments can be found in the Appendix under Q13. Some of these comments highlight the problems they had with accessing consistent support as well as positives.

Fig 17: Ways the support was helpful

	%
Able to speak to the same person each time	76
Regular support	61
Understood my needs	58
Environment suited their needs	26
Given written information about what to expect	21
Given clear directions about where to go	21
Other	24
Base: 38	

Groups and Depth Interviews – Ways support was helpful

Positive experiences of mental health services (especially from the NHS) were typically less common, indeed some of the respondents had no positive experiences to draw on.

"Positive experiences are very limited, with anything positive there is always a limit…like it can only go so far."

"You might get one good person like my GP, but she is operating in a system which doesn't cater for Autistic people so there is only ever so much she can do."

The majority of positive experiences were related to individual professionals and usually more to do with their attitude and approach rather than because they had training or experience (although there were some positive examples of third sector Autistic led counselling i.e. led by an Autistic mental health professional). These individuals included GP's, CPN's, private practitioners, Counsellors, Psychologists and Psychotherapists. They were described as: open minded, flexible, empathetic, honest or clear. The impact of their approach was that the respondents felt heard, accepted and believed. Interactions with these individual professionals tended to have a limited impact within the constraints of the NHS. Very often these individuals were the instigators of respondents pursuing a pathway to Autism diagnosis.

"We have a mental health practice nurse, and he goes over and above his duties, he listened and believed."

"I had a great CPN who was just honest and said I don't know anything about Autism, but they went away and did their own research. I felt like they really listened to me and made an effort to understand."

Third sector support in the form of post diagnosis support groups / courses or Autistic led counselling was seen as particularly helpful as they felt understood, accepted and able to work with people they trusted.

"NHS diagnosis tends to look at all the deficits and lacks and then they send you out into the world with a leaflet and all of these negative ideas about what it is to be Autistic but with no support, so you are already feeling 'less than' or 'othered'. The post diagnosis support I had really made me see there are positives and also validated the way I was feeling."

Many of those who had paid privately for therapy or counselling viewed their experience largely positively (aside from the huge cost). These respondents were able to choose to work with someone who specialised in, or had experience of working with, Autistic people. Most importantly the support was not time limited (restricted to x sessions) and respondents typically found the approach more flexible, less structured and more open ended – there was less expectation on them to follow a rigid route or achieve 'milestones' in a certain timeframe. It also provided an opportunity for them to develop trust.

"My private counsellor has put her 'Autistic knowledge' so that's really good – being flexible and able to approach it from a personal point of view rather than assuming I'm just a generic Autistic person."

A small number of respondents had positive experiences with GP's who had adopted a more flexible approach to suit their needs. This included: being able to see the same GP all the time, advance booking regular appointments / check ins, allowing them to communicate in writing or provide written information in an appointment, or allowing extra time for appointments.

"After 7 years of campaigning my GP has finally allowed me to communicate in writing and it has made a huge difference."

Other positive experiences were shared by one or two individuals such as:

- Consistency – being able to see the same person, at the same time and place
- Art therapy – not only talk based
- Autism mentors through university
- Occupational Health Counsellor through employer

"I have a mentor who helps me with planning and organising schedules and that's really helpful, but she also helps me understand my emotions."

3.8 Priorities for Mental Health Services

Online Survey – Type of support wanted

Respondents who had currently/previously experienced mental health issues (whether diagnosed or not) were asked what kind of mental health support they would want to receive. The vast majority of respondents highlighted the importance of Autism informed support (94%). Other key responses were the need for ongoing support as long as it was needed (76%) and one to one talking therapy from a trained therapist (76%).

Almost half said they wanted to find out about environmental/ sensory adaptations that might help (47%) or to have specially adapted resources and support (45%). Support to get help at work / college / university was also valued by 45%. Younger respondents (especially under 25 years) were more likely to highlight this as important.

There were 12% who added a comment and a full list of these can be found in the Appendix under Q10.

Fig 18: Mental Health Support Required

	%
Autism informed support	94
Ongoing support for as long as I needed it	76
One to one talking therapy from a trained therapist	76
Finding out about environmental / sensory adaptations that might help	47
Specially adapted resources and support	45
Support to get help with my employer / college / university	44
Just someone to talk to	35
Medication	31
Online therapy	18
Group therapy sessions	12
Don't know	6
Other	12
Base: 110	

Online Survey – Priorities for improving mental health services

All of the respondents were asked what their top three priorities for improving mental health services for Autistic adults would be.

Three priorities stand out from the following table: improving health professionals understanding, providing support specific to their needs and long term / ongoing mental health support. Also key for smaller proportions were early support when things get difficult to avoid mental health getting worse, mental health support post Autism diagnosis and more local mental health provision.

The findings were broadly consistent across sub-groups, but there were some variations. More local mental health provision was slightly more likely to be mentioned by those living in rural areas, and specifically the North and East. Respondents who also had a Learning Disability were slightly more likely to prioritise more accessible information about mental health issues. Those who had a currently diagnosed mental health condition were more likely to emphasise the importance of ongoing / long term support. Mental health support post Autism diagnosis was much more likely to be highlighted by those who were late diagnosed.

Fig 19: Priorities for Improving Mental Health Services

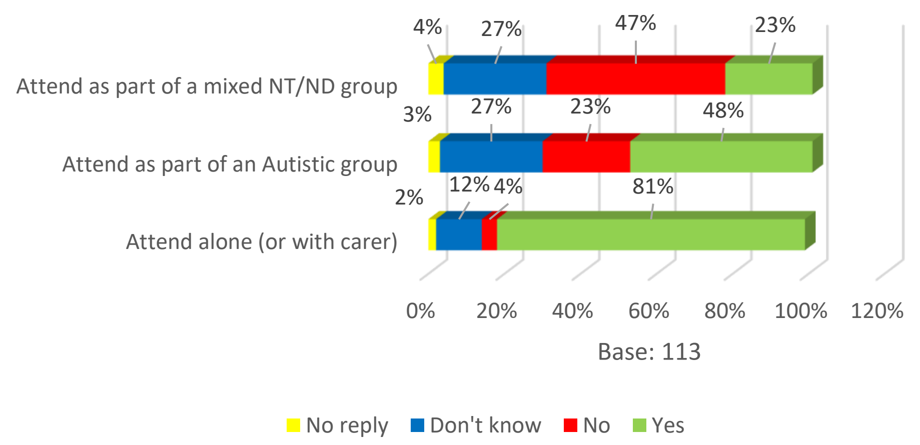
	%
Improve health professionals understanding around mental health and Autism	64
Support specific to the needs of Autistic people	57
Long term / ongoing mental health support	47
Early support when things get difficult to avoid mental health getting worse	36
Mental health support post Autism diagnosis	28
More local mental health provision	22
More advance information about how mental health services work	7
More accessible information about mental health issues	5
Accessing help from an organisation or charity I know and trust	5
Improve awareness of services available – better signposting	4
No reply	5
Base: 113	

Online Survey – Attitudes to self-referred community-based service

The respondents were asked if they had a mental health issue, and there was a community-based service that they could attend without a referral would they consider using it either alone (or with a carer) or as part of a group (with other Autistic people or as part of a mixed group with non-Autistic people). Attending such a service alone (or with a carer) was very well received – 81% would consider using it. Attending as part of a group was not as well received, only 48% would consider using it if it was an Autistic group and 23% if it was a mixed ND/NT (Neurdivergent/Neurotypical) group.

Younger respondents (aged under 25 years) and older respondents (55-64 years) were more likely to consider such a service as part of an Autistic group, than those aged 25-55 years. Respondents who also had a Learning Disability were generally slightly less interested in a self-referred community-based service of any kind. The data suggests that respondents who were not heterosexual or those who identified with a different gender than assigned at birth, were slightly less likely to consider a mixed NT/ND group setting.

Fig 20: Interest in a self-referred community based mental health service



Groups / Depths – Attitudes to self-referred community based service

The qualitative research was very consistent with the online survey in relation to the idea of a community based mental health service that people could self-refer into. The vast majority would consider using such a service if they could attend alone or with an advocate/carer. Self-referral was received very positively and being community based also made it more accessible. They suggested a number of criteria which would make such a service more accessible:

- If you could book online or by email (avoiding telephone contact)
- If there were options to drop in without an appointment
- If it was possible to have regular appointments with the same person
- If it was not limited to 6-8 sessions
- If it did not follow a rigid format and could be adapted to individual needs
- If it was Autistic led (ideal option) or the staff had a high degree of Autism training (ideally Autistic led)
- If it was not in a medical environment
- If the environment was adaptable to sensory needs
- If it was tolerant of executive functioning difficulties

"I like the self-referral part – each step is difficult so if you can take steps out it becomes more accessible."

A small proportion of the respondents would consider using such a service to participate in a group with other Autistic people. These respondents thought there were benefits in sharing experiences with other Autistic people. Some people did not think a group would be a helpful environment for them if their mental health was poor. There were a whole host of reasons for this but fundamentally some people did not feel confident in a group setting and worried that some individuals would dominate.

"The problem with groups is the pressure to talk, it might work if you could just sit and listen and take a break when you needed but then how would that help me?"

Almost none of the respondents would consider using such a service if it was a mixed group of NT and ND people. There was a strong perception that such a group just would not work, that nobody would benefit and indeed it could be very distressing for an Autistic person, who would feel pressured to mask and have difficulties communicating.

"I'd rather poke pins in my eyes than participate in a mixed group"

Online Survey – What would help Autistic people identify poor mental health and seek support

All of the respondents were asked an open-ended question about what would help Autistic people to identify if they need help to improve mental health and seek support. A full list of their comments can be found in the Appendix under Q17. These comments have been analysed and coded and are detailed in the table below. There is a huge wealth of information here supporting many of the points made throughout this report.

A significant minority (42%) did not answer this question. Feedback from the qualitative research would suggest that some respondents felt this question was less relevant to them as they were able to identify if they needed mental health support – it was a lack of appropriate service provision that was a bigger barrier.

A wide range of comments were made, those tabled below being the most common. Although relatively small numbers have made the points below, it is also worth noting that these same points were raised repeatedly in the qualitative research and in earlier questions from the online survey.

There was a strong sense that Autistic people themselves need education or information about things like anxiety, depression, burnout or sensory overload to help them understand their own mental health and adaptations could support them (21%). Similarly 7% highlighted a need for post diagnosis support - sometimes this was related to mental health specifically or how to manage their general wellbeing and for others it was about support to help them assimilate how they felt about the diagnosis and the impact on their lives.

Better training for health and social care professionals (14%) or specifically mental health professionals (12%) was also identified as valuable. Indeed a further 8% spoke about the need for Autism aware/informed services and 6% said there was a need for Autism specific or specialist services. 12% said they wanted to be listened to / valued / believed / taken seriously which was typically related to a lack of Autism understanding. Related to these points were 3% who were frustrated by mental health issues being attributed to Autism and 2% who thought there was a need for better understanding of co-occurring differences such as ADHD, eating disorders etc.

There were also 12% who identified a need for better continuity of relationships or the availability of ongoing informal support. A further 3% said they wanted long-term support as needed.

Fig 21: Factors that would help identify if they need mental health support and seek help

	%		%
Education for Autistic people about anxiety / depression / burnout / sensory overload	21	Making it easier to function in society / acknowledging this negatively impacts mental health	6
Better training for all health / social care professionals	14	Support tailored to individual needs	4
Being listened to / valued / believed / taken seriously	12	Don't attribute mental health issues to Autism	3
Better training for mental health professionals	12	Availability of long-term support as needed	3
Better continuity of relationships / ongoing informal support	12	Better understanding of co-occurring differences	2
Autism informed / aware services	8	Don't know	2
Post diagnosis support	7	Other	27
Autism specific / specialist services	6	No reply	42
Base: 113			

Online Survey – How to improve access to and experience of mental health services

All of the respondents were asked an open-ended question about how to improve access to, and experience of the right support for mental health at the right time for Autistic adults. A full list of their comments can be found in the Appendix under Q20, these comments have been analysed and coded and are detailed in the following table.

Again, a significant minority did not answer this question (35%), however the comments made clearly support the responses to other questions in the survey and also the feedback from the focus groups.

Better training for health and social care professionals (12%) and mental health professionals (14%) was the most frequently made comment. A further 6% said an Autism aware/informed service would improve access and a further 4% wanted specialist Autism services. A small proportion (3%) suggested that training should involve Autistic people. A further 5% said it was important to ensure that 'support' offered did not cause further trauma and there are some clear examples of this within the open-ended comments. Related to the training issue, a further 4% again mentioned the need for services to listen to, value, and believe them, and to take their needs seriously.

The need for adaptations around communication by providing clear information in advance was highlighted by 8%. This need for flexibility was also clear with 5% wanting a variety of communication routes (especially not a requirement to book by phone) a further 5% commenting on the need for the environment to be suitable/adaptable to individual needs.

The importance of ongoing / long term support as needed was mentioned by 5%. In a similar vein there was 12% who wanted to have some continuity of relationships on an ongoing informal basis. Being able to get support when it was needed was critical – 5% wanted reduced waiting lists, another 4% said it should be easier to get a referral or that barriers to referral should be removed and 3% wanted it to be easier to get early intervention to avoid a crisis situation.

Fig 22: Factors that would improve access to and experience of mental health services

	%		%
Better training for mental health staff	14	Specialist Autism services	4
Better training for all health / social care professionals	12	Being listened to / valued / believed / taken seriously	4
Better continuity of relationships / ongoing informal relationships e.g. designated key worker	12	Easier referral / self-referral / remove barriers to referral	4
Clear information – how to get there / what to expect / what to do next / photo of person being seen	8	Involve Autistic people in delivering training	3
Autism informed / aware services	6	Listen to / enable input from parents / carers / other advocates where wanted	3
Support post Autism diagnosis	6	Easier to get early intervention / support	3
Ongoing / long term support as needed	5	Making it easier to function in society / acknowledge this impacts mental health	2
Variety of communication routes – not relying on telephone	5	Don't know	2
Environment – consistent meeting space, adaptable to sensory needs	5	Other	38
Ensure support does not re-traumatise	5	No reply	35
Reduce waiting lists	5		
Base: 113			

Groups and Depth Interviews – How to improve access to and experience of mental health services

The respondents in the qualitative research came up with extensive suggestions to improve access to and experience of mental health services for Autistic adults. These suggestions very much align with the difficulties reported earlier.

- Training health and social care professionals, to ensure services are Autism informed
- Autistic Informed Support
- Remove barriers to receiving support timeously
- Make it easier to navigate the 'system'
- Enable flexibility of approach tailored to the individual
- Provide ongoing, informal support

Training

There was a need for training for frontline medical staff (e.g. anyone working in a General Practice setting) to ensure that they were better able to identify where Autism may be connected to ongoing mental health issues in someone not diagnosed and also to ensure they properly understand the relationship between Autism and mental health. It was important that this training was mandatory but did not take the form of simplistic online learning. Training was also seen as essential for mental health professionals who were often perceived to believe they had more knowledge and understanding and yet their approach was often seen as medicalised and based on misconceptions and stereotypes.

"The whole of society needs to understand Autism better but especially in the NHS. Lack of training is a barrier to us receiving appropriate treatment and it has to be addressed."

"Training is really important but not just some online thing you do in 2 hours, not just a tick box effort."

Some of the key suggestions for training were that it should:

- Use a social rather than medical model of Autism, emphasising Autistic individuals' strengths and potential given the right support and environment. Dispel common misunderstandings e.g. Autistic burnout being diagnosed as depression or individuals who were perceived to be 'coping' in some ways (employed, in a relationship etc) being seen as capable in all aspects of their lives without support.
- Foster patient listening, believing, understanding, and respecting Autistic individuals. Encourage professionals to be open to questions and willing to admit when they don't have all the answers.
- Provide a detailed understanding of the range of differences in the way an Autistic person might communicate (or prefer to communicate) e.g. the importance of asking explicit questions, the role masking might play. Also highlighting that many Autistic people could find it difficult to recognise and then verbalise their emotions.
- Ideally Autistic led, but as a minimum should be Autistic informed.
- Be trauma informed.
- Highlight the potential for co-occurring differences and the value of also having those diagnosed.
- Teach how to tailor support to individual needs.

"Professionals don't recognise degrees of distress expressed in a different way. They may need to probe more and understand differences in Autistic communication."

"GP's should listen sympathetically and understand then refer to someone trained in Autism who can signpost you to the right support and you should be monitored fortnightly or monthly."

"Distinguishing between a low mood and depression and melt down or burnt out – they are very different in Autistic people – so understanding the complexities."

<u>Autistic informed support</u>

In many ways the training as described above was seen to contribute significantly to Autism informed support. Some respondents thought it was necessary for support to be Autistic led for it to be really impactful. Autistic input into service design and delivery was highly valued.

"Not necessarily Autistic led because I understand that won't always be possible but Autistic informed. I'd like to speak to another Autistic person for that feeling of validation."

"It's really important we are consulted and involved in the process – so co-designing services from day one. When you consult with Neurodivergent people, the input we give covers Neurotypical people as well so if you design with Neurodivergent people in mind you're making services better for everyone."

"Involve Autistic people in the design and facilitation of programmes tailored to our foremost needs, linking physical and mental health. Some of the challenge is recognising how we feel and adapting processes to us."

For the support to be truly Autistic informed there was a need for services to deal holistically with individuals who may have complex profiles. There was a need to understand mental health difficulties in Autistic adults where they may be from BAME communities, or where there are differences in the way that gender and sexuality are perceived, or where there are co-occurring differences, or where there is CPTSD, or where there are eating disorders and so on. This was seen to require diversity in the workforce, training and above all open minds and flexible approaches.

"People are seen as too complex or with multiple diagnosis can end up in a revolving door situation because services are aimed at targeting only one issue."

"More joined up thinking. Autism falls with Learning Difficulties but if you don't have a Learning Difficulty then where do you go because Autism isn't a mental health condition."

"I have been told I have Complex PTSD and then told but we don't have any services to deal with that. I don't fit into this service because I'm Autistic and I can't go here because of that. There isn't a nice, neat box to put me in."

Remove barriers to timeous support

Fundamentally this priority is about reducing waiting lists and enabling quick access into appropriate services to avoid mental health worsening. It is also related to:

- Making it easier to get a referral or possible to self-refer into a service.
- Taking measures to encourage and support Autistic people to seek support before they reach a crisis point i.e. by addressing the other suggestions made in this section.

"Give me confidence that there is going to be support there at the right time."

Make it easier to navigate the system

A host of practical suggestions were made to make it easier for Autistic individuals to access the support they need.

- Adapt existing support to suit Autistic needs e.g. CBT doesn't work for many Autists.
- Take into account communication preferences to make it easier to make appointments and request prescriptions (e.g. minimising the need for phone calls).
- Accept and accommodate executive functioning issues e.g. missing appointments.
- Provide clear, written information about what to expect in advance – directions, pictures of the waiting room, pictures of the person being seen, how to prepare etc.
- Better sharing of information between health and social care.
- Ideally there should be consistency in the professional seen, appointment time and place.

"More information up front so I can read things and know what to expect."

"Reducing human contact makes it less frightening at the outset so definitely more things online."

Enable flexibility of approach tailored to the individual

- Accommodate communication preferences during appointments and allow people to bring written notes or write during appointments.
- Where it is desired enable people to bring someone to advocate for them or to speak on their behalf / fill in gaps.
- Allow more time for appointments if desired – adopt a slower pace. Equally some may prefer shorter appointments.

- Offer a range of therapy options to suit the individual e.g. 1-2-1, Autistic groups, digital appointments, creative/non-talking therapy.
- Provide an Autism informed environment in waiting rooms and consulting areas.

"Patience – I communicate through writing mostly so I need a minute to speak."

Provide ongoing, informal support

It was frequently highlighted during the research that many Autistic people experience 'cycles' of good and then poor mental health throughout their lives.

"The approach is short term, and they hand you back to the GP. My mental health fluctuates so I may distance myself from services for a time but then I need to re-engage."

To avoid the need to constantly re-engage with services and long periods of time on waiting lists, it was suggested that there was a need for ongoing, light touch, informal support which could quickly be escalated where required.

"Lots of us are able and have a lot of skills. It's not long-term, full-time care we need it's appropriate intervention at the right time so it's about flexibility."

"Mental health services are often reactive and set up to respond to crisis. It's so much better to have support so we can avoid going into crisis."

There were some variations in the exact format of how this support might work, but commonly it was thought that it should include the following elements:

- An opportunity for peer support which would offer validation and help Autistic people to better understand themselves. It should enable individuals to feel part of a wider community with shared common experiences.
- Targeted support at key times such as post diagnosis or transitioning from adult services.
- Autistic led mental health support – inspiring, encouraging and positive.
- The ability for people to drop-in and participate in talks and activities or just have a coffee and a chat.
- Have an informal focus on helping people to better understand their own mental health and the routes available to them should they need more support.
- Offer an advocacy service to support Autistic people to access mental health services.
- Based in the community not in a clinical setting.

Effectively what is being described here is a service not unlike some of the services which already exist in certain areas served by third sector organisations. Many respondents had no previous awareness of such a service and yet described the value it would have in their life were it to be available to them locally. It was felt that this would have many benefits for mental health and much more broadly:

- Helping Autistic people to recognise when they may be experiencing poor mental health but also providing a community where others may help them to identify mental health issues – regular check ins.
- Enable Autistic individuals to develop an ongoing relationship of trust and offer consistency in the way they are supported.
- Ongoing, light touch, informal support would help avoid Autistic people reaching crisis point and having to access secondary mental health care services.

- Such support would also have a positive impact on confidence and self-esteem, and indeed other areas of life such as employment, relationships, physical health etc.

"I didn't come out as Autistic until I was an adult and I remember how hard it was to disclose. You have to have confidence to talk about it and feel 'I don't need to hide it'"

"Boosting self esteem and enabling us to see positive aspects of autism as well."

"If people understand themselves better then their mental health is improved."

"We need to hook services up with social/practical help. How are you meant to have good mental health when you have poor housing, are unemployed etc. – it's not enough to frame it medically – our mental health is a sensible response to a shit situation."

"Connecting with the wider Autistic community helps you to reflect on what Autism means for you – managing disconnect, burnout, double empathy – we should be encouraged to do that."

4. Summary of Key Issues

Experience of diagnosed or undiagnosed mental health issues was very common – only 2 respondents from the online survey thought they had never had mental health issues. 63% had a current diagnosed mental health condition and a further 42% had a current undiagnosed mental health issue. In the qualitative research most respondents spoke about experiencing a continuous cycle of mental health variation, where it might be good for a while, and then almost inevitably would dip. Their experience of seeking and receiving mental health support was generally quite poor – only 11% got most or all of the support they needed. Of those who got any support, only 45% said it was helpful. Indeed, the qualitative research found that most positive experiences were related to the attitude and approach of individual health professionals who were perceived to have limited impact working within the constraints of the NHS.

Difficulties experienced when accessing services were extensive – only one hadn't had any difficulties, and most reported multiple and complex barriers. Fundamentally, there was a perceived lack of Autism understanding among health professionals (82%). Waiting lists (70%), and delays to receiving treatment were commonplace (and problematic because many Autistic people don't ask for help until they reach crisis point). There was a strong sense that services did not understand their needs (70%) and were not tailored or adapted to make them worthwhile. Two thirds spoke about a lack of ongoing support and difficulties navigating the system were commonplace (56% were anxious about accessing a new service, 50% didn't know where to go for help, and 55% experienced a lack of local services).

There is a lot of frustration, mistrust, and cynicism from within the community as a result of previous negative experiences. Enabling access to appropriate mental health services starts with the first contact they make to ask for help. Poor experiences at any stage in the process can cause some Autistic people to retreat and withdraw, increasing the chances of them experiencing a much more significant mental health crisis. It's very important a flexible approach is adopted from the first contact.

One of the key observations coming out of the research is the very strong desire for more Autistic involvement and direction in service design, training and delivery. Whilst in an ideal world many respondents wanted all services to be delivered by Autistic health professionals, the next best thing was for training to be designed and delivered by Autistic people.

The following recommendations are made based on the findings from this research alone.

Specific to Primary Care (including social care and community based support)

- Autism informed training for all frontline staff but especially GP's to improve Autism understanding and the relationship with mental health. The vast majority of respondents had approached their GP for help with mental health issues, and it is essential for them to have a much better understanding.
- Make it easier to make appointments, e.g. enabling online appointment booking or email booking, removing the requirement to explain to receptionists why they need to see a GP.
- Adults presenting with repeated mental health issues such as anxiety, depression, self-harm, or eating disorders to be more routinely screened for Autism to reduce the incidence of misdiagnosis and enable appropriate support.
- Improve awareness of mental health services (including third sector) across all health and social care organisations.
- Offer longer appointment times to Autistic people who may need longer to communicate.
- Enable them to bring a friend/family member/other advocate where desired.

Specific to Secondary Care Mental Health Services

- Autism informed training, specifically around how to adapt approaches for the wide range of Autistic people they may treat.
- Where waiting lists are long there should be communication about the expected waiting time, self-care suggestions, information about how to get help quicker if things get worse.
- Provide clear information in advance (directions, transport, photographs (locations and people), what to expect when they arrive, set waiting time expectations, how long will the appointment take, who they will see, what will be asked/discussed, what happens next).
- Establish any sensory and communication needs (ideally in advance) and adapt the environment and approach to suit their needs.
- Offer alternative approaches to suit their needs, e.g. 1-2-1, Autistic groups, digital, creative therapy etc.
- Enable longer or shorter appointments to meet their needs – allow time for questions to be processed and answers considered.

General Recommendations

- Enable Autistic people to communicate in their preferred way, e.g. offering digital appointments, allowing people to bring written notes, communicating in writing during the appointment.
- If appointments are running late keep the Autistic person informed.
- Keep questions specific and offer examples of the type of answer they might give.
- Make allowances for difficulties with executive functioning, e.g. missing appointments – offer reminders

Fundamental Need for Ongoing Support

The recommendations above relate to services as they are provided now and can be applied to many other settings, however, they don't address the needs of the 76% who said they wanted ongoing support for as long as they needed it. Although about a fifth of respondents thought they would always recognise if they were having mental health issues, there was a lot of variability. Over half thought they would sometimes be able to recognise them, and a quarter would do so not very often or rarely. In part, ongoing support would help Autistic individuals to recognise mental health issues early and seek support thus avoiding crisis. It would also avoid the need to constantly re-engage with services and spend long periods of time on waiting lists. Importantly this was very often not seen as a requirement for ongoing intensive mental health support but for a more informal, light touch approach which could be escalated quickly when necessary. There were key times when such support was particularly important in preventing mental health issues e.g. post diagnosis, transition to adult services. Often what was being described was very similar to some services offered in some areas by third sector One Stop Shops but on a much larger scale, accessible to more Autistic people all over Scotland.

One of the suggestions in the research was for a self-referred community based mental health service. This idea was received very positively by the respondents (assuming it followed the recommendations above and was only for Autistic people). Indeed, some respondents linked together their suggestions for ongoing, informal support in the community (described above) with a self-referred, Autism informed, mental health service – creating Autistic hubs where a wide range of services could be offered to support Autistic people to live full lives.

5. Future Priorities

It is worth noting that some of the respondents we spoke to were very frustrated about being asked to participate in the research because they felt the nature of the questions was very repetitive – there was a strong sense that these questions had been asked before and problems were well known. For future topics a literature review should be carried out in advance to help identify any gaps in understanding and knowledge. Then Autistic people should be involved in developing the topic area and defining the research objectives.

The respondents were asked about other topic areas which could be considered in the future using this broad approach. Most common were:

- Employment – getting into and maintaining employment, reasonable adjustments, training, mentoring/coaching, equality in the workplace
- Education – primary, secondary, higher and further – advocating, reasonable adjustments, support, positive role models, mentoring, supporting Autistic parents
- Ageing and Autism – housing, care homes, social care
- Diagnosis and post-diagnosis – making it easier to get tested, better screening in primary care/education/social work, support during and after diagnosis, late diagnosis, better screening for co-occurring differences (especially for late diagnosed), positive affirmation
- Improving awareness and understanding of Autism in the general public, and all areas of life in Scotland

Others which were more specific included:

- Eating disorders – appropriate treatment and care for Autistic individuals, given the high prevalence within the community
- Young people in care - improving diagnosis and support
- Engaging with local government
- Transitions for young adults – into further and higher education, volunteering, work
- Getting day to day support for executive functioning – life skills, coping skills
- Address the medical model of Autism

Others mentioned by a minority included:

- Promoting Autistic joy / friendship

Appendix – Questionnaire

Accessing Mental Health Services - Autistic Community

We have been commissioned by Scottish Government and COSLA and are working with Inspiring Scotland to improve understanding of the experiences Autistic people have identifying mental health issues and getting help. The findings will be used to improve mental health services for Autistic people.

Mental health includes our emotional, psychological, and social well-being. It affects how we think, feel, and act. It also helps determine how we handle stress, relate to others, and make choices. Mental health is important at every stage of life, from childhood and adolescence through to adulthood.

This research is anonymous and confidential. This questionnaire should take around 10 minutes to complete. Your feedback is returned directly to Assenti Research who are governed by the Market Research Society. If you have any questions about the research or any difficulties taking part please contact Sinead on 0774 0911976 or sinead@assenti-research.co.uk

This survey seeks the views of Autistic adults. The next stage will then be a series of more in-depth focus groups.

Q1 What helps you to have good mental health? (Tick all that apply)
Having a daily routine
Doing a job I enjoy
Feeling supported at work/in education
Support from friends or family
Having someone to talk to if I have a problem
Being part of a community
Special interests or hobbies
Exercise
Autism appropriate environments - avoiding sensory overload
Anything else? (Please explain below)

Q2 How often would you be able to recognise if you were experiencing mental health issues e.g. depression, anxiety, OCD (Obsessive Compulsive Disorder), low mood, eating disorder etc? (Tick one box)
Always
Sometimes
Not very often
Rarely
Not sure

Q3 What do you think makes (or has made) it difficult for you to recognise if there are changes in your own mental health? (Tick all that apply)
Changes in mental health can happen slowly over time
Spending a lot of time alone/being isolated
Difficulties recognising emotions
Anything else? (Please explain below)

Q4 Are you currently or have you previously had a diagnosed mental health condition which may include (but not limited to) depression, anxiety, eating disorder or OCD? (Tick one box)
I currently have a diagnosed mental health condition
I have previously had a diagnosed mental health condition
I have never had a diagnosed mental health condition

Q5 Have you experienced having an ongoing low mood or other mental health issues which haven't been diagnosed? (Tick one box)
Currently
Previously
No
Don't know

Q6 If Q4=3 or Q5=3,4 If you thought you were experiencing mental health difficulties where would you expect to go for support? (Tick all that apply)
Friends/family
GP
Employer
School/College/University
Charity/third sector organisation
Social Care Staff
Community based support e.g. Social Prescriber, Local Area Coordinator
Breathing Space website
Other websites about mental health
Private therapist
I probably wouldn't try to find support
I don't know
Anything else? (Please explain below)

Q7 Q4=1,2 or Q5=1,2 Did you seek support for your mental health issues? (Tick all that apply)
From friends/family
From your GP
From your employer
From school/college/university
From a charity/third sector organisation
Social Care Staff
Community based support e.g. Social Prescriber, Local Area Coordinator
Breathing Space website
Other websites about mental health
From a private therapist
No I did not look for any support
Anything else? (Please explain below)

Q8 Q7=11 What factors prevented you from trying to find support for your mental health issues? (Tick all that apply)
I've tried before and the waiting lists were too long
I've tried before and there was no help available
I've tried before and the support available didn't help
I didn't know what help was available
I didn't think services would understand my needs
I didn't think services would take me seriously

I wasn't sure if I needed help
I didn't feel confident enough to ask for help
Anything else? (Please explain below)

Q9 What might encourage you to seek help if you were experiencing mental health issues? (Tick all that apply)
If I thought I would be taken seriously
If I knew there was long term support available
Services being available that understand my needs
No waiting lists
Support from an organisation I already have a relationship with
Support from my employer
Support from my school/college/university
Support from friends/family
Support from a third sector organisation
Anything else? (Please explain below)

Q10 Q4=1,2 or Q5=1,2 If you were experiencing difficulties, what kind of mental health support would you want to receive? (Tick all that apply)
Just someone to talk to
One to one talking therapy from a trained therapist
Group therapy sessions
Medication
Autism informed support
Support to get help with my employer/college/uni
Specially adapted resources and support
Finding out about environmental/sensory adaptations that might help me
Online therapy
Ongoing support for as long as I needed it
I don't know
Anything else? (Please explain below)

Q11 Q4=1,2 or Q5=1,2 Were you able to access the support you were/are looking for? (Tick one box)
I got all the support I needed
I got most of the support I needed
I got some support
I got very little support
I got no support at all
I'm still waiting for support
I haven't looked for support

Q12 Q11=1,2,3,4 How helpful has the support you have received been? (Tick one box)
Very helpful
Quite helpful
Neither helpful nor unhelpful
Not very helpful
Not at all helpful

Q13 Q12=1/2 In what way was the support you received helpful? (Tick all that apply)
They understood my needs
I was given written information about what to expect
I was able to speak to the same person each time
I got regular support
I was given clear directions about where to go
The environment suited my needs
Anything else? (Please explain below)

Q14 Q4=1,2 or Q5=1,2 Thinking about mental health services, which of the following difficulties have you experienced? (Tick all that apply)
Waiting lists
Health professionals not understanding Autism
Health professionals attributed issues to Autism not poor mental health
Anxiety about accessing a new service
Services not understanding my needs
Being rejected because I wasn't 'unwell' enough
Not being 'believed' or listened to
Not being diagnosed with a mental health condition
Lack of local services
Lack of ongoing support
Not knowing what services were available or where to go for help
Difficulties communicating with health professionals
Lack of confidence/unwilling to ask for help
I haven't had any difficulties
Anything else? (Please explain below)

Q15 Which of the following would be your top three priorities for improving mental health services for Autistic adults? (Please tick three boxes)
More accessible information about mental health issues
Improve health professionals understanding around mental health and Autism/Learning Disabilities
More local mental health provision
Support specific to the needs of Autistic people or people with Learning Disabilities
Long term/ongoing mental health support
Improve awareness of services available - better signposting
More information in advance about how mental health services work
Early support when things get difficult to avoid their mental health getting worse
Mental health support after diagnosis
Accessing help from an organisation or charity I know and trust

Q16 If you had mental health difficulties and there was a community based service that you could attend without a referral would you consider using it.....? (Tick on box on each line)
To attend alone
To attend as part of group with other Autistic people
To attend as part of a group which might include Autistic and non Autistic people

Q17 How can we help Autistic people to identify if they need support to improve mental health and seek help? (Please type in below)

Q18 How can we improve access to and experiences of the right support for mental health at the right time for Autistic people? (Please type in below)

The following questions are asked to help us understand more about you and the services you need.

Q19 When did you receive your Autism diagnosis?
Child (under 16)
Young adult (16-20)
Adult (over 20)

Q20 Current Age (Tick one box)
16-24
25-34
35-44
45-54
55-64
65+
Prefer not to say

Q21 Which of these best describes the area where you live? (Tick one box)
Urban e.g. a town or city
Semi-rural e.g. a small town or village
Rural

Q22 Where in Scotland do you live? (Tick one box)
Central
West
East
North
South

Q23 Do you have......? (Tick all that apply)
A physical disability which affects your daily life
A learning disability which affects your daily life
A Neurodevelopmental condition in addition to Autism e.g. ADHD, Tourette's, FASD, DLD, Dyslexia etc
None of the above
Not sure

Q24 What is your ethnic group? (Tick one box)
African, Caribbean or Black
Asian
Mixed or multiple ethnic groups
White
Other ethnic group
Prefer not to say

Q25 Which of the following best describes your sexual orientation? (Tick one box)
Bisexual
Gay or lesbian
Straight or heterosexual
Other sexual orientation
Prefer not to say

Q26 Is the gender you identify with the same as assigned at birth? (Tick one box)
Yes
No
Prefer not to say

Thank you for helping with this research. We will provide feedback to let you know what action is being taken next. Please click 'Submit' to finish and send the questionnaire to us.

Appendix – Open Ended Comments

Q3 What do you think makes (or has made) it difficult for you to recognise if there are changes in your own mental health? (Other)

"I have only recently understood what emotions are, so had no idea previously what I was experiencing or how to respond to it."

"I suppose for things like anxiety I feel like I have always experienced, and it is a big problem I deal with, yet I still can struggle with identifying that that is what I am feeling. I think there is also burnout, I think this can make it hard because I can be doing okay and then, well, I am just so drained, and I am not okay anymore. I think rules are an issue too, like when something is wrong with my mental health I start to lose routines, but then I am upset about each individual time routine is messed up that I am too busy focusing on things like that to actually realise the trend, like I can be like ""ahhh this is messed up just like it was last week!"" but I am too upset by it and dealing with that upset to think about why I am losing these routines, I need others to point these things out."

"If I ask other people for confirmation that my mental health has changed, they often aren't sure what normal emotions are like for autistic people."

"Only having my own experience means I don't know what is actually typical and when I'm being different from the norm"

"Lack of formal support"

Q7 Did you seek support for your mental health issues? (Other)

"Social Work"

"Peer support"

"NHS and CAMHS also psych wards"

"Self-care: extra attention to exercise, meditation, reducing stressors"

"It’s tiring and before when I did ask for help the GP stared at me after I said I was feeling like nothing mattered anymore, and I didn’t see the point, and I am struggling a lot, and said she did not know what I was asking and that she did not understand how to help me"

"In my past experience, employer services don't always have well qualified people, or anyone qualified to deal with autism. I have been advised by autism support organisation to avoid. I contacted the adult autism support charity in Edinburgh, Number 6, who have been helpful in the past, but got no reply - which seems to be typical, so I know many autistic people no longer even try."

"CMHT"

"Pam assist a support service from work"

"Amongst many inappropriate NHS interventions (no understanding of Autism), I eventually was funded by Access to Work to attend a private counsellor. I cannot have this access on the NHS - there is not an appropriate service!"

"Psychiatry"

"Tried mental health services but they refused to even assess"

"I am aware that Meltdown & recovery can be seen by those ignorant of ASD as rapid cycling bipolar disorder. How many are misdiagnosed, forced to use meds, and risk sections as BP is a psychotic disorder. I forced discharge post dx 13 years ago with the help of PAS via CAB. I would not go near MH services here. A friends friends’ wife was sectioned 24th Dec 20. Hubby packed a bag. Clothes, phone & charger. No bag was searched. She hung herself w/ charger cable in a locked ward within hours of admittance. Died 1s t Jan 21. I won't engage. I briefly used a psychotherapist. For 2 sessions he repeatedly clicked his ankle joint. I said nothing but asked re his knowledge of ASD. He said he had none. 3rd visit I asked about ""ankle"". He was looking to see how I would react. It was damn annoying. As he was secretly assessing me, I walked out never went back. I waited 2 plus years for this appt"

"There is a huge difference between seeking support and support being given. Following this, the support offered is not autism informed. This is damaging"

Q9 What might encourage you to seek help if you were experiencing mental health issues? (Other)

"If I knew I could afford the support. If I knew that I would not need to educate the people I ask for support from. If I did not need to evaluate the risks of asking for help (e.g. one person's judgment means potentially having less chance to get access to support in the future). If I felt that services available actually went through unconscious bias training or were prepared to learn (if it's not being autistic that trips them up, it's being disabled, or being read as a woman, or being fat, or being an immigrant, or being queer, or... usually it's a mix of all of the above)"

"If I could speak to someone with experience working with autistic adults. Almost all my mental health issues stem from my autism, and having to explain that every time I see a professional can sometimes be a bit exhausting."

"Accessible cost"

"Care provided by practitioners with a good understanding of Autism"

"If I would not have to navigate complicated or difficult processes like going new places or having to explain to several different people why I want help then be expected to say what kind of help I want (isn't that their job?)"

"Understand autism, don't turn me down due to being autistic, adapt therapy to suit autistic people"

"Not just being told to make a cup of tea and have a bath"

"It would help if I knew who I would be talking to e.g. someone at GP surgery."

"I don’t know what or who to turn to. I often do not realise what is wrong and this can deteriorate if it isn’t picked up by another person."

"Clarity about the procedure; where do you start, how will appointments/screening go etc. Also knowing you won't be rejected because 'too complex' or something of the sort"

"Assistance that takes my autism into consideration during treatment."

"I may not be able to recognise my needs and therefore are dependent upon those around me advocating on my behalf"

"Hope that they would actually be able to help rather than being told either I'm too broken to help or that they're a mental health service and don't deal with autism (despite also having mental health problems)"

"Confidence that they had up to date understanding of what autism actually is. It’s exhausting having to teach someone basics about autism while you are very unwell. Especially if they do not listen"

"Finding mental health care professionals who have a genuine and in-depth understanding of autism. AFAIK conventional CBT is not compatible with many autistic individuals, who can struggle with the self-reflection, self-awareness, communicating their thoughts and emotions the list goes on. I don't know if there's any research there is on this but I think perhaps the double empathy problem means that NT mental health professionals will struggle to support autistic individuals as there are too many communication gaps."

"Support from someone/an organisation who fully understands Autism, and which is really prepared to make the reasonable adjustments to the environment - it is exhausting and disempowering to constantly have to ask/explain!!"

"The fact that I have a dependent autistic person who might become unwell because of my own issues with trauma and anxiety."

"Any organisation or individual supporting autistic individuals needs to know and understand autism. My experience and that of many, many others is the total opposite"

"Autism centred support for adults"

"The option for a text or email service from mental health services. I often need to call the duty mental health in the Adult Mental Health Team but don't because I can't always articulate what is happening in a verbal way"

Q10 If you were experiencing mental health difficulties, what kind of mental health support would you want to receive? (Other)

"Support groups for neuro diverse adults"

"Information - informed advice on e.g. whether medication might be a good fit or what to expect from it, or what mental health diagnosis might be a best fit and why etc. - in my experience, I have needed to bring up and insist on specific labels with any healthcare professional, with them at most being used to dismiss physical health concerns out of hand but never being given any form of support around it. I would also love more practical support - things like advice on how to adjust workouts or how to work around food sensitivities, as they both impact my mental health greatly and it is a nightmare to try and find actual advice for autistic people on those topics."

"Specifically adapted to suit me. Someone I can trust and feel comfortable talking too. Ongoing support not just for 6 weeks. Someone I can contact as soon as issues arise to stop me going into crisis. NAS have produced a document for mental health workers."

"Actual trauma therapies, which I've been refused, because (I was told) ""it doesn't work for autistic people"""

"Culturally appropriate, non-discriminatory support that is well-informed about and celebrates cultural, religious, gender &c diversity."

"Occupational Therapy - this has been the best form of support for me. My OTs I have and had have been so amazing and have helped me so much! I clicked the one to one talking therapy, but like autism informed therapy that is responsive to the communication needs of the client, so still that talking therapy model, but I won't be talking to a therapist, so I need a therapist who can work with this and different ways of communicating whilst still facilitating me access to psychological therapies"

"I have just recently been able to access a range of support from psychiatry, speech & language therapist and learning disability nurse which is helpful but remain on a waiting this for psychology and occupational therapy input."

"Trauma informed support that will help to resolve the root causes rather than simply try and cover up symptoms temporarily then the cycle stars again."

"I think things are somewhat skewed by lock-down and not yet being comfortable with the relaxation with social distancing, whilst at the same time struggling with the lack of social contact."

"People who are willing to listen and take mental health seriously. and having my feelings validated."

"Asd specific support organisation for me with ASD, excellent functional language ability and a autodidact polymath personality. Anything that stops the crippling social isolation"

"It's hard to believe these questions...this is fundamental. A dentist would pull out teeth without appropriate training and practice. This survey angers me hugely. We need resources and support...not more surveys. The problems faced have been well documented...many times over...."

"Options other than talking e.g. art therapy, text/email conversations"

Q13 In what ways was the support received helpful? (Other)

"The private therapy has been much better than anything provided by NHS or third sector as it's not limited to 10 sessions. Since the pandemic it's been better cos I'm meeting them online instead of having to go to a place"

"I was prescribed propanol which has helped my anxiety a lot"

"I got a short-term concession rate for talk therapy"

"I am receiving a variety of inputs at the moment including prescribed medication from the psychiatrist that has helped my mood."

"It was private paid for by myself - private Autism therapist"

"It took a very long time 2 years to get OT mental health who was excellent!"

"It was difficult, and I had to wait to find a local private therapist, plus it was expensive."

"All support derailed by Covid to one degree or another, it was tricky to form a relationship with an OT and Psychotherapist over Video/Phone. ""Paused"" by mutual agreement with therapist till OT had helped sort out work/organisational issues, except things petered out with OT, no small measure

due to remote setting. Good support from No.6 but not always consistent and can't address underlying anxiety + low-mood and also petered out."
"I was prescribed medication for depression and anxiety"

Q14 Thinking about mental health services, which of the following have you experienced? (Other)

"I've been attempting to get support for quite a while, and it has now left me feeling actively unsafe attempting to get any health support through the NHS - medical or not. Previous conversations around mental health - which did not lead to any kind of support! - were used to deny me physical health support. So was my formal autism diagnosis. This means that asking for mental health support has been both actively traumatising, and is objectively an unwise course of action for me to take - especially in a global pandemic (I've been told before that me not being able to breathe and being dizzy any time I stand up were symptoms of anxiety, without this being actually checked - of course I was not offered any kind of support for anxiety alongside this.) I've also received very dubious advice around other topics - e.g. that breaking off contact with people I felt unsafe around made me a bad person (private therapist), or that I needed to fix things with them (NHS GP). It felt like, in moments when I most needed help because I made it out of an abusive situation, I kept being told that 1. I was inventing my mental illness (doing it to myself), 2. that I was a bad person for wanting to be safe, and 3. that I was wasting precious resources that should be used for people who 'actually deserve them'. I have had the strong impression that health professionals felt I was wasting their time by asking for help. This links into not being believed, but I wanted to spell it out separately - it is very hard to feel safe even attempting to access healthcare when healthcare professional respond to you like you are a nuisance and they'd rather you go die in a ditch somewhere, because (apparently) being suicidal is a normal part of being autistic so why would you even ask for help?"
"High costs for private therapist or only temporary concession rate care when I really need more reliable and ongoing care. Misdiagnoses that have been attributed correctly (now) to autism and/or ADHD but were previously dismissed as 'just anxiety' or similar I really needed post-diagnostic support for adult diagnosis, and it's been a dismal and lonely experience attempting to sort all this out for myself with very little support."
"Misdiagnosis, inappropriate / wrong treatment due to misdiagnosis, cumulative trauma due to inappropriate treatment due to misdiagnosis - this is common for late diagnosed autistic women and there is no support for it within autism / mental health services! 30+ years of gaslighting by professionals and labeled/misdiagnosed as having BPD or bipolar or whatever, then medicated and hospitalised and restrained for years when I needed sensory adaptions and support for being autistic. Now am just expected to forget that and trust professionals, because I am autistic but don't have a mental health condition? OK! (I think I am traumatised, as any neurotypical person would be in the same situation)"
"As someone who isn't vocal with health professionals it's extremely difficult at times. Some professionals aren't happy to read what I want to say and during lockdown I had no support as services weren’t happy to email or text (also cause they only have landlines) and I can't speak so I was just left for over a year with no support, thankfully I had my schools support but during summer I deteriorated unnecessarily"
"Double empathy problem"
"Three years after GP referral for anxiety and OCD and 18 months after assessment from Royal Ed outreach team as needing one to one therapy still waiting. It’s not all about the pandemic. Mental health services in crisis long before that."
"In Edinburgh Autism support is supplied through a separate (NOT WHEELCHAIR ACCESSIBLE) service. Every time I try to access mental health support I am told that support for autism is at Number 6 - who don't supply the type of support I want anyway - and I can't access it due to being in a wheelchair."

"I am full time caregiver for three young kids and am beholden to their schedules. I spend my day trying to organise them and at the end of the day I have no mental capacity remaining to organise myself, nor do I have a way to get help on a regular basis as I do not really have care options while I'm attending appointments."
"I have to depend upon my parent / guardian acting on my behalf to relay or identify my needs"
"In one instance about five years ago, a Psychiatric Registrar, verbally challenged me, quite aggressively when I suggested that I might need more support for my Autism and ADHD, than the ADHD meds being prescribed for me."
"I used EAct to force my GP practice to allow me to call the one GP I trust whenever I need to. He has had me on 15mg valium for over a year now. A Reasonable Adjustment - as I argued GP was my ONLY support and being so clever with Savant memory skills I was ""being treated as a problem patient not a patient with a problem"". I have Ehlers Danlos T1 as well. In constant pain. I hate life"
"It's inherently hard to reach out...and significantly more so when you have had a lifetime of rejection...because you've been let down and mistreated so many times"
"No adult autism services locally. No ongoing autism support structures."
"Health professionals not reading my notes and me having to explain everything."

Q17 How can we help Autistic people to identify if they need support to improve mental health and seek help?

"So many of us are so used to feeling anxiety we don't even know that's not a 'normal' experience. Finding out other folks don't have anxiety all the time was revolutionary for me. Improving education in partnership with autistic people, improving working conditions and housing, all will help prevent these issues developing in the first place."
"Introduce mandatory autism awareness training for all health and social care staff."
"Resources presented by other autistic people who have experienced it"
"Earlier intervention on understanding your own emotions. Feeling valued and listened to when you do ask for help."
"Better understanding of autism from GP, to mental health team staff too. Also training comorbidities, i.e. complex PTSD, gender diversity, OCD, etc."
"Acknowledge that living in a world created for neurotypicals will cause individuals with autism to suffer poor mental health. Living within society will cause anxiety for many."
"Have the supports available and have easy access. People who understand autism so they can communicate with understanding."
"Post-diagnostic support is the most important, but it needs to be properly-informed support, not simply parroting the stereotypes."
"Listen to us, regular check ins by healthcare e.g. like diabetic clinics"
"Have an open dialogue about issues unique to autistic people they may not have identified, such as burnout and sensory overload etc."
"I think most people do but to different degree so should be assessed for each individual"
"I think autistic people need reassurance that they will not be belittled or viewed as not worthy of helping. Autistic people can lead very full lives but sometimes we need help to manage our emotions and put in place accommodations to manage our executive dysfunction."
"Understand that everything isn't Autism and when feeling very overwhelmed more than normal outside the usual situation that something is wrong."
"Improve the knowledge of GP's and other front line staff that how people express things can be different. Also improve general awareness as I had many years of depression, suicidal ideation that was due to undiagnosed ADHD and autism, not understanding my different cognitive style and sensory needs. however GP would only consider anxiety and depression and didn't even try to explore anything else. My mental health has improved due to my own efforts to learn from online courses and finding a private therapist that understood neurodivergence. The NHS CBT was terrible

and made me feel worse as it was very simplistic and not appropriate for people who think differently."

"I can't think of anything"

"Addressing the 'seek help' part first - ensure that seeking help actually leads to help and not more trauma. I don't feel safe attempting to access healthcare for mental OR physical health anymore, because attempting to access help when I went through a mental health crisis was actively traumatising. At my lowest point, when I was actively suicidal, it was choosing to no longer seek help that helped me keep myself safe, because it kept me from being continuously retraumatised. It is not helpful to motivate autistic people to seek help when all that will do is leave them more isolated and more traumatised, with potential long-term repercussions for their ability to access any form of healthcare.   To address being able to identify when we need support, signposting resources for and by autistic people would be a good start. Finding autistic peers talking about their experiences has been invaluable in identifying the language to use to describe what I am dealing with. It would also help if healthcare professionals had a similar understanding of mental health, as they could be invaluable in asking the right questions and helping people find the labels to describe their experience - this would mean moving away from the rigid understanding at times of what mental illness looks like, and instead listening more to personal experiences. E.g. we might not always express emotions the same way, and it would be invaluable if that wasn't used to dismiss us, but instead something that support services could help us identify, understand, and explain, empowering us to be able to seek targeted help in the future."

"1- I need to know that I need help 2- I need help for as long as I need it 3- I need to be able to access it when I need it and not three years later 4- I need to be able to access something I can afford that is ongoing 5- I need appropriate support, not ""just"" because I'm autistic, but I am also marginalised in other ways with ADHD, I'm queer and nonbinary (afab,) and I have multiple complex chronic diseases. A support group of all straight cis people isn't so helpful for me, for instance. I have only been able to find the most appropriate care in one-on-one therapy that can be individualised."

"Providing a 'touch base' or regular catch-up service after diagnosis. Offer training or assistance to family members to help recognise mental health issues autistic people may encounter. Provide specific contact information for dedicated health professionals with a guaranteed reply with 24-48 hours."

"Help us understand what it looks and feels like to be mentally well, versus not so well so we can seek help. I live alone and would happily not eat for days or shower etc. and would just tell loved ones I was ok. A professional case worker or someone to check in regularly with could be helpful so they could identify changes when mental health is slipping"

"Awareness of how mental health issues present in autistic people would be great - I was surprised to read Royal College of Psychiatrists report and learn that anxiety is not an inherent part of autism and that I could seek help for it. There's a lot of misconceptions, even among autism professionals (and mental health professionals) about how we suffer, how we communicate that, and how to help us"

"There is an argument that there should be more effective communication between both the patient and the supporter to determine whether the patient needs help. However, the body language of the person requesting mental health support should be enough evidence for the services to offer support. This is the majority of communication is delivered via body language. Thus, during the consultation with a GP, the GP should be able to offer support, in the form of medication and/or referral to other services, to the patient based on the patient's body language. The GP must be trained in recognising when the patient needs mental health support and should offer this support."

"Prompts to ask us to check how we are feeling. Validation of feelings and assurances that we will be taken seriously, no matter how trivial we think our problems are. Encouragement to be open and provide a non-judgmental, trained, professional that will take what we say seriously and not simply brush us off as many do."

"To have support centres like one stop shops in all cities/areas. Have courses and literature run by the one stop shops. Especially important after diagnosis. More understanding by mental health staff who need trained in autism. Need to be trained to recognise autism traits. Autistic people need a support/key worker ideally someone that got to know them through diagnosis that they can contact about mental health. Need regular catch ups to identify when problems. Like other conditions have someone you can go and see when you have problems. Not enough autism specialists. Might not be able to identify they have a problem and need help so family, friends, work colleagues, teachers, GP's, tutors etc. need to understand autism. If society were more understanding of autism there would be less need for mental health input."

"Not my experience. I am aware of my need. But I feel all autistic people should automatically have advocacy for accessing all medical/ mental health services. Mainly because the high pressure of GP appointment which you have 5min to get your point across, mostly I feel dismissed, and misunderstood."

"Provide information about executive dysfunction and how to navigate it."

"More information on accessible platforms."

"Recognise the diversity of the Autistic community. We're not all cishet White Christian men. We are immigrants, nonbinary or gender fluid, atheist or polytheist, and we can see very quickly when cultural prejudices about Autism or skin colour or our names or gender presentation means we are - yet again - dehumanised. We've been masking our whole lives, and any mental health provider (whether that's a gatekeeper like a receptionist or an expert psychologist) who forces us to continue masking is part of the problem."

"I would really like there to be better signposting of existing services, or there to be existing services specific to autistic people for mental health. It's hard for me to even ask for help in the first place, because when I speak to GPs and therapists, they seem to know very little about autism and I often end up explaining why and it turns into me trying to educate them about autism and why I'm struggling. I wish people would believe me, and I'm really tired. I often wonder about the point of it all. I'm struggling but I don't know how to get help. And I'm a late diagnosis, I want to be the one being helped by the therapist to understand my sensory needs and brain and why I'm struggling."

"Better understanding with GP's and appropriate specific Autistic support."

"I don't know"

"Support the family as well as they know their autistic adult but are rejected because it is an emotional relationship. The family need help to use the right words and how to support the person before it is a crisis. The family also need to know where to direct their family member to seek help. The autistic adult needs an independent trusted person they can contact at least once a month."

"Proper training in autism and understanding of autism. Being listened to properly and not being dismissed and just being prescribed medication. Better communication skills from the health professionals who have essential training in autism and all that implies."

"I don't think that is the biggest issue. The problem is not enough services available and not autism friendly."

"Having a professional experienced autism trained member of the local mental health team that could sign post individuals for accessing services."

"Their lives are so beset daily by anxieties of every kind, they mostly do not recognise that this is not normal. If their lives could be more regular- with accessible employment, understanding health care workers, accessible and supporting social groups- then the full focus could then go on mental health but as long as they are barred from all the foregoing, it is hard for them not to have all-pervasive anxiety and dread. I could not believe how appallingly the employment branch of the Scottish Government treated an AI I know when he was seeking employment- absolutely no understanding, lost his test results demanded he do it all again. I thought he was actually too clever to work with such a group of ignorant clowns. Nor did they offer him a job, though he did take all the tests again. If that is what they are dealing with, mental health is going to be poor. And that is the government-setting standards! Think of the rest of life. Start educating those who are in your employ."

"Identify clear symptoms that we can refer to"
"Raise awareness at an early age through education."
"Apps that can monitor moods over time or having online questionnaires to detect problems. Using quantitative rather than qualitative measures would make it easier for Autistic people to recognise when things are starting to go wrong and also when they need urgent help."
"I don't know."
"During childhood years our experiences with services including health were more holistically approached. Now we experience no follow up once initial presenting issue is managed and drop of systems only to be re referred further done the line. Difficult for others to get to know me and to ascertain my overall needs."
"An online self-assessment questionnaire with signposting to local services that can help."
"Reassure them and prove that they will be taken seriously, provide autism specific services informed by autistic people not just staff taught about autism stereotypes. Accept that people can have autism and mental health issues, anxiety in particular and that it shouldn't be just an accepted part of autism or refused support on that basis. Most other autistic people I have encountered are well aware if they have mental health issues. It's getting adequate support for them that's the issue."
"An app"
"As soon as diagnosed my son needed help to understand his diagnosis and to understand that OCD and anxiety was part of it and always would be. We had to go private for therapists because waiting lists were far to long and he needed help straight away. He was 16yrs old and had a tough time at high school so sad to see him suffer we've paid thousand of pounds to get him where he is today with a job and controlling his OCD I think many suicidal teens are probs HFA"
"I think there should be a provision which supports those with a disability over the life course. I am autistic and I actually find it easier speaking to someone out with my family and friend circle. But at the same time I do like consistency. I believe that a professional would be able to recognise changes in mental health state - even by just dropping a call once or twice a year. They could then encourage the individual or refer them for further support. Since my diagnosis I do not feel supported by anyone. I even have to remind my GP that I am autistic- which should be on my records."
"I have trouble describing how I feel, even when suicidal. If health professionals were to recognise that as due to my autism, maybe I would be taken more seriously? Need more overall support (GP, workplace, etc.) because being autistic, I don't know how to advocate for myself to receive adequate support. Long waiting lists means my mental well-being is not taken seriously which further exacerbates my mental health."
"Be more aware and GPs build up relationships with people. See only one GP. Put more resources into local communities. Especially rural communities"
"I think that many Autistic adults (especially with a late diagnosis), often don't feel their needs are 'valid enough' to seek support. They have become used to a lifetime of retreating inwards and trying to cope on their own. When you are used to only showing the outside world the 'mask' that you have been hiding behind for many years, it is incredibly difficult to change this scenario. It is not helped by a benefit system that has no understanding of Autism, so the wrong questions are asked, and you are judged by a stereotype of the condition so therefore seen as 'slightly autistic' or not 'unwell' enough. It feels like you are trying to 'prove' that you have something 'wrong' with you, which in itself is unhelpful and does not convey how very difficult life can be at times. There needs to be much more training across the board around Neurodiversity/disability, and any related mental health issues that can often come hand in hand, like anxiety and depression. Often in Autistic adults the disability is hidden (on the surface), and consequently many feel that their difficulties are not believed. I personally am often aware that things have got too much for me and I need some support, but there is nowhere to access this as and when it is happening. There are also times when I fail to see a difficult episode of mental health on the horizon. Sometimes I need help before this point."

"Ambitious about Autism has a toolkit called ""Know your normal"" which helped me a lot because I was able to notice when my ""normal"" was shifting and I could try and work out why it was doing that. Understanding more concrete signs of mental ill-health is really useful.   For example, instead of ""low mood,"" framing it as the impacts on daily life could help. Asking if someone is struggling to cook/clean/shower, is more sensitive to sensory stimuli than normal, is having non-verbal episodes or communication difficulties, is isolating themselves more than normal, etc. would be much more helpful. I don't notice my own low moods, but I have begun to be able to notice when my habits and routines start to slip and that helps me realise that I might need some help.   It's so hard for lots of Autistic people to understand our emotions and our physical feelings so it's hard to know what words to use to describe my emotions and how to match what I'm feeling with a list of symptoms. I was experiencing intense anxiety for a while and didn't realise it was anxiety for months until I explained it to my mentor at uni. He was really patient with how I described things and did his best to understand *my* way of communicating and after a while we were able to work out that the feelings I had been having were ""anxiety.""   Another thing is that it's often quite difficult to seek help for various reasons. I know several Autistic people that are unable to make phone calls, but several GPs prefer phone calls. A few use the relay phone service. It's also scary because you never really know what's going to happen at an appointment. Better signposting would also be really helpful. Flowcharts are great"

"A 'help line' when we aren't under the GP or mental health services that is known to us"

"We need confidence and self-assurance to understand and believe our own experiences and feelings after spending years and years being told that our perceptions are wrong. I don't trust myself that I need help until things are so bad that other notice and comment and validate my needing support. E.g. through being noticeably underweight due to restricted eating, so depressed I'm struggling to function and/or so anxious I'm having panic attacks at the simple thought of leaving the house to walk my dog or buy food or top up the electric meter."

"Work with individuals to create a post diagnosis plan to identify issues and areas that could be improved and what help is available to them"

"Autistic people know fine; we are just not listened to, experience rejection and are told everything is down to us being autistic."

"Explain what good mental health looks like. It's not "normal" to be terrified and completely exhausted by everyday life."

"Availability of screening services would be a good start"

"Help us understand Autism and that it is a neurotype that doesn't need to be changed or trained. Let us see that it's ok to be different. Help us identify our sensory profiles so that we can start to identify what our stressors are before we hit overwhelm. Produce information for, and train, teachers, schools, support staff, medical settings, Police to query if the person in front of them is maybe in meltdown rather than being aggressive etc. Normalise the fact there are different neurotypes and they have different needs. Stop shoving square pegs into round holes!"

"It would help to have support in the first instance because I have autism. With some support, it may help me to identify when I really need support for my mental health issues or whether what I'm feeling is a normal way to feel in situations that are stressful or upsetting. It would be great to have someone that knows me as a person, but also understands my conditions in relation to how they effect me as an individual. I find that people, employers and health care workers especially, assume things about me that aren't actually based on me as an individual. It feels degrading and humiliating."

"You start by not constantly telling autistic people from a young age that they're weird and have to get used to being constantly uncomfortable in order to 'fit in' and make friends- you stop teaching us that our boundaries being violated by teachers, parents, and medical professionals is 'normal' and 'acceptable' and you stop teaching us to hide 'symptoms' of autism, because all of this teaches us that being distressed is normal and not something to protest about, this creates a lot of our problems with ill mental health in the first place and often makes it impossible for us to seek help because all the 'help' we've had has actively told us that we have to be uncomfortable in order to be accepted.

In short- we start our lives knowing when we are struggling and when we need help, what we need, what we need to avoid etc., the problem comes in when we're told our perception of all of this is wrong and we aren't allowed to advocate for our needs. If you want to help us, you stop this stuff before it starts and make sure we're always taken seriously on all of this, that means actively banning anything that uses ABA or PBS or related 'therapies' that seek to normalise us while encouraging (and at times forcing) us to put our comfort and needs aside."
"Some ramming square pegs in round holes, address the root cause. In the long run as a whole will benefit. https://www.psychologytoday.com/gb/blog/everyday-neurodiversity/202108/are-we-giving-autistic-children-ptsd-school Same principles apply to workplaces, other organisations etc."
"As an adult female with Autism, I've found it very hard to be taken seriously by my GP. So when I have tried to seek health, I've been instead left to question if there is even anything wrong with me instead"
"I would be interested to know if you consulted with Autistic people in framing your questions for this survey! You have already asked what would help."
"Don't assume if you have a professional job and or degree that means things are fine,"
"Help them to understand autism better and how it can affect you. Identify issues related to autism and issues which may be because of autism but are related to mental health   Explain why autism can also cause people to develop mental health issues and have somewhere specific for people with autism to get support."
"Spend time to listen to autistic people and noticing when they are struggling. Asking them gently about anything that is affecting them and having a calm discussion."
"1) Please make the NHS take us seriously when we do identify a problem, and please do not allow the NHS to measure how we are coping with the same tools used for non-autistic people. I was referred by my GP to MH due to ongoing suicidal thoughts. I am in a difficult life situation. I have too much on, and no help at all from friends and family. However, MH team seem to think I have too much going on to do a CBT on top of everything else, so they have told me to do the Right Click programme instead of helping me deal with trauma. In the meantime I am left to cope with daily life alone, because each service assess their bit and they all conclude I do not fit the profile of who they are meant to be helping. The reality is that when I say I am autistic they do not ""see the autism in me"". They expect someone who ""looks less normal"". This is because people who provide those services do not understand the invisibility of autism. I may be articulate in writing, but I cannot interact face to face at the same level, and this is not understood. And it is not possible to communicate in writing in every sphere of life. In fact, doctors insist on speaking and face to face interaction. This is replicated across all services. I fall through the cracks and my MH deteriorates through burnout, but that goes on unreported because no one thinks my difficulties are big enough for their budget. It is death by a thousand cuts. 2) When I was first diagnosed there was no provision to help women on the autistic spectrum. Although my diagnosis provided me with much needed validation, there was no support or follow up to help me navigate the world as a recognised autistic person. At nearly 50 years old, I still had very little awareness of my body and my emotions and how to regulate these. In the meantime I continued to be expected to perform at the same level as non-autistic individuals because of my social position as a mother, wife, worker, student, etc. Bearing in mind that the reason for autistic adults to seek a diagnosis usually follows from a traumatic event which leads us to question the way we function, and that this tends to be accompanied by autistic burnout, there should be an assumption that following diagnosis the person will require long-term MH support to assimilate their new identity, which should be a positive experience, but will no doubt come with challenges. I see it as the equivalent of a settlement programme. A person has just arrived to settle in a new country. They may know the language, they may like the climate, but they come with all their baggage, and will still need a road map. So in a nutshell, we need to be taken seriously, there needs to be MH professionals preferably autistic, who will listen and take us seriously when we seek help, and we need that help to be reliable and on-ongoing."

"We need lasting, consistent support. Coming to the end of a run and being told, that's it. Off you go. Knowing full well that Depression, Anxiety, Self-Harm are symptoms of my autism and just a bad day away. Mental health social workers, a named person responsible for monitoring and advocating with us - opening up to Frontline to recruit same from fresh Graduates"

"Just ask autistic people and listen to our replies. Believe what we say, even if the answer isn't what you expect."

"Mental health services need to be trained in autism. Currently they just ignore it and treat the issues as behavioural."

"Stop treating us as 'weirdos' ... so little real understanding of autistic women in particular. Medication is rarely the answer but often the medical solution."

"Do not discriminate Asperger's types by NOT providing ASD specific supports to all dx with ASD."

"Easy read information People who are trained in just autism"

"What a vague open question. This shows the lack of understanding of the creator. Shocking... I can't speak for ""autistic people"" because each autistic individual is...AN INDIVIDUAL...just like ""neurotypical people"" Please see multiple surveys and studies done before... I've stopped trying to pull the question apart. It's hurting my brain the language is vague. I just realised it also presupposes that ""autistic people"" don't know how to identify they need support...I've been asking for almost 14 years. Still waiting. Shocking. Maybe if there were mental health services that actually cater for and understand autism in general. It's a basic thing really. Shame it's taking up resources in a survey to find out same information as has already been discovered, recorded...and ignored"

"Better support in the workplace. Adaptations actually put in place! 7 months and still waiting for City of Edinburgh Council to put the coaching from Access to Work in place. They seem to be more preoccupied with trying to show I can't do the job I have been doing for 30 years instead of supporting me."

"Provide more long term funded autism and neurodivergent safe spaces, online and in person provision, the one stop shop initiatives are trail blazing, as is the work of Scottish women's autism network (SWAN) but is limited to small geographic areas, a lot of people are missing out due to this postcode lottery."

"Post diagnostic support groups to discuss identification of mental health needs and to create an action plan/visuals with autistic people as part of this support"

"The problem for autistic people is not necessarily that we can't identify that we need support, it's identifying a service where we can find that support. It's important for us that services are consistent in their support. If we try to seek help from a person or service, but are rejected or let down by them, then we'll be reluctant to try again; we tend to assume that the same thing will happen. When we are mentally unwell, we are not in a fit state to phone round 4-5 different services begging for help – we need to know which services we can rely on. When I was experiencing suicidal thoughts recently, I contacted the local Mental Health Assessment Service (MHAS), where a nurse told me that it was up to me whether I took my life or not. He said that he hoped I wouldn't kill myself, but if I felt like killing myself, then I had the choice to do so. He didn't offer me any support, but instead left me to take an overdose. I contacted my GP soon after to discuss my suicidal thoughts, but she said all she could do was tell me to contact MHAS – and there didn't seem any point in doing that, given their earlier response to me. Therefore if my GP and MHAS can't help me, where am I meant to go for help?"

Q19 How can we improve access to and experience of the right support for mental health at the right time for adults who are Autistic or have a Learning Disability? (Other)

"Photos of the person we are seeing. Clear instructions on how to get there. Therapists/MH staff being trained in autism by autistic people."

"Autism Awareness training for all health and social care staff and improve the models of service delivery. Recruit more professionals who care enough to learn more about autistic people."

"Funding! Making autism support services wheelchair accessible. Catering for the fact that people have complex intersectional needs."

"A lot of the information is about you are autistic or have mental health difficulties. It doesn't feel like people think you can have both and so when it's hard you don't want to ask for help because you feel people will say it's just autism. Before I was diagnosed as young person I really struggled, having an earlier autism diagnosis would have also helped me understand my mental health as a lot of my mental health struggles came from not knowing I was autistic and struggling with the world around me. It's not one or the other they are all intertwined and you need an understanding of both. Being autistic in a world that isn't designed for autistic individuals is traumatic, before and after diagnosis. You wouldn't say that someone's anxiety stems from them being neurotypical and not support them with that, it's still anxiety and both need support"

"Better accessibility to GP appointments without need to explain to receptionist. This is a real stumbling block. I am not able to explain my needs without crying, and I feel way to vulnerable to cry on the phone to a receptionist. But if I could just book a GP appointment without explanation then I could then be honest with GP about how I feel. But currently I choose not to call GP surgery as I never know which GP might call back, or when. It is to stressful for me to discuss my needs with abrupt receptionist, await call from unknown doctor, at unknown time, so I avoid calling and therefore any issues will escalate before I get the support I need. And I am likely to only get support when crisis hits. Also the nature of inaccessible mental health support at the weekends and evenings is difficult. 90 minutes for 111 to answer a call. Don't really know how I would access urgent care of I needed it. Way too much responsibility put on services like Samaritans etc., but they cannot advise on medical needs, and the complexity of issues is often too much for them.   Also accessing everything by phone call is very difficult as there are not the visual cues that I need to ascertain how the other person feels and to help me understand the communication. I often misunderstand phone calls and their content."

"I'm not sure"

"Understand that it is a continual struggle that needs constant support"

"Include this in the autism strategy and make sure the strategy is implemented."

"Two things are essential: First, recognising that autistic people are not necessarily more prone to mental ill-health than anyone else; the issue is rather that we are trying to live in a society which is not designed for us and does not recognise our way of experiencing and processing the world. Consider how you might feel if you were trying to live in a society which was not only incomprehensible and unpredictable, but actually designed to discriminate against you; among people who constantly misunderstand you and tell you that you are the one at fault, and that your very being is deficient and disordered; that you are doomed to a life of failure? Bullied, gaslighted, confused, in constant pain from sensory sensitivities – it is a wonder that any of us emerge unscathed (some of us do, which speaks to our resilience). That is a very good reason why autism does, mostly, come with one or more co-occurring conditions. The concept of ""minority stress"", which has been predominantly used to explain the health disparities within the LGBTQIA+ community, posits that social disadvantage and marginalisation results in an increased burden, which in turn can result in mental and physical health disparities. And second, not medicalising normal and natural distress. Address the environment, the natural effects of trauma, the unhelpful narratives with which the person has lived for years...don't tell someone they are ill, and medicate them, when they are simply experiencing sadness, fear, anger. I don't entirely understand the question. Which is significant in

itself, since I am an intelligent, professional woman who uses words for a living. Use simple and clear language, don't be vague. What does this question mean? Probably the only thing I can think of, given that I am not sure what you are asking, is ""educate GPs"". Preferably find actually autistic people to do the educating. There are plenty of us out there who would be more than happy to create trainings for GPs."
"Regular checkups and listen to us when we do reach out"
"Ensure teachers in schools can identify autism traits, especially in girls, and make sure all the professionals involved in treatment understand autism and that it is a complicated condition"
"More services available"
"Ensure that all NHS regions have mental health workers/psychologists/psychiatrists that have an understanding of autistic people's needs."
"Same person. Clear information. Same local location. Good understanding of Autism. Understanding that it's difficult to talk about feelings."
"Make sure staff engage with learning resources informed by and including actually autistic folk and don’t base their inputs on out of date, child based stereotypes"
"To help support people who are autistic and to be there for them and talk to them if they need anything"
"Address the gatekeeping around services. A lot of the time, you need to 'prove' that you are struggling 'enough' to access support, which causes issues on multiple levels. Health professionals often expect you to express your distress in a way that instinctively makes sense to them, which does not tend to translate across neurotypes very well and usually leads to us being told we are, in essence, having too many feelings, not having enough feelings, and having the wrong feelings somehow all at the same time and all the time. The result tends to be (unless you are very lucky) that you simply do not get access to support. There also is a lack of mental health support services in general, so it can be very hard to find one when you need it without months or years of waiting time, especially if you are also operating within a budget. As such, financial support would actually make a very big difference in accessing mental health support. In terms of charities, education etc., one of the issues tends to be that you need to fill out multiple documents before you request any support, and the support you receive may or may not be actually informed by an understanding of autism and/or mental health. There are a lot of barriers in the way before you can even ask for help. Having support to fill out those types of documents could help, as well as requiring services to have a baseline understanding. It's also not unusual for autistic people to be turned away from mental health services for being autistic, especially when in distress, because of a lack of understanding and awareness and the stigma associated both with mental illness and with autism. Having dedicated mental health support for autistic people that does not require us to manage someone else's feelings while in distress (e.g. by attempting to express our emotions in a more 'neurotypical' way) would make a big difference."
"I really need providers to know about *all* my underlying issues and conditions. A GP is simply too general and often too over worked- and too reliant on the average treatment protocols. I am not average. No one is really, but I'm a bit of an outlier. So when I am able to reach out for support, I don't want to have to fight even harder when I am least capable of doing so. Some kind of post-diagnostic support therapy/treatment or specialist representative who could coordinate available services would have saved me a lot of pain and distress. *One* person I could reach out to as my ""rep"" to say I’m feeling really depressed this year and I need support, and they could help me search for an appropriate provider or system that is autism knowledgeable. If I don't know *how* to even look for the right person other than googling ""autism mental health Edinburgh"" or similar that is a barrier in and of itself. Why bother when all my spoons are trying to keep me alive. The fewer steps the better. The simpler steps the better. Someone who checks in on me in appropriate ways (i.e., not a phone call) would be a good way to screen for potential problems and catch them before they get worse."
"Clinicians understanding Autism, and how the problems intermingle"

"Provide specific contact information for dedicated health professionals with a guaranteed reply with 24-48 hours."

"Post diagnostic care. I got a diagnosis but no actual support about what that means for me. I've suffered from depression and anxiety for years, now I know there has been an underlying cause but there is no support available to actually sort myself out. My GP can only offer me counselling of 8 sessions and then I get put back on the (year long) waiting list. What was the point of diagnosing me if we aren't doing anything with the diagnosis. Also not being pressured into group therapy, I personally get too caught up in other people's stories etc. and compare myself too much and don't find it helpful"

"Make it easy! There's so many barriers- making a phone call to the GP, explaining to receptionist, then explaining to the GP and fighting for a referral, then waiting to be seen (for months and months), then more unknowns and explanations). It's really stressful and torturous"

"For recently diagnosed individuals, the diagnosing body should offer a set time (e.g., one to two months) mental health support to the recently diagnosed person. As someone who was diagnosed late, it was a life-changing experience and took a while to fully accept my neurodivergence. Medical professionals should be available to aid in breaking the stigma and helping the individual adjust to the diagnosis to understand themselves better, and thus their mental health."

"Clear instructions and directions. Limited red tape and bureaucracy."

"The only useful mental health support I have received has been through private therapy which I could not possibly afford on my own. It has been paid for by my university. Such a service should be more easily available through the NHS"

"To have support centres like one stop shops in all cities/areas. Currently none in Glasgow - Scotland's largest city. Have courses and literature run by the one stop shops. Especially important after diagnosis. More understanding by mental health staff who need trained in autism. Need to be trained to recognise autism traits. Autistic people need a support/key worker ideally someone that got to know them through diagnosis that they can contact about mental health or a properly trained CPN etc. Need regular catch ups to identify when problems occur. Like other conditions have someone you can go and see when you have problems. Not enough autism specialists. Might not be able to identify they have a problem and need help so family, friends, work colleagues, teachers, GP's, tutors etc. need to understand autism. If society were more understanding of autism there would be less need for mental health input. Training, training, training! Mandatory training for relevant professions. Involve autistic adults in delivering the training."

"Advertise on social media to people interested in autism or who are in autism Facebook groups. This way, autistic people know what support is available for when/if they need it. Have shorter waiting lists. Have detailed explanations of the process of getting support and what will happen if you have an appointment."

"Forcing change isn't helpful, but sometimes is needed if that person is at harm. People aren't as happy to wait especially if they need immediate support. More access to tools for those with difficulty communication. Being believed. Tools such as social stories and talking mats used widely for people with autism. In therapy rooms fidgets being available if things get too stressful, and time outs being allowed. Community appointments being allowed or walks outside etc."

"I would love to be able to access therapy where the therapists understand autism related mental health difficulties, and can help me. People viewing it as something which needs a cure, or as less than human also seems to be a problem, and is pretty horrible to experience. Easier access to mental health, less time of waiting lists. Even a text helpline where those on the other end understand autism would be amazing, because most helplines are now closed or require a verbal call. This is hard for both nonverbal autistic people, and those who struggle with auditory processing. But I liked a lot of the suggestions in the tick boxes earlier on."

"All comes down to money and resources."

"Ensure the first person they meet with is knowledgeable about autism in adults, especially in women. I had a very upsetting experience with a GP trainee at local mental health centre who was supposedly assessing me for an autism diagnosis. The whole experience of the centre - waiting area, the way I was treated, was traumatising. Ensure requests/enquiries are answered and not ignored (e.g. emails to autism charities that are government funded to provide a service). Ensure people get initial engagement and help, while waiting for specialist help."

"The autistic person needs a trusted person who will listen to their problems. The trust will need to be built over time and is not a quick fix as autistic adults often find it difficult to express themselves or recognise their own needs."

"Listening to parents and family of autistic individuals as they have much experience and insight of their family member. As well as the person themselves to get a good grasp of the issues and problems that can arise. Their knowledge and experience is invaluable, and should be accessed and used to help as much as possible."

"The very nature of mental illness makes it difficult to access and maintain contact with services without support from family and friends. There has to be more acknowledgment of these unpaid carers within the system. If you are supporting an adult with mental health issues you are often dismissed, even if the adult asks for you to be part of the process. Therapy can only be with one person is the regular quote. However, someone has to ensure appointments are made and kept and follow up work done. How naive are the so called professionals if the think someone with mental health issues can manage that for themselves. After waiting years rather than months to access services to then receive hospital letter saying you will be removed from the system if you don't respond within three weeks is shocking. These are people whose condition means they lack the motivation to make these decisions in a timely manner or indeed in the case of the person I care for, doesn't have the executive function to deal with it. Letters usually only have a turnaround time of 10 days as they arrive a week after the date on the letter. My previous experience (pre pandemic) was that appointments were cancelled on the day due to staffing issues and left open ended without rearrangement. There was also constant staff changes even in a six week therapy block. Autistic people cannot cope with this. It's hardly likely to have improved. My experience as an unpaid carer supporting someone trying to access serious help for the third time is that they have no idea how the flawed system impacts on already troubled lives. The system is broken and was even before the recent crisis."

"Making sure that every local authority has a specific autism trained professional body to speak up on behalf of people and families with autism and help and support them to access mental health care and ongoing support."

"Unsure as hard getting appointments in first place"

"That is a demand- ""right support""- so individual information at the ""right time"" (a message from above needed here surely?) Not all AIs are the same- they are individuals. So you have to aim for well-trained general services which involve at base level, ready contact with AIs (all ages- no stopping at 18 or 25 as now!), families (though they do not always have the answer), an effective support service. Good communication upwards and downwards should ensure a responsive system. But it takes money and training; volunteers with autism experience might provide supplementary help."

"Have a dedicated service which can be a phone call or online chat away - perhaps like the Samaritans"

"Edinburgh needs to reintegrate Autistic people into the ""normal"" mental health system. As a wheelchair user I am completely excluded from any support with my Autism in Edinburgh. I also want to be able to address mental health issues and cognitive issues/sensory issues at the same appointment as they often overlap."

"I don't know."

"Continuity of care, need time to get to know people and for people to understand me or my needs. If I didn't have my parent acting on my behalf, I would be unable to access any support independently and would therefore fall through the system as it is designed at present."

"There needs to be greater understanding of autistic priorities, e.g. I would like much greater help in managing myself in the workplace and relationships with colleagues, which has a big impact on my mental health. But there are only a few organisations in Scotland capable of delivering that sort of assistance and they're scattered across Scotland. Employment is a huge and ongoing issue for autistic people, as it tends to occupy our whole lives whereas neurotypicals find it easier to move between their different roles in and out of the workplace."

"Find out how the person can engage. Tailor support to their needs. Have specific strategies that may help autistic people -I know that there are therapies that are thought to be better suited to autistic people. Have properly informed practitioners who understand autism. Ideally limit the trauma we encounter throughout our lives from not fitting into what other people feel is 'normal'"

"Trained individuals"

"Waiting times and GPs knowing exactly where and who to access"

"Every time I have attempted to seek mental health support. I have been encouraged to take prescribed drugs. I do not believe that this should be the default thing that health professionals do- they just told me that the waiting lists were far too long and I could be there waiting over a year to be seen. I honestly wish there could be specific health professionals with training in autism. I sought help from my university counsellors which did not even understand the problems surrounding autism."

"Put more local resources into rural communities. Don't expect us to travel an hour to access a resource"

"I think if there were more local services that were relaxed, friendly, tuned in contact points for people to access when things start to slip for them, or even on a regular basis to keep afloat, it could possibly avert more serious scenarios. When things have got really bad it is much more likely the individual will just hide from the world, feeling no one understands and not coping, and if they do reach out in crisis (or someone notices), then they are faced with waiting lists for psychological support or sadly, intervention. It feels there is nothing out there, until you have got to a very serious level of requiring help."

"I think the biggest thing in my experience has been that people generally don't have the patience or understanding for my ways of communication. When I've had mental health support with someone that does have patience, it's been incredible because we're able to work together to identify my emotions and figure out practical ways to help me. I also have epilepsy and I have trouble describing the physical sensations of seizures. Most of my neurologists have felt quite dismissive, but I had a neurology nurse a few months ago that clearly had no idea what I was talking about but took me seriously, wrote it down in the notes, and did her best to understand. I tend to use onomatopoeias for how i feel things ""zap!"" or ""creaaak"" are both ways I might describe emotions so I do understand that it's hard for people to take that seriously sometimes, but I have no other words and it's frustrating. Being understanding and accepting of the use of AAC and people bringing comfort items is also big. I may have misunderstood the question, but I hope this was still helpful?"

"As I said before a phone number or email/web address to contact someone to say you feel you are going down again and need support instead of GP"

"Having someone who understands the person properly. Who doesn't judge and accepts the person as they are. Who supports the person. Also, having longer than 16 sessions. Longer support in order to be able to build a good and trusting relationship with the therapist."

"Guidance after diagnosis needs to be more than ""oh well you've got a diagnosis (autism) now, what more do you want? Go away and Google it"" as I was told by the mental health service having moved to a new area immediately (within 2 weeks) after having been diagnosed. Support needs to be more readily available and more quickly. Different methods of support need to be available as support that has already been unsuccessful being repeated is simply more traumatising and reinforces a belief that we're too broken to be fixed and are failures at even trying to get better and are unhelpable"

"Increased understanding of autism within GPs and mental health professionals (more training) to ensure people with ASD are not put off accessing support by the lack of understanding they receive.

Also to ensure that the issues they are facing are not misunderstood. Create a long-term strategy informed by research of the impact of ASD on mental health and create a programme people can access long term without having to be continuously referred to their community mental health team."

"Funding. Training on autism. Formal advocate services for autistic people."

"Simple explanation of the steps of being referred. What to expect is very important to autistic people. The unknown is very scary. I've been assessed 5+ times in the last 3 months by different mental health staff. Rehashing the same trauma over and over. No one knows what to do with me or anything about autism. Training on autistic burnout and introspection issues. Some kind of reassurance the person you will be referred to knows about current thinking in autism. Ideas have changed a lot in the last few years. Less reliance on phoning. It's very difficult for lots of autistic people and increases anxiety. Being able to email or message for admin such as making appointments as well as check ins with CPNs etc. would make things so much better. It gives us time to process what is being said and what we want to communicate."

"Actually have some services which are accessible without a medical referral would be a good start. I'm not ill I'm just autistic me who needs some support"

"See previous rant response! Normalise Autism and make services accessible in formats that individuals require. Some will prefer online, some in person, a lot find telephone VERY difficult. Options are required. Meeting places should be consistent and comfortable and sensory friendly."

"To have an appointed support agency that allows me to form a relationship with someone. It doesn't need to be a weekly or monthly support, but someone to help identify when I would need more support when I feel very down and anxious. Someone that could help represent me when I shut down and feel too overwhelmed to find out how to get help."

"You have easy access to counsellors in schools for ALL students, so that they can get help regardless of whether they have been diagnosed yet or not, you make sure that all college and uni students have similar access, and you make sure that all mental health services across the board are funded as well as they need to be. Not all autistic people are diagnosed, and not all autistic people will ever know they are autistic, so the only way to make sure you help us is to make sure that a variety of styles of mental health support are fully funded for ALL residents of Scotland and that they are accessible at ALL times to everyone, that way you catch all autistic people and make sure that whenever we feel we need help, the help is there, it's well funded and it's accessible, regardless of our situation regarding a formal diagnosis."

"Get qualified professional with personal shared experience, they will be in the best position to help support other NT individuals. I guess it would help if the NHS didn't make it so fraught for Mental Health Professionals to share/disclose any ND diagnoses."

"Providing GPs (usually the first port of call) with a basic working knowledge of Autism in all presentations (so not just in male children!)"

"Again you have already asked this! It is about improving access to services with a specific understanding of Autistic people's needs. These service should be mixed in nature depending on the issue at hand and should be both long and short term in duration."

"Don't know."

"Training and understanding of autism"

"A dedicated health department specifically for autism with specialist support workers i.e. mental health, occupational therapy, communication therapy. Link workers in schools to support people and signpost to the service. Health Visitors to be trained to recognise potential Autism and refer for early assessment."

"Better training for mental health workers, less waiting on a list to access support, more inclusive support services. Workers also need to adapt reasonable adjustments for autistic people to how they prefer to be communicated. Preparing the support so autistic people know what to expect and also make the support centred around what works best for the autistic person."

"See previous answer, verbatim. Lasting, consistent care. Not finite available only at point of crisis."
"I think the GPs are severely lacking in education of autism. They have no idea what it's like to be autistic and they really don't care to know either. They're so unwilling to refer you for the right kind of help, i.e. a clinical psychologist or similarly qualified professional. Not everyone simply needs someone to sit and listen - how does that help if you have a mental health condition. Referring you to someone who asks you five "tick the box" questions (e.g. agree, disagree questions) will not allow for a thorough assessment that can diagnose a mental health condition. Simply put, the GPs need a huge amount of education on mental health, autism, and also on how autism can lead to poor mental health."
"Doctors taking them seriously"
"We can't deal with waiting lists - by the time we need help it's a real crisis because we've been masking for so long. Help has to be fast."
"Autism specific services"
"Nationwide and 'on demand' services."
"More comfortable private places for appointments to take place   If the information was in easy read"
"See previous answer...another vague question with too many words. Shockingly discriminatory against the ""autistic people"" you are being paid to consult. How many autistic individuals were involved in creating the survey questions??   Invest in needs-based services and stop investing in surveys"
"Ongoing support - access to Number 6 on a regular basis - needs funding!"
"Collaboration with Autism Initiatives Scotland and SWAN, support them to deliver services to the WHOLE of Scotland, they have the plans, the projects and the expertise."
"1. Education for health professionals e.g. understanding autism and how it differs in females, understanding different ways of communicating, knowing how to ask questions without overloading the person. 2. Different options for communication e.g. text, email, telephone, online meetings. 3. Environments which have the ability to be adapted e.g. dimming of lights, quiet spaces, different seating e.g. options to sit on an exercise ball or on the floor"
"More autism awareness training is needed for people, not just in the NHS but in services such as the police too. For example, when I was referred to A&E recently, the nurse told me on arrival that A&E "wasn't a suitable place for someone with autism". She sent me away without allowing me to see a doctor, simply because I'm autistic. When I was referred to my local community mental health team, I was given an appt with a psychiatrist who said he "wanted to check that my autism had cleared up". How can the team support me effectively if they don't even understand what autism is, and that it's a lifelong condition, not a skin rash? A few weeks ago, I was fast asleep at home when I was suddenly woken by my front door being smashed in. On rushing out to my hallway, I was faced with a burly man dressed head to toe in black, yelling at me to stay where I was. I thought he was a burglar or attacker. He ordered me to climb out of my window, before changing his mind and ordering me into my bathroom instead. His 3 colleagues then came into my house, at which point I discovered they were actually police officers. They searched my house and tried to seize my mobile phone. Despite the fact that I was half-naked and male officers were present, they did not allow me to get dressed. I overheard one officer asking his colleague if I was "ready to go yet", but they didn't tell me where they were planning on taking me. It was absolutely terrifying, and the officers caused so much damage that my house was left uninhabitable. Apparently, the officers had been asked by my manager to do a "welfare check". The police knew I had autism, depression and anxiety. Instead of ringing my doorbell and having a calm chat with me though, they decided that the best way to check on someone with autism was to smash down my door and frighten me so much that I collapsed on the floor with a panic attack. The result is that I'm now being treated for PTSD and am too scared to be honest with anyone about my mental health in case the police do another "welfare check" on me."

Appendix – Topic Guide

Inspiring Scotland
Mental Health Services for Autistic Adults
Autistic Community Discussion Guide

Introduction to the Discussion

- Our purpose here today/tonight is to think about how mental health services can be improved for adults who are Autistic. We know that there is a myriad of things that can contribute to poor mental health for Autistic people especially, but we really want our discussion today to focus on your experience of accessing services.
- Mental health includes our emotional, psychological and social well-being. It affects how we think, feel and act. It can influence how we handle stress, relate to others and make choices. Mental health is important at every stage of life, from childhood and adolescence through adulthood. We are carrying out separate research with parents and carers of Autistic adults so our focus here is on your perspective.
- It is also important to say that we aren't asking you to share any personal details about your mental health, we're more interested in how well you are or have been supported and how services can be improved.
- We have a lot to discuss in a limited time try to briefly summarise your points and if we don't manage to hear everything you want to say then please email Sinead so we can make sure everyone's experiences are included.
- If you have been affected by any of the issues that are raised in the group, then please contact autismenquiries@inspiringscotland.org.uk at any time after the group has ended. We are offering up to two half hour sessions to talk through the issue with someone in our autistic led support.

Experience of Mental Health Issues

- Could we do a quick show of hands so I can understand how many of you have first-hand experience…
    - Raise your hand if you have had a diagnosed mental health condition in the past or have a current diagnosis
    - Raise your hand if you have ever experienced an ongoing low mood or other mental health issue which hasn't been diagnosed
    - Raise your hand if you have never had any mental health issues at all
- I want you to think about times when your mental health has maybe not been so good and tell me about any positive experiences of support services you might have had – so that might have been a particular service that you accessed, how you were able to access the service, or it might be an individual health professional who was really good – I want to understand what you think has worked well? (Probe for each on why it was positive)
- Now let's look at any difficulties that you have had in getting the right support for your mental health? – what have been the challenges?
    - (For each one mentioned if not obvious) – how could that have been done better or made easier?
- Those of you who have maybe had some mental health difficulties, but you haven't gone to your GP or another mental health service, was there anything that put you off going down that route?

Priorities

- If you were in charge of mental health services and you could design a service to suit your needs, what would be important? (e.g., services understanding Autism, long term support etc) – why?

    - What would an Autism informed, or Autism appropriate mental health service be like?
- In the online research we carried out there was quite a lot of emphasis on early intervention to prevent things escalating into a crisis situation – what are your thoughts on that – do you think early intervention is important? – why?
    - What would early intervention look like or involve?
- Quite a few people in our survey mentioned there was a need for mental health support post ‘diagnosis’, can you explain why that might be valuable? – what kind of support would work best post diagnosis?
- There was also quite a lot of feedback from the survey about the importance of long term or ongoing support – is that something you think would be valuable? – why/why not? – what sort of ongoing support would be useful?
- If there was a community based mental health service that you could access without a referral, would that be something you might use? – Why/why not?
    - Would it be something you would want to attend as part of a group or by yourselves? – why? (If happy to attend as part of a group – Autistic only or missed with NT?)
- Is there anything else we haven’t mentioned that you think is important to bring up before we finish?
- Scottish Government and COSLA will be tackling other issues like mental health. Are there any other issues you think need to be a priority for Scottish Government and COSLA that can be explored through the Policy Forum?

Thank and close