

“You need support, validation, good coping skills. You need and deserve acceptance”¹: Autistic Adult Experiences of Counselling

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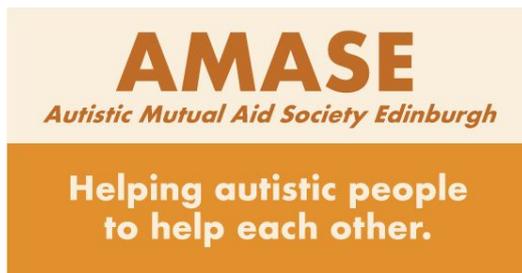
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www.amase.org.uk

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Abstract

Autistic people experience higher rates of mental health difficulties, yet face a number of barriers and challenges when needing to access effective counselling services. Some of these barriers are practical, such as the sensory environment of the counselling room, and communication and admin demands from the service, and some are to do with misunderstanding and miscommunication, or the counsellor not adapting their approach in a way that best suits autistic clients. In this paper, we explore a number of ways which, based on client reports and counsellor interviews, counsellors and counselling services can and have adapted their approaches and understanding to better serve autistic clients, as well as covering more difficult experiences that underlie some of the common issues that arise. Our findings also highlight that claims of autism specialism amongst practitioners often aren't a guarantee of positive experiences, and in fact may lead to the opposite if outdated or inaccurate information about autism was being used. Many of the valuable adaptations and recommendations we identified hinge on flexibility of approach, clarity, openness, as well as an up to date understanding of autism and key related differences. This is vital knowledge which autistic clients often feel is lacking, but this knowledge also might need to be held lightly by the practitioner in order to work collaboratively with each individual.

Background

The AMASE (Autistic Mutual Aid Society Edinburgh) "*Too Complicated to Treat*" report published in 2018 highlighted for us the many challenges autistic people in Scotland are experiencing in access to mental health care and support, a finding that has also been validated by a number of other research papers (e.g. Camm-Crosbie et al, 2019; Doherty et al, 2019). While the AMASE report covered a range of mental health service access related issues, including initial access to and existence of appropriate services, the findings also suggested that when autistic people do manage to access services, there can be a gulf in understanding of autism amongst practitioners, and often a lack in the provision of appropriate accommodations.

To investigate this further, identify key problem areas, and also look at examples of the types of support and accommodation that have been beneficial, we conducted a survey focused specifically on autistic people's experiences of talk therapies such as counselling.

Several studies (e.g. Cooper et al, 2008; The Royal College of Psychiatrists College 2020) have suggested that tailored approaches are important in mental health related treatment for autistic people and that using tools designed for neurotypical people on autistic people can be unhelpful or misleading. However, few studies have directly asked autistic people more generally what has or hasn't worked for them.

This document summarises the themes identified from an online survey carried out on Survey Monkey and disseminated via Twitter in Feb and March 2020.

The responses to this survey show a number of consistent trends in what problems commonly emerge for autistic clients in talk therapy, and also what has worked well. We think that there is a lot that can be learned by drawing from this collective expertise.

We, the authors of this report, would like to unreservedly thank everyone who participated in the survey: the honesty, clarity and detail provided clearly showed the desire of everyone to be a part of something that could help others in the future.

About the authors

Sonny is a co-founder and chair of AMASE (Autistic Mutual Aid Society Edinburgh), an independent Autistic People's Organisation based in Edinburgh, Scotland. In 2018 Sonny co-authored a report on barriers for autistic people in accessing mental health services in Scotland (www.amase.org.uk/mhreport). They are currently training to become a qualified counsellor.

Colin is an experienced mental health counsellor based in Edinburgh. He works predominantly with adults who have lived through adverse or traumatic experiences growing up and who struggle with a range of psychological, physiological and emotional distress. He has an interest in the overlap of autistic experience and distress.

Both authors, and the overwhelming majority of readers, advisors and contributors to this report, are all on the autism spectrum.

Funding and support

AMASE supported the authors in promoting the survey. There was no external funding.

Methodology

The Data

We constructed ten questions asking our respondents to describe aspects of their experience of mental health talk therapies (including counselling, psychotherapy, cognitive behavioural therapy, and other forms of talk therapy). This was targeted at adults (18 and over) who are autistic.

The survey was created using Survey Monkey. We prefixed the questions with some background to the purpose of the survey (see appendix).

The survey was disseminated through Twitter to autistic communities we had access to, who shared it on, and via AMASE (Autistic Mutual Aid Society Edinburgh). 66 replies were received before we closed the survey. The survey was open for two weeks.

The only inclusion criteria was that respondents were adults, 18 or over, who are either formally diagnosed or self-identified as autistic.

We also ran hour-long, more open-ended interviews with four Edinburgh-based counsellors who have had experience working with autistic clients to capture some additional viewpoints from the counsellor's perspective. The material from these interviews were used to add to, and give further context to, the analysis of our survey responses.

Evaluation

We used Thematic Analysis to organise, review and analyse the themes we developed from the data. Thematic Analysis is ideal for describing and reporting themes found within a set of rich qualitative data. Further details on Thematic Analysis and the detail of how we carried out the steps can be found in Brown and Clarke (2006), Nowall et al (2017) and Maguire and Delahunt (2017).

Although both authors are familiar with research methods and have carried out research previously, Thematic Analysis was chosen as a method that was flexible and easily applied to the data. We

followed the usual steps of familiarisation of the data through reading through the responses several times and identifying codes from this (which we did separately and then compared and consolidated) which then fitted into subthemes. We then reviewed the data again against the themes they supported to ensure they really did support it. We then pulled the sub-themes together into broader themes for the findings below.

Limitations

Although we are presenting this as a piece of research and have used recognised research methods and approaches, our primary aim was to determine how to help autistic adults access and utilise counselling.

As such we are aware of a number of limitations to this as research including the following:

- The population we targeted would have mostly excluded autistic individuals who did not use Twitter
- We did not collect specific demographic data and therefore do not know the full demographics of the respondents and therefore whether the data represents only a subset of all autistic adults. From the information that was shared by individual respondents we know that we did have representation from various genders and age ranges.
- Although we included in the 'talking therapies', counselling, cognitive behavioural therapy, psychotherapy, and so on, we did not specifically ask what type of 'therapy' an individual received. In many cases respondents did refer to the type of therapy
- Although we included receipt of talking therapies through the NHS, charities, other organisations and private practices, we did not specifically ask where a respondent received their therapy. In many cases respondents did refer to the setting for their therapy.
- Although some respondents noted the medium through which they had received counselling, such as over Skype, we did not specifically ask respondents about how they had engaged in counselling and so cannot identify whether the medium had any impact on some of the responses - we know from the comments, however, that the large majority of respondents had received counselling 'in the room' with the counsellor
- The sample was small (though large for a qualitative survey)

Results

Respondents reported on their experiences with talk therapies, reflecting on what went well for them, what didn't, and things they feel might have helped or could be done better. We grouped our associated themes into five broader categories. Select quotes from the respondents and our counsellor interviews (indicated after each quote) have been added to illustrate what was said.

1. The Counselling Experience

Anxiety and uncertainty are big parts of the autistic experience. Respondents emphasised the need for certainty around how the counselling would work, what is and isn't okay, what is and isn't expected. Part of knowing the rules is also about the client knowing what they want from counselling. Some respondents also stated that they just didn't know what to say in the sessions, or how to use them. A number of responses talked about the value of the counsellor explaining how counselling worked, what sort of help the counsellor could give and what clients could expect. It was also suggested that it would be helpful to provide this information in written form to clients.

“One thing that would have helped is if the counsellor could have explained what I could expect from them”

“[It was a challenge when counsellors didn't make] clear the limitations of the counselling situation”

“Both services, and particularly the university counselling service, gave lots of information in advance about what to expect - I was still absolutely terrified, but this at least got me down to a point where I could actually face going!”

These experiences also came out strongly in our counsellor interviews. However, it's not fair to assume here that autistic clients have less of an understanding than non-autistic clients of how counselling works. One of our interviewees highlights this, noting that the need for clarity that her autistic clients bring in their questions around what counselling is and how it works has made her clearer with all of her clients - her autistic clients are just more likely to be “upfront” about it, and more impacted by any uncertainty:

“if there was a distinction [between autistic/non-autistic clients], it might be that my clients that have autism might be more upfront about [uncertainties about the counselling process] with me [...] because I guess they might be contending with that [kind of uncertainty around interactions] on a kind of daily basis out there.” (counsellor interview)

As well as the counselling endeavour, the client is also meeting someone new, in a new place – all of which is potentially challenging, causing discomfort and higher levels of anxiety.

“It was very difficult to adjust to and to start to feel comfortable talking to someone I didn't know. The communication went quite poorly at the beginning because I was incredibly anxious and scared”

“I feel unseen and othered because I don't do well with an environment that requires me to trust and confide in a relative stranger who may or may not listen to my boundaries depending on whether they understand them or feel like trusting me.”

Our counsellor interviews also brought out the potential challenges of longer 'settling in' times being needed in some cases with autistic clients, or more uncertainty going into establishing the counselling relationship:

"I'm used to [getting a comfortable "conversational rhythm"] taking a couple of sessions; it might take three or four, but I think it took us six out of our eleven." (counsellor interview)

"between me and [the autistic client], there might be kind of perhaps more awkwardness or uncertainty from them about how the counseling relationship was going to be." (counsellor interview)

Even where a client has had previous experience of counselling, they may not know the 'rules' for this specific experience, or may need extra time and reassurance to build up a sense of comfort and trust with a new person. Respondents highlighted the need for the counsellor to be clear but also giving the clients space and permission to ask for clarification.

"I was not really sure what it [counselling] was and i didn't feel it was ever explained to me"

"[The counsellor] didn't help me to understand how to work with a counsellor"

The value of being explicit about the counselling process was also echoed in our counsellor interviews.

"from the very beginning of sessions [it was] important for me to have explained kind of literally what was expected during the session; so there might be silences at points [...] and how might they feel about that? Or the general way that it's going to work is that the client is going to be doing quite a bit of the talking and I will be asking questions to kind of deepen my understanding of where they're at; to be really quite explicit about literally what's going on in the session." (counsellor interview)

"I felt like I wanted to be explicit with clients about 'here are things we could do'." (counsellor interview)

There were a number of comments around the theme of welcoming, which respondents valued, and helped them feel safer and more able to express themselves. These included the counsellor being warm and inviting, speaking in a soft, calm voice, getting a sense that the counsellor wanted to help, finding the counsellor caring and kind, and feeling accepted and validated. These qualities or attitudes helped build trust and rapport, particularly in making the new situation of counselling less anxiety inducing, but also in helping the client to be able to ask clarifying questions, advocate for themselves, and mask less.

"they [the counsellor] were a warm, naturally direct person"

"[it helps when counsellors] acknowledge how difficult we find things (like a small change in routine) and validate our experiences."

In contrast, respondents also talked about how detrimental it was to their experience when they didn't feel validated or accepted by their counsellors.

"[...] many times we have trauma from drs and professionals disregarding our lived experience"

Some also talked about the value of a good rapport or connection, especially from a counsellor who the client senses is possibly autistic or similarly neurodivergent.

“I would love if counsellors would advertise that they're autistic or think they're somewhere on the spectrum! My therapist was the first one I tried and as soon as I saw her I "recognised" the autism, [...] and felt like we could work well together.” “I am sure that part of why we work well together is because her brain is like mine in some ways, and I like that a lot.”

Feelings of safety were also developed through clients feeling that they had control of the space through self-advocacy and the use of accommodations. This is explored in depth in the next section, *The Physical Space*.

All of these points highlight the importance for our respondents of clarity around the counselling experience, what it is, and what it isn't. It is also clear that starting counselling, and seeing a new counsellor or service, can be an extremely anxiety-inducing thing for many autistic clients, many of whom might have also had the anxiety of negative past experiences of support services and counsellors to contend with, in terms of being misinterpreted or 'written off'. The need for warmth, explicit reassurance, and feeling 'seen' and believed from the very beginning is shown to be incredibly important for countering many of these early fears and potential misgivings, and in building a more trusting and productive counsellor-client relationship.

2. The Physical Space (and other practicalities)

There are aspects of the space – the building, reception, toilets and the counselling room itself, which can be challenging for autistic clients.

Light, noise and smells are common sensory challenges for autistic people. Addressing some of the sensory challenges of the space might include closing blinds or curtains if the sun is strong, closing a window if there's too much noise outside, switching off fluorescent lights because of the distraction from changing colours or noise, removing a ticking clock and so on.

“Some of the counselling rooms were very bright (from sunlight) and this made things uncomfortable for me.”

“My current therapist has been very careful and clear about settings and comfort in the space. She'll turn the lights down or off if I need that, she keeps her voice low, she keeps her body in a steady posture. She has weighted blankets and fidgets in her office. I feel like I'm in control of my presence in her office, which makes it easier to feel safe and be able to be vulnerable in ways that work for me. Previous therapists have never offered this level of accommodation, and it never even occurred to me to ask. Rooms were always bright and cheery, and they put me on edge in ways I didn't understand at the time.”

“[the counsellor] made changes for me which have had an impact, for instance there was a small ticking clock [in] the room which I found very difficult to be with and he put a silent clock in the room”

Making the space in the room easier for autistic clients to use might also include the arrangement of the furniture: for example, some respondents mentioned a preference for sitting on the floor rather than in the chair. This might also extend to how a client is in the room, which might include allowing the client to knit or play with a fidget toy. Some also talked about experiencing overwhelm at having to sit too close to their counsellor, having to face them, or feeling a pressure to make eye contact.

“I'm always allowed to change how I am in the room. So if I want to be on the floor, or sit with my legs up that's always fine and we adjust. If I need to not be facing her [the counsellor] we adjust too. This has given me a lot more freedom and relieved frustration.”

“without me asking, she [the counsellor] rearranged the chairs so we could talk comfortably without needing to face each other”

“My current therapist lets me knit while we talk which is hugely helpful both as an autism stim and an ADHD focus tool.”

These were also things that our counsellor interviews regularly identified as important. Early, often ongoing, accommodations were particularly important for their autistic clients.

“I guess if I was completely unaware of autism, I might never have thought to look around the room. Consider how the seats are configured. Consider the smell of the room, the lighting in the room. My own perfume.” (counsellor interview)

“with configurations of the room, I would check with my clients about what felt comfortable for them, allow them to move the chairs as they felt comfortable. And with that being like an ongoing process as well.” (counsellor interview)

Just having a better sense of how the space might look ahead of time could help alleviate uncertainty and anxiety in some clients:

One respondent suggested that *“having [an] online ‘walk through’ or at least photos of therapy location and rooms”* would be helpful.

Relating to these practical considerations, respondents repeatedly brought up how important it was for them to feel able to ask or say when they are uncomfortable in the space, and for the counsellor to check in periodically and be aware of and anticipate any sensory issues that might arise. Again there is also a theme of needing validation and recognition here, of autistic people’s differences in experiencing their sensory environment - that it shouldn’t be dismissed or seen as a problem to fix, but accommodated. Some also pointed out that it was helpful when counsellors pointed to possible sensory challenges they might not have been aware of themselves.

“the most important thing [for counsellors] is to ask what people want/need and be flexible. Especially to ask because it’s sometimes really hard to bring up what I need without feeling like it’s stupid.”

“You will need to educate your counsellor about your own autistic needs.”

Our counsellor interviews also picked up on the need for counsellors to sometimes take the lead in exploring potential sensory challenges that might be present, sometimes even through practical experimentation rather than asking direct questions.

“I suggest things [about the sensory environment], and they’re like, “okay”, and then just, it goes away. So that’s part of why I started bringing fidget toys in, because I had a client who clearly, what they had with them, was not sufficient either for emotional self-regulation or to distract them enough so that [they] could be present with me. And when I started bringing stuff in, they started using the stuff that I brought in, and then that was part of what shifted things.” (counsellor interview)

These also extend to ‘the space’ when doing counselling by phone or video call, albeit there are likely to be different needs and challenges. While some respondents felt that counselling by telephone or video would not suit them, others felt that it might be easier than attending in person. Our survey was carried out before the COVID-19 lockdown came in in the UK, but with the associated growth and normalisation of remote counselling, further research is needed on how autistic clients are responding and adapting to this change.

“it was telephone counselling; she understood that structured, planned phone calls where I could control the environment are very different from unplanned ones. She was very flexible with timing when I needed to change the usual slot. Her setup was that the client had to make the call as part of taking responsibility, which for me was better than anticipating the phone ringing.”

“At first I thought that a downside would have been doing it over the computer as I am no good at talking on the telephone so I thought I would find the skype calls stressful too but it has been fine and actually much easier than having to go to an appointment somewhere.”

Pertinent to the above point, a number of respondents raised the problem of accessibility of phone communications in things like organising or confirming appointments. Respondents also mentioned other areas of practical difficulty in accessing and using counselling services, such as uncertainty or lack of clarity around administrative procedures and financial challenges.

“I also struggled with some of the administration around the counselling - deadlines for providing filled questionnaires, confirming attendance at appointments, what felt like threats being sent that if I missed counselling sessions I'd be discharged without notice. Executive function is a big problem for me and I was almost constantly terrified that I was going to be kicked out and left without help because of the very thing I was seeking help for.”

“I very literally can't afford counselling, and increasingly I can't afford to go on without it either.”

“She [the counsellor] respected my wish to communicate any admin matters between sessions, changes to dates etc by email”

In many ways the responses on physical accommodations and other practicalities point to and connect with the more general importance of both self-advocacy and self-knowledge, for autistic clients. Our respondents wanted counsellors who wouldn't just listen to their requests, but also help provide the safety and encouragement for them to self-advocate and make those requests or ask those questions. Responses also talked about needing support in helping to identify what kinds of help and accommodations they might need, and an open exploration of creative and helpful solutions in addressing the sensory and other practical challenges that come up. More on self advocacy and collaboration is explored in section 4, *Working Together*, but it is worth noting here that the sensory environment, and to some extent seating, was brought up by respondents as one of the most common areas of collaboration and an opportunity to ask and check in between clients and counsellors.

3. Feelings and Distress

Anxiety and being anxious came up a lot in our survey responses. One of the underlying themes was that a lot of autistic folk might not present as being anxious in ways that are considered typical – there may be few external cues that the person is anxious, or the cues are not being picked up by the counsellor or correctly interpreted.

“I never feel understood or accepted. I feel like I am on a different wavelength and the usual methods don't work [...] It makes me terrified to go back [to counselling]”

“For me, a cbt focus in itself is unhelpful. All it does is point out more things I "should" be masking and teaches me to put more effort into masking rather than understanding myself and others properly. It taught me that the things I do and think are "wrong", which increased my anxiety and convinced me I was making up my feelings and problems.”

“This feels like a really important one for me about really, really understanding that while someone might have difficulties with social interaction, that doesn't equate to a lack of feeling or a lack of empathy. I mean quite the opposite, it's like actually how important it is to understand that someone with autism is likely to be experiencing much more intense emotions than other people at points.”
(counsellor interview)

This may also be true of other feelings experienced by the client, with a number of respondents emphasising the need for counsellors to check in with them about what they might be feeling, and believe their degree of distress (even if they are not obviously emoting).

“I worry that due to my tendency to hide my feelings, she [the counsellor] may not fully grasp the difficulty I experience in day-to-day living.”

“We might be having a harder time than it looks like on the surface. We might hold things inside because we worry we are overreacting. In the past, others may have made us feel like a burden, so we might do a lot of internal labour without telling our therapist. We might not be able to articulate our feelings. We might need to communicate nonverbally.”

“[The counsellor] talked a lot, kept letting me know he saw my feelings despite my 'lack of affect'. Was open and real with me.”

Processing delays and alexithymia are also important to take into consideration. The former may mean that anxiety, or other feelings, are experienced later in the session or after the client has left; the latter may mean that a client is not necessarily aware of being anxious, or unsure if they are feeling an emotion or physical sensation, or aware of emotions but unable to name them.

“we [autistic folk] can often have alexithymia, where we can't recognise our own emotions, or can't put them into words. i certainly have that problem, but because i am generally articulate about other things, people miss it and assume i will be articulate about everything. i'm not.”

“When I talked about how I felt she [the counsellor] told me I was detached from how I felt, presumably because I am [...] autistic and wasn't performing the “correct” behaviours to signal genuine feeling. I started to really believe I must be completely detached from my emotions, even though I was experiencing intense emotions and what I wanted was the tools to cope with them.”

"[...] I am often unaware of my own emotions or unable to describe them, I am so overwhelmed by emotions I have physical symptoms of distress, and I am exceedingly upset when my routines/plans are disrupted."

This was echoed in our counsellor interviews, both in terms of clients struggling with identifying their feelings, but also clients feeling that that might be 'part of' them being autistic.

"very generalizing here, but someone with autism might often be more direct, but at points, they might find it really difficult to put into words actually what they're feeling." (counsellor interview)

"There was the, you know, "I'm autistic so I don't know what my feelings are". And my response to that is, "well, let's figure that out". They're like, "but I'm autistic, so I can't figure that out. I don't know what my feelings are"." (counsellor interview)

And on processing time and emotions:

"Fixed sessions may not always be the best solution because of our need for processing time."

"Sometimes he [the counsellor] ended a session with something quite emotional and then asked if I was okay enough to leave on time, but there didn't feel like much space to say no so I think I would've liked a built in 5 minute cooling down period at the end where we talked about non-emotional things or so."

Although anxiety is closely associated with autism, it is separate, and likely to have arisen at least partly from being different from the majority, and living in a world that isn't designed for autistic people. Education about this is important, as some of the responses talked about counsellors who considered anxiety a genetic or inevitable part of being autistic, and so did not address it.

"In this therapy we are working to understand where my core beliefs come from. We try to separate the things that are part of the autism, from the things that are anxiety based and could be changed."

"we shouldn't accept that anxiety or indeed any other mental health difficulty is just part of autism or inevitable if you're autistic in a neurotypical world."

There are also a lot of things that can contribute to anxiety that might be relevant to the counselling process and how it is carried out, including sensory overload, cognitive load, change, unpredictability, and so on. This emphasises both the need for counsellors to regularly check in on potential anxiety, but also to maintain an open mind as to its cause and how to address it.

A number of replies highlighted the need for counsellors to understand about autistic meltdowns and how they are different from panic attacks and what can lead to them.

"I talked about sensory overload and meltdowns and how my spiralling worries around heat tend to revolve around the worry it will trigger a meltdown. She asked if that had ever happened, and I said that my meltdowns rarely ever have one singular cause, there's a "last straw" trigger but there's almost always other things going on. As we progressed it became clear she took this to mean that it had never happened and wasn't a realistic worry at all, which was frustrating!"

"[I would like counsellors to know about] sensory differences and how they differ from phobias, and meltdowns/shutdowns and how they differ from anxiety and panic attacks (not that you can't have all of the above or they can't be linked, of course!)."

Distress more broadly was also an important theme for many respondents: being overwhelmed by emotion; upset when plans or routines are disrupted; masking covering distress to the outside world; stimming as a means to calm distress. Often, distress is not expressed in a neurotypical way and it is important for counsellors to hear when someone says, "I am distressed", even if they may not appear distressed.

"listen to my words, not my tone. I'd like them to pay attention to autistic body language. I have very clear tells when I'm distressed: they're just not what a neurotypical person would do."

"There was one counselor who focused on my failure to keep track of my outbursts/explosions. [...] She could not / would not see an utterly overwhelmed, in complete survival mode, struggling person."

"just because someone may be very skilled at masking doesn't mean they aren't in pain."

Counsellors interviewed also talked about the emotional distress and meltdowns in their autistic clients, how that can be challenging, and how they worked with them.

"Something I find might find more difficult with working with autistic clients: I guess there have been experiences of being with someone when they've been in a really intense emotional state, and how, I guess just from it from a human perspective and a kind of counsellor's perspective, being with someone when they're in such a deep level of distress, it can leave me feeling kind of like not enough, you know, at that point that it feels like, you know, you kind of, there's that desire to help and then kind of an awareness that there isn't really much that you can really do in that moment. So I guess that that can feel difficult from maybe a more personal perspective." (counsellor interview)

"if someone's having a shutdown, [I might] say 'would it help to move our chairs?' As far as they were able to kind of stay in contact with me, to see if there was anything physically that could be done to kind of help in that situation." (counsellor interview)

Learning emotional regulation was very important to many respondents, as well as learning about the impact of sensory issues, trauma, and how other challenges and problems 'fit' within the broader picture, in order to build strategies and self acceptance.

"I believe what I need now is to learn emotional regulation and to manage post-traumatic stress as well as issues with executing functioning and time management"

"I tend to intellectualize my problems and then assume that describing them will fix things, and therapy techniques that get me out of logical-brain and into squishy-emotional brain are really valuable"

Autistic people often report being misread by others (Crompton *et al*, 2020; Heasman and Gillespie, 2018), including professionals, and disbelieved, when it comes to anxiety and emotional distress. At the same time, many autistic people can struggle with naming or identifying their emotions, and regulating them. Based on the frequency with which emotions, meltdown and distress were mentioned by our respondents, there is an urgent need by practitioners to check in and believe clients when it comes to distress, understand how anxiety and distress intersect with the autistic experience (e.g. meltdowns, sensory overload, etc), and potentially support autistic clients with exploring those intersections and with emotion regulation.

4. Working Together

Counselling training rarely includes working with neurodivergent individuals, and the specific needs and challenges they may bring. Many respondents mentioned the value of flexibility in their counsellors, especially in adapting their counselling approaches, the practicalities of the space, and even in ways of thinking. This section will explore some of the adaptations and approaches that our respondents felt worked well, as well as ways in which clients and counsellors could collaborate well to arrive at approaches that are better suited for the client.

Some respondents wanted there to be a more obvious structure to therapy sessions, and found just sitting down and being expected to speak quite difficult.

“Sitting there in complete silence to try to encourage (pressure) me to talk - I need more structure than that and wanted them to ask questions”

To help with talking and structure, some respondents talked about the value for them of writing down bullet points ahead of time for what they wanted to say in the sessions. Several also talked about taking notes in the session so that they could remember what was talked about.

“If you think it’s going to be hard to talk in a session, or in an introductory meeting to see if a particular counsellor is right for you, then it can be really helpful to have things written down that you want to bring up. There can be a lot to absorb in counselling, and a lot of strong emotions, and sometimes it can help to make notes during a session, or afterwards. I’ve got a lot out of doing this, and it’s also helped me to use what I learned in counselling in the long term.”

I found it helpful to write down a bullet-point summary of the problem to refer to in the initial session/registration, and to take notes if I think of something I should raise with them [the counsellor]

I take a note-pad, and explain that I’ll write down questions or points for clarification, to avoid either blurting, or not-listening-because-I-was-holding-a-thought.”

Paperwork and homework used as part of the counselling process was mentioned as being a struggle for several respondents, though others also found practical homework tasks useful. This seems to both be down to individual preferences and circumstances, and also the rationale for the task, and the degree of anxiety it might elicit. Form filling and restrictive or ambiguous questionnaires can be particularly anxiety-provoking for some autistic clients, but tasks that are practical and more client-led can also be helpful. Some also found the recommendation of relevant reading materials helpful.

“And we dropped the “how do you feel today” questionnaire because I found it difficult and not helpful”

“found it particularly helpful that the counsellor recommended some additional reading, including Neurotribes by Silberman and Aspergirls by Simone”

“I also struggled with some of the administration around the counselling - deadlines for providing filled questionnaires, confirming attendance at appointments [...]”

Respondents were also more specific about the nature of written information given by the counsellor that was helpful or unhelpful. For instance, being provided a summary of what was talked about in the session was welcomed by one respondent, while others talked about the importance of having clear

instructions for agreed on 'homework' or other tasks. In contrast, too much information, or ambiguous or unclear information was described as being quite difficult for our respondents.

"[I had a problem with] Homework exercises that I did not have exec function to complete (which they stopped)"

"I also appreciated being given clear "homework" instructions and next steps to take."

"[I would have liked if the counsellor would have] provided me with a summary of what was said each session and how it fitted into the big picture of what we are discussing."

The duration of sessions was also discussed. A couple of respondents found that a full hour was too much. For one client having therapy via Skype, they were able to negotiate shorter, more frequent, sessions.

"We run most sessions over Skype. - We bank the time if I run out of energy. So if I only manage 15 minutes of a 1 hour session we can reschedule the other 45 minutes."

However, a number of respondents also expressed a desire for longer sessions, more sessions (or both). The need for more processing time to think about questions or process and recognise emotions that come up were often given as reasons for this, as well as the time needed to build trust and understanding.

"Possibly have 90 minute long sessions. I need 5-10 minutes at the start to warm up and get used to speaking and being with someone alone in a room."

"people with autism may need longer to open up, begin to engage , process, trust - this means that the number of therapy sessions needs to be flexible and preferably open ended as pressure of time and autism don't mix very well."

Some respondents highlighted that counsellors didn't understand that by ending the session with something emotional, the client wasn't in a good place to leave. The importance of having some 'buffer' time to recover from the (emotional) intensity, task switching, or cognitive load of the counselling session was suggested: this might include some time towards the end of the session where the discussion could become less intense, as well as ensuring some time and a space after counselling to 'recover'.

"It [counselling] can be overwhelming, so make sure you have some "buffer" time around it to recover"

In terms of approaches, some respondents talked positively about counsellors who encouraged or allowed the client to express themselves in other ways, such as through art, play or music.

"Art was also helpful for giving me an alternate way to express myself when I'm going mute from stress."

"[...] the only positive experiences i had was with art therapy, where i did not have to use words to express myself and the therapist did not assume she knew what i meant"

"Generally, I have benefitted from those that involved more than just talking (like play or art) or where I could talk figuratively or through a puppet. Purely cognitive counselling has not helped me at all,

because I'm intelligent enough to figure things out intellectually by myself, but it doesn't touch my emotions. "

Respondents by and large tended not to expect or require their counsellors to be 'autism experts', but they did need them to be willing to adapt to the needs of autistic clients, which does point to the need for more autism understanding within the counselling profession. This is explored further in section 5, 'How much do you know about autism?'.

Along with some autism knowledge, the ability of counsellors to adapt and be flexible with autistic clients hinges on there being a healthy degree of collaboration and co-creation in the counselling relationship. A number of respondents emphasised the importance of a collaborative relationship, which can range from information sharing (and an openness to that on the part of the counsellor), to trying out approaches and problem solving, and discussing what the client finds helpful and not so helpful, adapting the counsellor's approach in line with this.

"[What was helpful was a] willingness to adapt and discuss why we were doing what we were doing "

This collaboration also can also include discussing the goals and expectations of counselling, in arriving at what the client wants to address. For instance, some respondents would have liked their counsellor to specifically address and normalise their experiences within the context of broader autistic experiences, while others found that counsellors did not validate their experiences in relation to autism, or were reluctant to explore its implications.

"he's [the counsellor] never said "Oh that's difficult for many autistic people" or anything, which would sometimes be a bit more validating because now we're working on me as an individual but it would be nice to recognise more that I'm an individual within a group"

"I felt like she then identified everything I did as being an autistic trait, which in a lot of cases was true but didn't really help anything"

"It would have been helpful if she had acknowledged my feelings and suggestions, and maybe looked further into what being autistic means."

Some of the most useful experiences our respondents reported of counselling related to this theme of validation relating to their struggles with being autistic in a non-autistic world (some never having experienced that before). In contrast, some of the worst experiences, including those that put respondents off seeking further counselling, related to their autism-related struggles being dismissed or reinterpreted. For more on this, see the last section in relation to autistic identity.

"The therapists I saw usually treated this as though it were unfounded anxiety or low self-esteem, encouraged me to believe that I was great and not to worry, and disbelieved that I could have any actual difficulties interacting with other people."

"I also didn't feel like she took my experiences seriously, as she constantly dismissed them by saying it couldn't be that bad/severe, or that maybe I just needed to change my attitude."

There is a theme of autistic clients needing their counsellors to start with some basic reference points with regards to neurodiversity, gender, and LGBT+ issues in order to reach a more positive, productive and collaborative therapeutic alliance. For instance, autistic women have long been overlooked for diagnosis, and autistic people are also far more likely to be gender non-conforming, non-binary or trans than non-autistic people (Warrier et al 2020).

A lot of this relates to a need for counsellors to resist or challenge their own and society's ideas around normalisation and typicality. Some respondents reported counsellors trying to make them more 'normal', focusing on their 'atypical' behaviours, which was seen as very unhelpful and often upsetting.

"My experience with talk therapy from age 17 to 20 was traumatic. The therapist seemed very kind at first, but was constantly gaslighting me, invalidating my feelings, pressuring me to talk when I didn't want to, and forcing her idea of "normal" on me."

"I'm also trans, specifically nonbinary, and there are almost no therapists out there who are fluent in gender diversity and having therapists constantly misgender me is really draining."

"With previous therapists they have tried to change me, pushing me towards behaving and fitting in."

"Prior ones [counsellors] have had absurd hang ups on making me look "less autistic" but little/no attention paid to actually helping me function better."

One theme that many respondents brought up that is particularly pertinent to collaboration and co-creation in the counselling relationship is the ability of clients to self-advocate, and how they might be supported in or prevented from doing that. On a basic level, this is related to the client feeling able to say what accommodations they need, and feeling safe that their needs will be taken seriously, which is touched on in sections 1 and 2: the client and counsellor establishing a rapport and shared expectations around communication, what is possible in counselling, and what counselling is for, and exploring what physical accommodations might be helpful. There is also a sense, however, that these early steps can be an effective way both for the client to build confidence in self advocacy and how negotiation and collaboration could go in this new relationship, but also figure out if this counsellor might be right for them:

"Check how much they [the counsellor] know about autism. Check you can stim in sessions. Maybe give them a list of your sensitivities in advance and point them at some background reading that resonates with you if you know of any"

And on the counsellor's part, an awareness that the client might be struggling with feeling safe enough to ask questions or make requests:

"A lot of my autistic clients [say], "is it okay to ask for this?" And something I hear a lot of people say [is], "well, it's always okay to ask for things right?" And well, no, actually, it's not, right? It might damage the relationship, it might cost social capital, it might, you know - how do I know if there's nothing wrong with it? How do I know if there's something wrong with me even wanting something?"
(counsellor interview)

A lot of the themes around working together relate to the building of the counselling relationship, in a way that empowers the autistic client to advocate for themselves, and feel in a position to take the lead, while the counsellor is flexible, open, willing to find creative solutions, and potentially understands enough about some of the context around autism and related themes to be a ready and able collaborator.

5. How much do you know about autism?

In common with the findings of the AMASE access to mental health report (Hallett, S. & Crompton, C.J., 2018), many respondents to this survey were unhappy about their counsellor's knowledge of autism, including the misconceptions some had. This was a particular issue relating to those who claimed some specialist knowledge or experience of autism. Notably, those who'd worked with autistic children, or who had young autistic family members, seemed to be particularly commented on by our respondents as having a poor understanding of their experiences, or unhelpful expectations or approaches.

"didn't know anything about autism, but he thought he did because he spent a semester helping to diagnose preschoolers. He said that there was no way I was autistic because I was in grad school, married, and had empathy,"

"My counselor knew very little. She dismissed any suggestions of mine that I might be on the spectrum because 'I made eye contact with her on several occasions'."

In contrast, while respondents did generally hope for more autism knowledge amongst counsellors, several were pleased that despite their counsellor's initial lack of autism knowledge, their openness and willingness to learn made their experience as clients positive and productive.

"she [the counsellor] educated herself [on autism] before the next session surprisingly well and was very open to how I expressed my feelings and experiences."

"At first there were a lot of sessions of just her [the counsellor] learning about autism and trans issues, from me and from her own research [...] in hindsight I think it was actually a really good way to start building that early therapeutic relationship and for her to get to know me"

"Neither of my counsellors knew much about autism at all - and to be fair, they both admitted as such. This also meant that neither of them had any big misconceptions, so that's something! I was worried about having my autistic traits challenged and dismissed, but for the most part they took what I said at face value and believed me, which is so important. "

Counsellors interviewed talked about the importance that knowledge is held lightly, but also that some knowledge and understanding of autism is nonetheless important. In particular, helping them consider things they might not otherwise have thought of, or being more deeply aware of any potential preconceptions or assumptions.

"one of the things that I was really struck by when [I was involved in autism training] was some stuff that just really hadn't occurred to me" (counsellor interview)

"it's helpful having this kind of sort of sketch of information about what it might be like working with an autistic client, but it's quite helpful for me as well to kind of hold that somewhat lightly." (counsellor interview)

"coming from a neurotypical perspective, I really am aware that there is this potential gap between me and someone with autism. And I think that's really important for me to be aware of that gap and that I might just not get it sometimes" (counsellor interview)

These points highlight an interesting trend in our responses, in which the most negative and some of the more positive experiences often seemed to involve practitioners who claimed some specialism or knowledge of autism, while none or little knowledge of autism largely sat in between, trending towards

positive depending on the counsellor's openness and flexibility. This is in line with how much poor quality or outdated information around autism is still regularly in circulation. It suggests that while many of our respondents would have liked their counsellors to have known more about autism, those with counsellors with outdated, overly rigid, or misguided autism knowledge, or experience based largely on autistic children, tend to have far more negative experiences than those with counsellors with no knowledge at all, but an open willingness to learn.

"She claimed autism was her specialty, but she was steeped in the pathology paradigm. She tried to stop me from stimming or having interests she deemed childish. And she called autism a disease."

"The first counselor who was awful actually specialized in autism. She had a lot of preconceived notions of what it meant to be autistic and they weren't flexible to including an adult female with high intelligence."

"I have, so far only met one counsellor that has any formal understanding about Autism and honestly this was from an outdated and often judgemental stance of severe disability."

Respondents talked about often needing to educate their counsellors on autism, as well as on gender and other related topics. While some saw this as helpful in building the relationship, creating a sense of collaboration and connection, or giving them a stronger sense of confidence and trust, others questioned the responsibility that this put on them, and along with it a sense of frustration, especially when the counsellor claimed to have expertise or knowledge, but had unhelpful misconceptions. There was also the issue of the time it took up, especially factoring in cost and/or limited number of sessions available. Some respondents were also very new to their autism diagnosis, or for other reasons struggled to explain things about autism that they felt their counsellor should already know and even could help them understand.

"In the counselling they [the counsellor] knew roughly about [autism] and had practiced basic ways of helping (like sitting sideways so no eye contact), but still needed a lot of 'background' from me which ate into my limited session time - though they got better as they went on"

"...I didn't want to continue paying a substantial hourly fee solely for the chance to educate someone about autism; I needed her to be my therapist."

"They [the counsellor] should be working to understand you. You have to be willing to share what you can, but it's not your job to teach your therapist about autism. And if you don't have to, just don't."

"I primarily need help with anxiety and depression, but it gets really frustrating to then have to explain how autism works or give a Gender 101 talk before we can get to my actual problems."

A number of respondents highlighted the value of identifying aspects of their experience that are specifically about being autistic (i.e. basic differences in their neurology) from aspects that are more to do with things like anxiety, and therefore could be changed. For example, several respondents talked appreciatively about spending some time in the early sessions exploring how being autistic impacted them, what sensory challenges they had, how their communication was affected and so on – all in order to understand where some of their issues came from and how best to work with them.

"Yes, the counsellor is a specialist autism counsellor which has made all the difference. I have had lots of counselling and talk therapy over the years prior to my diagnosis and none of it has really helped because we weren't looking at my difficulties through the right lens."

In the early sessions we spent a lot of time discussing how my autism affected me, what sensory issues I have, how my communication is affected etc so we can understand where my difficulties come from and how best to work on them.”

In terms of potential sources of autism information, several respondents expressed concern about the ways autistic people are described in journals, by charities and in information issued by health authorities, which could be pathologising or misleading, including presenting autistic folk as emotionless and poor at communicating and empathising.

“There is a growing concern for me how the information studies in the academic world filter down into the practice of therapy...”

“They [the counsellor] did in some cases offer some insight into my condition early on but mostly forced me to realise i had to educate myself on autism and not trust the therapists i was seeing, even when good counsellors, since education and understanding about autism was often couched in misogyny and frankly incorrect "hot takes" of autism they had heard about on a three day course”

Respondents overwhelmingly wanted their counsellors to know about: issues around gender and autism, autistic women, masking, the need for accommodations, heterogeneity of the autistic population, unhelpful stereotypes, challenges around social ‘rules’ and expectations, sensory issues, the social model of disability, autistic identity, stimming, alexithymia, processing time, autistic forms of distress (different presentation, as well as meltdowns, shutdowns and burnout), and executive functioning. Some respondents suggested it may be valuable for there to be counselling services aimed specifically at autistic clients, or access to counsellors who are autistic themselves, to account for the need for this specific knowledge.

Counsellors interviewed also talked about wanting to understand more about the intersection of autism and gender.

“I was seeing a lot more stuff mostly about [autistic] women and girls and a little teeny bit about women, girls and other gender minorities. And I was like, Oh, this is an underserved population. I want to pay more attention to this, both because I want to be a better friend and a better ally, but also because then I want to be a better counsellor” (counsellor interview)

A lot of respondents also wanted counsellors to know about cPTSD / PTSD / trauma which may be especially prevalent in the autistic community.

“all autistic people have interpersonal trauma issues”

“it's unfortunate that more counsellors have no experience of autism, especially women's experiences and symptoms, which aren't of course always the same as male autism.”

“There needs to be more autism specific psychological therapy available through the NHS. And more understanding of autism generally, because things end up getting to crisis point before anyone in the NHS even starts to think about finding appropriate help (and there still isn't any).”

While more autism knowledge in their counsellors was desired by many respondents, some expressed wariness around telling mental health professionals that they are autistic because they are worried about the (incorrect / unhelpful) assumptions that might be made about them as a result.

“I didn't tell them [the counsellor] I was autistic as I was afraid they would treat me badly.”

“I am going to talk to a clinical psychologist this month to talk about a mental health issue. I haven't decided whether I will tell her that I am autistic. The reason is that I am worried that she will make all sorts of assumptions about me that might make it harder for me to get help with the problem that I am having”

Alongside counsellor knowledge of autism, respondents also talked about the importance for them of exploring their own learning about autism, and broader self understanding and acceptance that came about. There were a lot of comments on the value of realising a sense of autistic identity.

“You are not broken, you do not need to be cured of [being neurodivergent]. You need support, validation, good coping skills. You need and deserve acceptance”.

“Therapy gave me the confidence to start making connections outside of session and ultimately allowed me to find my tribe. I firmly believe I would not be here today had I not connected with a therapist. I had virtually lost hope. Talking gave me hope, and for that I am immensely grateful.”

Along with the points mentioned above, respondents talked about wanting counsellors who also understood the intersections between autism and other co-occurring conditions. Respondents had sought counselling for a number of different issues, including anxiety, depression, PTSD, low self-esteem, eating issues, etc. However, several respondents had had experiences of being told that they could not have PTSD, or that their anxiety and depression were just a part of their autism, so nothing could be done about it. Several respondents also had experiences of being repeatedly misdiagnosed.

“I was mistakenly diagnosed with severe ME, which I now recognise to have been a textbook - albeit very extreme - presentation of autistic burnout. I did not feel helped or understood.”

“There were multiple telephone assessments, this is an issue as I'm quite 'flat' and to-the-point, without NVCs [non-verbal communications], that 'dullness' is usually taken to be depression, it's not, that's my normal”

Many respondents felt a need to understand and accept themselves more, and wanted help with that process, along with a hope of finding one's 'tribe' or community. This, along with what they want counsellors to understand better, and the challenges many have already encountered with health professionals, points to a need for counsellors working with autistic clients to start with some basic reference points and points of understanding, along with an openness and willingness to explore with the client.

Discussion & Recommendations

Our survey has highlighted a number of issues relating to autistic access to, and participation in, talk therapies. These include **barriers to access**, such as sensory challenges, requiring phone communication, and lack of clear information and guidance; **communication barriers**, such as practitioners misunderstanding or not believing autistic people, or autistic clients struggling to get appropriate support in getting their needs across; and **barriers related to autism awareness and understanding** amongst practitioners, including lack of knowledge amongst counsellors, outdated or inaccurate knowledge, including amongst those described as autism specialists, and **lack of broader knowledge in areas related to autism**, such as gender, co-occurring conditions, etc. These themes are also consistent with previous research into autistic barriers to healthcare more generally (Doherty et al, 2019).

This report also covers some newer ground in delving deeper into the specific impacts of these barriers on the client in a counselling context, as well as exploring ways in which talk therapies can be adapted to better suit autistic clients. It is clear that there are areas of excellent practice happening that are going under-recognised, and changing lives, as well as far too much troublingly poor practice that is at best turning individuals off further talk therapy, and at worse, further traumatising autistic people. Autistic people are a vulnerable population when it comes to mental health difficulties and outcomes, and also disproportionately impacted by barriers to appropriate social and mental health support, so this is a particularly important area for practitioners and health care providers to understand better.

From the findings of this report, the examples of good practice and negative experiences, as well as other input from our respondents, we propose the following recommendations:

ACCESS

- There needs to be better provision of clear information, and better education, on what counselling is, what it's for, and what to expect for autistic people. There could also be better support for autistic clients in how to get the most out of counselling, and how to self-advocate in counselling situations.
- Counselling services need to be more accessible for autistic clients, which can mean that communication methods need to be flexible, and there is more support around the practical aspects of accessing a service.
- Counselling spaces need to be adaptable for the sensory needs of autistic clients, and counsellors should be mindful of these needs when working with autistic clients, and proactive in finding solutions to accessibility issues.
- Homework and paperwork (forms) provided in sessions should have a sound rationale for the client, and need to be clear and accessible. Alternative approaches should be explored when necessary.

PRACTICE

- Practitioners working with autistic clients need to be mindful of differences in communication and emotional cues. Counsellors should be proactive in checking in, and autistic clients need to be believed when they say they are in distress.
- Counsellors working with autistic clients should be flexible and open in their approaches, and able to adapt their practice to the client, including with communication styles, session structure, overall approach, etc.

- Collaborative approaches that encourage self-advocacy, self-acceptance and self-understanding may be particularly helpful for many autistic clients. This often needs to start with clarity, reassurance, and a sense of safety from the therapist.
- Practical solutions and understanding, especially around interpersonal issues, sensory and emotional regulation, and executive functioning, may be really valuable for some autistic clients, but caution must be taken that the therapist is not attempting to (purposefully or inadvertently) 'make the client more neurotypical', or impose their own normative values or assumptions.

UNDERSTANDING

- Counsellors should have some understanding of the life-context of what being autistic might mean for a person, including a grounding in what is/isn't accurate about autism (particularly common misconceptions), and what common challenges autistic people might experience, both socially and more personally.
- Practitioners should be aware of issues around expressing and identifying emotions (including shutdowns, meltdowns and burnout) and not apply neurotypical standards to reading or assessing autistic emotions.
- Counsellors should be aware of the Double Empathy Problem (Milton, 2018) when working with autistic clients.
- Counsellors should be aware of gender and LGBT+ issues, particularly women and gender minorities, and how those issues relate to the autistic population.
- It would be helpful for counsellors to have some understanding of the ways in which autism can intersect with commonly co-occurring conditions and issues, particularly trauma, anxiety, and physical health issues.
- It would be helpful for practitioners to understand something of the broader context around autistic community, neurodiversity, social model of disability, and the value for some of forming an autistic identity and/or 'finding their tribe'.
- Counsellors should be more educated on autism through first-person accounts of autistic experience, and writing, training and research led by autistic people. They should also 'hold this knowledge lightly', acknowledging the heterogeneous nature of the autistic population, and be open to new information and ideas.

Additionally, we hope that this will encourage autism-, and more broadly neurodiversity-related training, led by autistic people, to be a part of counselling training curricula, and that there might be more support for greater autistic and otherwise neurodivergent representation at all levels of counselling and broader mental health care - as practitioners, trainers, supervisors and policymakers. In particular, recognising the importance of training led by autistic counsellors.

Autistic people may be a neurological minority, but they are a significantly under-served one. We also believe that some of the recommendations and findings in this report can be helpful more generally in encouraging greater accessibility, flexibility, and understanding by therapists and therapeutic services, in better-serving a far broader range of marginalised communities. The diversity of the autistic population, and the challenges to talk therapy approaches and practitioners that it brings, have lessons to teach counsellors working with anyone.

We hope that the findings and recommendations from this report will help to encourage practitioners to seek more information on autism, the autistic community, and ways to make their practice more accessible for autistic clients. If there's one thing the respondents' generous contributions have put across, it's that autistic people have a wealth of knowledge about what we need and how we'd like to be supported, but suffer too often from not being listened to, believed, or understood - we hope that

this will also make clear the need for practitioners seeking further information and resources to prioritise seeking out writing, research and training by autistic writers, practitioners and trainers.

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Appendix

Survey questions and preamble

The questions are fairly open because we want to hear your stories and experiences. You do not have to answer all of the questions. Say as much or as little as you want, and only what you are comfortable with telling us. There are no right or wrong ways of answering these questions.

Tell us about one or more of your counselling experiences

You could talk about whether it was positive or negative overall. About communication, whether you felt understood, whether it helped you, etc.

How much did your counsellor know about autism?

Did you feel that your counsellor had a good understanding of autistic differences, challenges and needs? Did they have any misconceptions or misunderstandings?

Tell us about things your counsellor did that were particularly helpful, and why

This could include anything from how the sessions and room was set up, to how you felt with them and communicated with them. If you can give specific examples, that would be helpful.

Tell us about things your counsellor did that were particularly unhelpful, and why

Is there anything you'd have liked your counsellor to have done differently?

What would you like counsellors to know about autism?

What advice would you give other autistic people who are considering counselling?

What would you like them to know? Is there anything you did, asked for, or told your counsellor that helped?

Would you like to tell us anything else relating to counselling for autistic people?

This could be something about your experiences or about yourself that the other questions don't cover, or any other thoughts.

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