Too complicated to treat? Autistic people seeking mental health support in Scotland

Report on the survey carried out by the Autistic Mutual Aid Society Edinburgh, Spring 2018

AMASE
Autistic Mutual Aid Society Edinburgh

Helping autistic people to help each other.

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AMASE is an independent autistic people's organisation based in Edinburgh. All of the committee are on the autistic spectrum, and our goal is to help autistic people to help make each other's lives better through peer support, advocacy and education.

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Autistic Mutual Aid Society Edinburgh 2018

Summary

Autistic people are at significantly higher risk of mental health conditions, including depression[1], anxiety[2], and suicidal feelings[3], compared with the general population[4]. Using a survey, we collected the experiences of autistic people in accessing mental health services in Scotland. Questions focused on challenges faced, what is working well, and what autistic people would like to see done differently.

The survey also explored what role the Autism One Stop Shops play in the mental health of autistic people. Results suggest that autistic people are being denied access to mental health care as a result of being autistic.

Key themes included:

1. Autistic people being directly denied mental health services due to their autism diagnosis
2. Autistic people not being listened to or taken seriously when they are trying to communicate their mental health distress
3. Problems with the basic accessibility of GP surgeries and mental health services
4. A lack of understanding of autism and the mental health of autistic people amongst health professionals

In this report, we describe the findings from this survey, and call for action to address the mental health inequalities faced by autistic people in Scotland. Autism Rights Group Highland published in 2011 a report[5] on mental health amongst autistic people that highlights very similar issues - it is notable that very little seems to have changed in the past seven years, despite the implementation of the Scottish Strategy for Autism. Mental health is still listed as an urgent priority amongst many autism and autistic organisations across the UK.

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[1] Rai, D. et al (2018). Association Between Autism Spectrum Disorders With or Without Intellectual Disability and Depression in Young Adulthood. JAMA Network Open, 1(4), e181465-e181465.

[2] Mattila, M. L. et al.. (2010). Comorbid psychiatric disorders associated with Asperger syndrome/high-functioning autism: a community-and clinic-based study. Journal of autism and developmental disorders, 40(9), 1080-1093.

[3] Cassidy, S. et al (2018). Risk markers for suicidality in autistic adults. Molecular autism, 9(1), 42.

[4] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), 232-238.

[5] ARGH & HUG (2011). The Views of People on the Autistic Spectrum on Their Mental Health Needs and Mental Health Services. http://www.arghighland.co.uk/pdf/arghhug.pdf

AMASE’s Key Recommendations Summarised

Our recommendations can be read in full on page 19.

1. Access to services: autistic people should not be denied access to mental health services. Services must take sensory and communication needs into account.

2. Take autistic people’s distress seriously: autistic people need to be listened to and believed when they report distress. Improved training is required.

3. Provide stability for specialist support: recognise areas of best practice; long term funding for the One Stop Shops model is needed. Provide trained advocates and intermediaries.

4. Create post-diagnostic support pathways: provide a route for newly-diagnosed autistic people to access mental health and other support, and connect with peers.

5. Develop treatment with autistic people in mind: prioritise research on autism and mental health.

6. Involve autistic people in planning for change: empower autistic people to take the lead and guide what needs to be changed.

The Survey and Sample

AMASE publicised the survey on Twitter[6], via our email and facebook networks, and at a drop-in discussion event we organised in Edinburgh.

In total, 50 autistic individuals[7] across Scotland were surveyed anonymously using the online questionnaire.

The Questions

The questions were mostly qualitative, although quantitative data on mental health conditions was also collected. The questions were as follows:

Q1 *Where in Scotland are you?*
Q2 *Have you experienced any of the following mental health problems?*
[The options were: Depression, Anxiety, OCD, PTSD, Substance Addiction, Any other mental health conditions (please specify)]
Q3 *Please describe your experiences with mental health services, including with GPs addressing mental health issues, e.g. what services have you used? Have your experiences been generally positive or negative?*
Q4 *Has being autistic ever been a barrier to accessing mental health support? If so, how?*
Q5 *What would you like the government to know about autism and mental health? What would you ask them to change or improve?*
Q6 *Has Number 6 (or any other One Stop Shop - please specify) had an impact on your mental health and wellbeing? If so, how?*

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[6] URLs: https://twitter.com/AmasEdin/status/976756927857295361 and https://twitter.com/AmasEdin/status/981638767852376066

[7] A total 51 responses were received, but 1 was excluded as all of the questions except Q1 were skipped.

Findings

Q1: Location

Due to our initial focus on the Edinburgh area, where AMASE is based, 42% of respondents described themselves as being based in the Edinburgh area, followed by 18% in the Lothians, and 16% in the Highland Council area. Other respondents' locations included Glasgow and its surrounding areas, Fife, Dumfries and Galloway, Ayrshire, Angus, and Shetland and Orkney.

Q2: Mental Health Conditions

The following mental health conditions affect or have affected the 50 respondents in the online survey, in the following proportions:

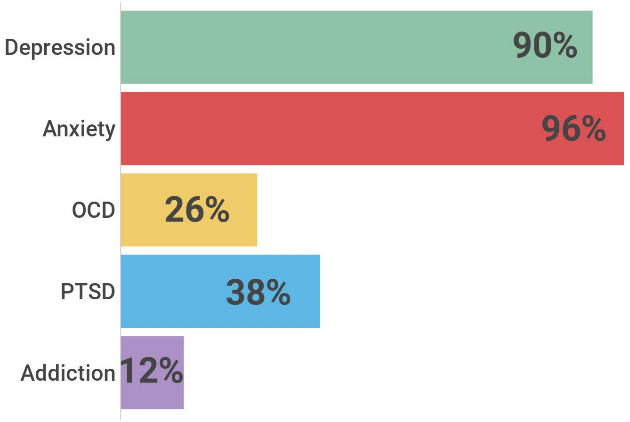
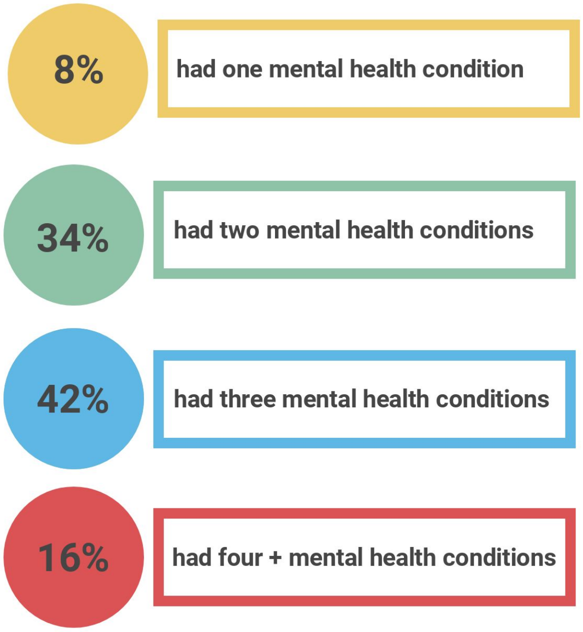


fig. 1: Mental health conditions experienced by our respondents



This aligns with previous research[8], suggesting high prevalence rates of mental health conditions in the autistic community, though it is unusually high, even by the standards of published estimates.

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[8] Rai, D. et al (2018). Association Between Autism Spectrum Disorders With or Without Intellectual Disability and Depression in Young Adulthood. JAMA Network Open, 1(4), e181465-e181465.; Mattila, M. L. et al.. (2010). Comorbid psychiatric disorders associated with Asperger syndrome/high-functioning autism: a community-and clinic-based study. Journal of autism and developmental disorders, 40(9), 1080-1093.; Cassidy, S. et al (2018). Risk markers for suicidality in autistic adults. Molecular autism, 9(1), 42.

Q3 & 4: Services and Experiences

We decided to analyse questions 3 and 4 together for each respondent due to the significant overlap in areas respondents covered across the two questions:

Q3 *Please describe your experiences with mental health services, including with GPs addressing mental health issues, e.g. what services have you used? Have your experiences been generally positive or negative?*

Q4 *Has being autistic ever been a barrier to accessing mental health support? If so, how?*

A note on interpretation of the following responses

It is worth noting that as the data is mostly qualitative, it is not possible to know precise figures for positive/negative experiences and specific issues encountered; the data can only be interpreted based on the information provided. A respondent may for instance cite issues with access but not specify exactly why, or describe positive or negative experiences without fully knowing why they were positive or negative. However, we believe that the results and issues raised have been consistent enough across the sample that they help to highlight what areas most critically need addressing, what kinds of things are having a positive impact, and what areas may warrant further investigation. The fact that a significant number of respondents mentioned any given issue doesn't mean that other respondents did not also have experiences with that issue. It is likely that many more were affected but did not specifically mention it.

Overall experiences with accessing mental health services

52% of respondents reported having overall negative experiences with mental health services, compared with 18% positive, and 16% mixed. The remainder were too ambiguous or did not provide sufficient information to conclude a clear category for their answer.

Fig. 2: reported overall experiences with mental health services

Use of services

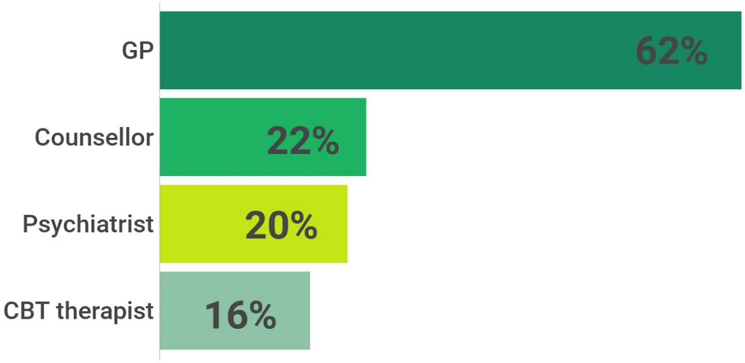

Fig. 3 Services used by the respondents for mental health support

62% of our respondents mentioned using GP services for mental health issues, by far the most commonly-used service. This is followed by counselling (22%), psychiatrist (20%), CBT (16%). Community mental health teams, mental health nurses, community psychiatric nurses, and Child and Adolescent Mental Health service were also mentioned by a smaller number of respondents.

GPs

GPs were identified as being a key service for accessing mental health support by our survey, both because they were the most commonly accessed service, being the first port of call for most individuals, but also because they are often the main way to access more specific mental health services.

39% of respondents who had gone to their GP for mental health related issues described their experiences as negative, 22% as positive, and the remainder were mixed or did not specify.

Listening and understanding

"my GP is non judgemental and understanding"

Positive experiences of GPs' largely focused on their understanding, listening, and lack of judgemental attitudes, but respondents also highlighted that there was a limit to what the GPs could do in the time that was available.

Access and discussion time

"My GP is fantastic, but there is a limit to what she can do in the space of a 10 minute appointment."

Indeed, around a third of respondents cited issues with getting an appointment with the GP, or communicating their needs in the time available, due to the way in which GP appointments and surgeries are set up.

"I find making phone calls very difficult. An online booking system may help"

"I moved and it took me 8 months to get round to registering with the GP"

Nearly a fifth of all respondents specifically mentioned telephone use as a major barrier to accessing GPs and other MH services, with additional barriers when registering with new GP practices. A preliminary survey, by Autistic Spectrum Healthcare[9], found 53% of autistic people said that using the phone to access GP surgeries was a problem, rising even higher when asked about it directly in their larger survey, still ongoing. Other research has also highlighted the importance of accommodating varied autistic communication needs in healthcare settings[10].

Some of our respondents also mentioned anxiety related to communicating with GP receptionists, sensory issues with the waiting area and travel to the GP surgery. These anxieties and communication difficulties were regularly cited as being all the more problematic when the person is in significant mental health related distress.

"there just isn't time for detailed discussion."

"the knowledge that a GP appointment is 10 minutes makes me really anxious"

"We […] need more time to process / answer questions."

12% of all respondents talked about having insufficient time to communicate their concerns adequately in GP appointments. Although some mentioned being able to access longer appointments, this did not seem to either be widely known about or available.

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[9] Doherty, M. (2018). Autistic Spectrum Healthcare, unpublished data.

[10] Nicolaidis, C., Kripke, C. C., & Raymaker, D. (2014). Primary care for adults on the autism spectrum. Medical Clinics, 98(5), 1169-1191.

Medications

“I was just told 'continue to take these medications as the best of a bad bunch and come back in 12 months’.”

“GPs tend to prescribe medication at a dosage that is based on experiences of people without autism. However, the same does not work for people with autism.”

Almost a quarter of respondents raised concerns about medication being the first or only port of call, mostly by GPs. These respondents described enduring a variety of negative side-effects, or the medications not working for long periods, with little or no additional observation or support.

Lack of listening, understanding and empathy

“I was so upset [by GP experience]. It took me ages to build up the courage to go back again.”

Mirroring the sentiments of the most positive GP experiences, the most common and most negatively impactful issue our respondents raised regarding accessing GP services for mental health problems was issues related to lack of listening, empathy, and understanding of autism and the autistic experience. This is a theme that is echoed extensively throughout our respondents’ experiences of all services, and will be explored in more detail in the next section.

The prominence of experiences with GP services in this survey highlights that as a main point of access for mental health support, it is critical that they are made genuinely accessible for autistic people. More needs to be done to enable autistic patients to adequately communicate their concerns, be listened to and be understood.

Autism as a barrier to accessing mental health services

64% of respondents said that they felt being autistic was a barrier to accessing mental health services, 8% didn’t think it was a barrier, and the remainder were undecided or didn’t say.

Communication, understanding, empathy

“I don't talk much, I just wish when I did people listened and realised that since I am speaking something is up.”

As touched on in the GP section, issues with communication, empathy and listening came up as a major recurring theme throughout our survey, across all services mentioned. Many respondents highlighted that it wasn't that they weren't communicating their distress, but that all too often they weren't being listened to or taken seriously. This is an example of the 'double empathy problem'[11]: that people with very different experiences of the world struggle to empathise with each other; in particular, non-autistic people often fail to empathise with autistic people.

"They ALWAYS treat me like I'm just a bit stressed and I'll be fine. I was suicidal"

42% of respondents wrote about these communication issues being a major barrier, with a number describing extreme distress (suicidal or in danger of self-harm) not being taken seriously because of differences in presentation in autistic people not being taken into account or understood by the professionals involved. This is particularly significant in the light of recent research showing that autistic people with low support needs are nine times more likely to take their own lives[12].

"many professionals have seemed unable to take my problems and distress seriously, even when I have reached crisis point, because I don't seem to present in a way that they expect."

14% of respondents specifically used "didn't take me seriously" or a very similar phrase to describe professionals' attitudes towards their mental health distress.

"The counsellor said that we were just wasting time, and that I needed to take it seriously."

"Doctors have accused me of lying to get hold of medication in order to lose weight."

A number of respondents also described misunderstandings between themselves and GPs or mental health professionals leading to problems and additional distress. Some respondents also said that they had too few therapy sessions, the sessions were too short, or there was too little continuity of care, for them to be able to build up trust and rapport with their therapist or other MH professional and adequately communicate what was distressing them.

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[11] Milton, D. (2018). The Double Empathy Problem. Network Autism. https://network.autism.org.uk/knowledge/insight-opinion/double-empathy-problem

[12] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), 232-238.

Understanding autism

"He understood all the different things that I was experiencing, and also understood autism. He modified some of the [CBT] approaches to take account of the fact that I can't say how I'm feeling."

36% of respondents described problems relating to MH professionals or GPs not having adequate knowledge of autism, or having mistaken ideas about autism. The quote above describes one of the most positive experiences from a respondent, and conveys the importance many respondents felt both regarding understanding of autism by professionals, and ability of a professional to listen and adapt therapies for the individual, taking into account their neurological differences.

Aside from not taking into account communication differences, ways of showing distress, and the greater unpredictability of medications, respondents also questioned the appropriateness of some of the services they were referred to, group therapy for instance being a particular source of anxiety.

Nearly a fifth of respondents talked about being referred to services that they felt were either inappropriate for their needs, or unequipped to handle mental health issues, such as autism drop-in services with no expertise in mental health, or mental health services with no understanding of autism.

"One psychologist dismissed Autism as purely a childhood condition."

Troublingly, some of the misconceptions about autism described by our respondents came from professionals with a significant degree of authority, such as psychologists and psychiatrists, suggesting there is still a significant amount of ongoing training needed to ensure that practitioners' knowledge is updated as our understanding of autism evolves. needed across all services. Both misconceptions and lack of knowledge about autism seem to contribute to the significance of an autism diagnosis being ignored or not understood in the context of mental healthcare.

"I feel like a lot of people ignored my autism"

14% of respondents specifically complained of their neurological differences not being taken into account or understood.

Autism diagnosis as a direct obstacle

"I have been denied mental health support due to having an autism diagnosis."

Acknowledgement of an autism diagnosis is not a guarantee of more appropriate mental healthcare, as over a quarter of our respondents found, when they were directly denied mental health support or access to mental health services due to being autistic. Some of these respondents were directed to autism services with no mental health expertise or provision, as mentioned, but a significant number were also either directly told, or left with the impression, that there was nothing at all available to help them.

"As soon as my [ASC] diagnosis was confirmed I was kicked off the [MH] waiting list"

Respondents described being removed from mental health support and services by GPs, mental health teams, and other professionals as soon as their autism diagnosis was made or became known.

"[CMHT] said I was too complicated for [them] to treat"

"I'm told that the depression and anxiety is normal for me"

Several respondents told of professionals describing them as being too complicated or complex for treatment, or that they have the expected amount of mental health distress for an autistic person. In all, a striking 40% of respondents described being told or feeling that there was nothing at all out there to support them with their mental health difficulties.

Other issues

"There is also no intermediary support during long waiting times, which can lead to very distressing crises."

"Worst experience was being on a waiting list to see a psychologist for 12 months despite being suicidal."

Even when respondents are referred to potentially appropriate services, the time it can take to access them can represent a significant problem, especially when there is no intermediary support in place, and the person is going through a mental health crisis. A fifth of respondents talked about the impact of long waiting times of months or even years, several of them citing that they were in crisis or suicidal throughout that time.

While this is not uncommon in mental health services, we suggest that the problem is aggravated by a failure to recognise when autistic people are really in crisis, and referral to inappropriate services.

Further Disengagement with Services

"I have not sought help for many years despite crises due to distrust of those professionals."

Asides from the obvious distressing outcomes of patients not receiving timely and appropriate mental health support and treatment, the negative experiences described by our respondents have also led 10% of respondents to say that they will either not go back to their GP/mental health service again, or have avoided seeking help from them for significant periods of time.

14% of respondents described their mental health as having gotten worse directly as a result of their experiences with seeking help from GPs and MH services.

Conclusions from Q3 & 4

That over a quarter of respondents reported being denied access to mental health services due to having an autism diagnosis is deeply concerning, and suggests that far too many vulnerable autistic people are falling through the gaps instead of receiving the support they desperately need and are legally entitled to under equality legislation.

Individuals not being taken seriously or believed by health professionals when they are in significant mental health distress is another striking problem. Not only is it deeply troubling that people in crisis are being dismissed, too many are being actively put off seeking further help due to these negative experiences, and for too many it is leading to an even greater deterioration in their mental health. It is clear that there needs to be far greater understanding of the ways in which autistic people in distress might communicate their distress, how being autistic can impact on mental health, how that can look, and how therapies could be best adapted.

Overall the responses show that there needs to be a far greater focus on accessibility, understanding and education around autism and mental health. There needs to be clearer policies and education to ensure autistic people aren't being denied mental healthcare, guidelines on best practice, better training for health professionals on empathising with autistic individuals with mental health needs, and a review of what mental health services are available that are appropriate for autistic individuals, and where there are gaps in service provision.

Q5: Respondents’ Suggested Changes and Improvements

Q5: What would you like the government to know about autism and mental health? What would you ask them to change or improve?

In question 5, we asked respondents for their own views on what they’d like to see in mental health provision for autistic people in Scotland.

“I'd like them to know that many of us are being shut out from treatment because some doctors and other practitioners have decided that it's normal and acceptable for autistic people to suffer.”

44% of respondents said that they wanted to see better training and education on autism and mental health for all health professionals. Many raised the issue that problematic assumptions and misconceptions about autism were leading to a serious lack of understanding about and empathy towards what they were going through, and what help they needed. 16% specifically talked about wanting professionals and health services to have a better understanding of autistic communication differences and access needs.

Additionally several respondents wanted more targeted training and understanding about the specific mental health problems that can affect late-diagnosed adults, autistic women, and other less well-recognised groups within the autistic population. This is supported by research showing greater risks of some mental health problems within autistic populations with lower support needs[13].

“If someone with autism is asking for help, give it to them.”

Echoing responses to questions 3 and 4, 10% of respondents mentioned again the urgent need for health professionals to listen and take autistic people seriously when they are describing their mental health concerns and distress.

“Provide services and therapists that are specifically for autistic people with mental health worries.”

“We desperately need the security of guaranteed long term accessible support such as the one stop shops where we can access practical help and also solidarity with others who know our struggles first hand.”

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[13] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), 232-238.

A further 10% suggested having in place specifically trained autism-specific mental health specialists, services or advocates who are able to understand the specific needs of autistic people with mental health problems. A number also talked about the value of good existing support services for autistic people, such as the autism One Stop Shops, as well as the importance of investing more in these services to expand their resources and ensure that they are not at risk of closure.

"It would be so much better if I didn't have to wait until crisis point to get help."
"We need stability in the staff we deal with."

Other respondents talked about the importance of continuity of care and not allowing problems to reach crisis point before they begin to be addressed.

"There needs to be a better pre and post diagnostic pathway that provides support and screening for mental health and other conditions common in autistics."

A number of respondents also asked for better integration of mental health support into the autism pre and post-diagnostic pathways, given that many people will have gotten a late diagnosis as a result of mental health difficulties, and lack of support following diagnosis can also lead to and exacerbate mental health problems.

Q6: One Stop Shops

Q6: Has Number 6 (or any other One Stop Shop - please specify) had an impact on your mental health and wellbeing? If so, how?

The Autism One Stop Shops mentioned in this survey (Edinburgh, Perth and Highland) are drop-in services for autistic adults, designed to be a safe space that they can go to, as well as a space for social activities with peers. These One Stop Shops are facilitated by staff generally with a range of expertise in diagnosis, employment, benefits, housing, etc, on which they can provide support and advocacy, and who are on hand to chat and give support one-to-one or in groups with service users about any concerns they may have. They play a part in facilitating and empowering autistic-led groups and peer support. Highland, for instance, exists in partnership with ARGH (Autism Rights Group Highland), an APO (Autistic People's Organisation).

ARGH highlighted in their 2017 *Highland One Stop Shop: User Evaluation*[14] its impact on the wellbeing of its service users. The One Stop Shops are also a service that many autistic adults are directed towards by health professionals and diagnosticians, sometimes in lieu of mental health services. We decided that it could be important to ask our respondents what role, if any, their local One Stop Shop, if they have access to one, plays in their mental health and wellbeing.

Experiences

The OSSs mentioned by the respondents were Number 6 in Edinburgh, Number 3 in Perth, and Highland (HOSS) in Inverness.

Of the 50 respondents, **66%** had used one or more of the OSSs mentioned. Of those:
64% described the OSSs as being positive for their mental health,
18% had mixed experiences,
15% felt it didn't help their mental health overall.
The remaining 3% of answers were either neutral or did not elaborate sufficiently to draw clear conclusions.

"For the first time in my life, I feel that I have a safe and non-judgmental place to go to, with people I trust to talk with, whether I am in crisis, or just have small worries I'd like to prevent from getting bigger, or even for just practical advice on work."

The positive experiences tended to highlight the importance of the OSSs helping to provide greater stability in day to day life, being a non-judgemental source of advice, reassurance and a place to talk, and providing access to peers and allies who have a good knowledge of autism.

"They listen to my concerns or need for support and make me feel like a person, my feelings are valid and they will try and support me in the ways they can"

"I trust and value the staff for their empathetic skills and understanding of autism"

Several mentioned the impact of having people to talk to who could empathise with autistic experience, both peers and staff, and of being listened to and taken seriously.

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[14] Brook, K., Crompton, C.J. & Fletcher-Watson, S. (2017) The Highland One Stop Shop User Evaluation, Autism Rights Group Highland.

“By providing support in [benefits] and other day to day matters meant I could finally break free from an abusive relationship [...] I believe that without [their] help I would possibly be dead or very likely in a much worse position mentally.”

“Since discovering Number 6, I have made more progress in my mental health and general stability and wellbeing than I think I ever have.”

Many respondents described dramatically positive impacts that the OSSs had on their lives. While most of the support described is not mental health specific, the improvement in stability, having a safe space, and access to peers and empathetic allies and mentors has clearly been valuable in improving the respondents’ mental health and general wellbeing.

“I only wish that they had more resources in general, and someone trained in mental health problems, so that they could help more people (and be easier to access), and be less powerless in the face of crises.”

“Attempted to get other support but they are so oversubscribed that I've had no luck.”

The other responses tended to focus on anxieties around how the services are structured and issues with accessibility, sometimes relating to the services’ lack of resources or capacity, or their inability to signpost to other more relevant services due to those services not being available.

“We would be lost without them.”

“Their lack of guaranteed yearly funding terrifies me, as I don't know what I'd do without them.”

Although it was not raised in the survey questions, several individuals also expressed anxieties or related comments about the idea of the services’ longevity being in question, likely partly due to the Highland One Stop Shop’s continued threats of closure through lack of funding, although it should be noted that these fears didn’t exclusively come from HOSS service users.

One Stop Shops: Conclusions

The overwhelmingly positive experiences reported of the OSSs in relation to mental health (64% positive, 15% negative) stand in stark contrast to experiences reported with mental health services and GPs in the rest of the survey, in which 52% of respondents described overall negative experiences compared to just 18% having had mostly positive experiences. While nearly half of all respondents reported specific problems with being listened to, taken seriously or being misunderstood by GPs and MH professionals, the comments on the OSSs repeatedly highlight the value placed by service users on being listened to, understood and empathised with. The OSSs mentioned are doing far better in MH support of autistic people in Scotland than many GPs and specific MH services. The negative experiences above highlight the impact of cuts to valued services; adequate resources to sustain reliable services are crucial.

We feel that lessons can be learnt from what the OSSs seem to be doing well in this regard, and their contribution to autistic people’s mental health should be better recognised, understood and supported long term.

Conclusions and Recommendations

"I want the government to know that if we are given the right support we really can thrive."

1. Basic access to services

A significant number of autistic people have reported being denied access to essential mental health support and services due to their autism diagnosis. AMASE feels that this is unacceptable and a failure of health professionals' duty of care towards at risk members of a vulnerable population. We would like to call for an urgent review of why this is happening, education of GPs and other health service providers that this is not an acceptable response, and action towards identifying and addressing gaps in appropriate mental health service provision for autistic people across Scotland.

We would also like to see a review of accessibility to GP surgeries and mental health services in respect to autistic service users, and further exploration of how these services can be made more accessible. Services that require phone access for appointments, opting-in or registration need to be more accessible to those unable to use the phone for whatever reason. We would encourage the roll out of email or online booking systems to broaden access.

2. Take autistic people's distress seriously

The survey highlighted a troubling gulf in communication between autistic patients and health service providers, as well as the dramatic difference good communication and understanding can make.

AMASE would like to see the message spread across health services that autistic people need to be taken seriously, irrespective of non-verbal cues, when they report being in mental health distress. Trained intermediaries could do much to facilitate these conversations.

We would also like to see a review of autism training across the NHS and social care providers, with a renewed emphasis on communication differences, understanding of the autistic experience, recognising the 'double empathy problem' and the significance of being autistic when it comes to a person's mental health.

We strongly recommend that this training and education be led by autistic people who have either (preferably both) professional or personal experience of mental health difficulties, alongside other professionals with extensive experience working with autistic people who have encountered mental health difficulties. We feel that only through working and talking with autistic people as equals, and listening to our experiences and perspectives, can non-autistic health professionals truly gain adequate understanding and empathy towards their autistic patients.

3. Provide stability for specialist support

The survey highlighted the One Stop Shops as a service that is helping many autistic people achieve some kind of stability in their mental health and general wellbeing, in contrast with the difficulties and problems experienced with GPs and mental health services. AMASE would like to see more widespread acknowledgement of the value of the OSSs in this area, and understanding of the implications of the gap they are currently filling in support services for autistic people. The degree to which health services are relying on and referring to them as a source of mental health support for their autistic patients, despite them not being a specific mental health service, should also be understood.

AMASE strongly recommends that the existing OSSs' funding should be secured indefinitely, the model of the most effective ones highlighted in this survey rolled out to other local authorities, and that they be empowered with the resources to take on greater expertise in advising on mental health provision and advocating for their service users.

AMASE also recommends the identification and creation of trained intermediaries and advocates, with expertise in autism and mental health, and particularly in empathising and communicating with autistic people, to help ensure that autistic people are accessing the services they need, and able to communicate their mental health concerns effectively with mental health services and professionals. Autistic people already have a legal right to independent advocacy[15] - we would like to see this properly implemented and fully accessible.

4. Create post-diagnostic support pathways

Despite adult autism diagnoses often arising from mental health crises, the lack of post-diagnostic support and signposting to helpful services and resources is clearly problematic. AMASE recommends a careful review of the post-diagnostic pathway for late-diagnosed autistic adults across Scotland. We would like to see more research into and awareness of the mental health impacts being undiagnosed until adulthood can have on autistic people, and screening for common mental health conditions and other common co-occurring conditions as part of the autism diagnosis process.

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[15] Mental Health (Care and Treatment) (Scotland) Act

We would also like to see more exploration into the value of non-pathologising self-knowledge and peer support for autistic people and their long term wellbeing.

5. Develop treatment with autistic people in mind

Currently the majority of approaches to mental health care and treatment are developed through testing on non-autistic patients. We would like to see more research into the impacts and outcomes of conventional mental health therapies and medications on autistic people, as well as how they can be best adapted to better suit people with neurological differences.

6. Involve autistic people in planning for change

"I would ask them to fully embrace 'nothing about us, without us'. I feel that co-production is key to this. Everything needs to change, but they must be guided by the voice of people with lived experience."

AMASE would like to re-emphasise the importance of including and empowering autistic people to take the lead and guiding what needs to be changed, in line with the Scottish Government's Delivery Plan for the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)[16].

Many of the gravest problems highlighted in this report have directly or indirectly stemmed from autistic people not being listened to, taken seriously, or understood. The first step to changing this is to listen to autistic people. Respect our lived and professional experiences; believe us when we say that there is a problem.

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[16] https://consult.gov.scot/equality-unit/rights-of-persons-with-disabilities/

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