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EXPERIENCES OF SOCIAL ANXIETY AMONG AUTISTIC AND NON-AUTISTIC PEOPLE

A REPORT FOR PARTICIPANTS

Thank you for taking part in our recent study about social anxiety in autistic adults. We have now collated results from the survey and wanted to let you know what we found. We hope the summary on these pages is meaningful to you and does justice to your experiences.

We invite you to get in touch to let us know what you think about this summary. It is important that the results seem representative to you, and we would appreciate any comments and reflections from you.

We provide this report in two parts. In the first part, we describe what you told us about social anxiety. In the second part, we summarise what you said about therapy for social anxiety.

We have also completed some interviews with participants about social anxiety – these relate to a different study and we will report on those at a later date.

PART ONE: SOCIAL ANXIETY EXPERIENCES

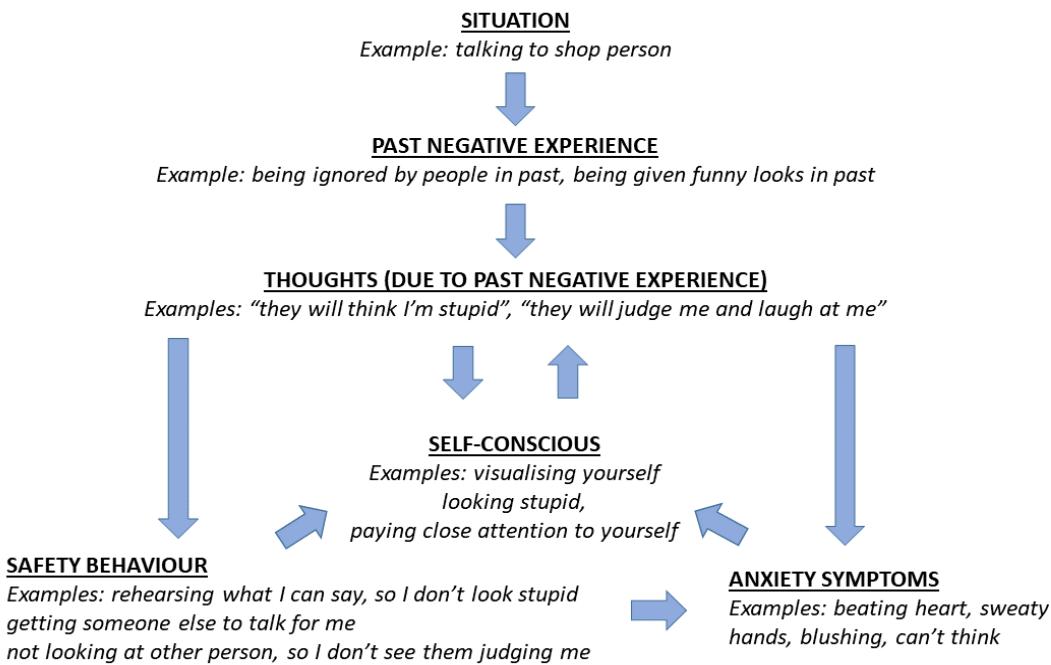
Background

For our study, we wanted to understand more about social anxiety in autistic adults. Social anxiety is typically described as fears we may have about being seen negatively by other people. However, in our study, we defined social anxiety a bit more broadly to encompass any fears we may have about social situations. We know that many autistic adults have anxiety about social situations – this may be about half of autistic adults, so this is a significant cause of distress and difficulty for autistic people. Neurotypical people also experience social anxiety, and there is a lot of research that has helped therapists understand the processes of social anxiety in neurotypical people. These processes are described in the Clark and Wells model (which we outline below). Therapists have created a therapy based on the Clark and Wells model, which is very effective for neurotypical people.

Please see a diagram and description of the Clark and Wells model below.

In the Clark and Wells model shown below, we can see that people have certain social situations that are harder for them – trigger situations. There might be negative past experiences that make those situations harder for them. Based on those negative experiences, the person might have

developed difficult beliefs, e.g., that people don't like them or will judge them. Therefore, when they are in social situations, the person might experience negative thoughts popping into their head.



When these thoughts happen, this tends to lead to three things. Firstly, a person tends to become self-conscious and focus on themselves. They might get a negative picture in their head of themselves in that situation or they might become very aware of how they feel or how they are coming across in the situation. In addition, they might use what we call "safety behaviours". These are things we do in social situations to feel safe and combat our fears. However, these behaviours can end up being unhelpful and can confirm our anxieties. The third bit at the bottom refers to symptoms of anxiety in the body like a beating heart, feeling tense and sweaty. As you can see, the different elements are interconnected and feed into each other.

However, we don't know whether this process applies in the same way to autistic people as neurotypical people. We also don't know whether therapy based on the model is likely to help autistic people. In our study, we hoped to fill in some gaps about these things. This will help us advise therapists, and over time we might be able to develop better therapies.

What We Did

We invited autistic and non-autistic people to complete a survey. Approximately 250 autistic adults took part in the study, alongside 100 non-autistic adults. In the survey, there were several questionnaires about your thoughts, feelings and behaviours and how these relate to social anxiety. Our questionnaires focused on aspects of social anxiety that have been recognised as important in neurotypical people in the Clark and Wells model shown above. This allowed us to establish whether these factors are the same in autistic people, or whether there are differences. We also asked you some open questions about social anxiety and any experiences of therapy you might have had. In our open questions, we hoped to get more specific information from you about ways in which social anxiety might be different in autistic people.

Results

Key Points

Overall, there were similarities and differences between autistic and non-autistic people in terms of social anxiety.

Some factors were common to both autistic and neurotypical people. These included all the aspects of the Clark and Wells model shown above. All these aspects seemed relevant to autistic people, but these factors did NOT tell the whole story about social anxiety in autistic people.

Other triggers for social anxiety were much more specific to autistic people. Autism-specific triggers included person-related factors (such as processing information differently, having sensory differences, etc.) as well as environment-related factors (such as encountering discrimination and stigma relating to one's social differences).

All these findings are explained in detail below.

Analysing the Clark and Wells Model

We used statistical methods to analyse the Clark and Wells model in autistic people. This analysis showed that autistic people tended to experience higher levels of each element of the model. This included: more negative social experiences, more negative thoughts in social situations, higher use of safety behaviours, and more self-focused attention. All these factors were closely related to a person's level of social anxiety.

Our analysis also showed that autistic people have more social fears than expected by the different factors of the Clark and Wells model. This suggests that other factors are also important, specifically for autistic people.

It was a very similar message when we looked at the link between traits (rather than a diagnosis) of autism and social fears. The Clark and Wells model only partly explained the link. Again, other factors not included in the model are important, specifically for autistic people.

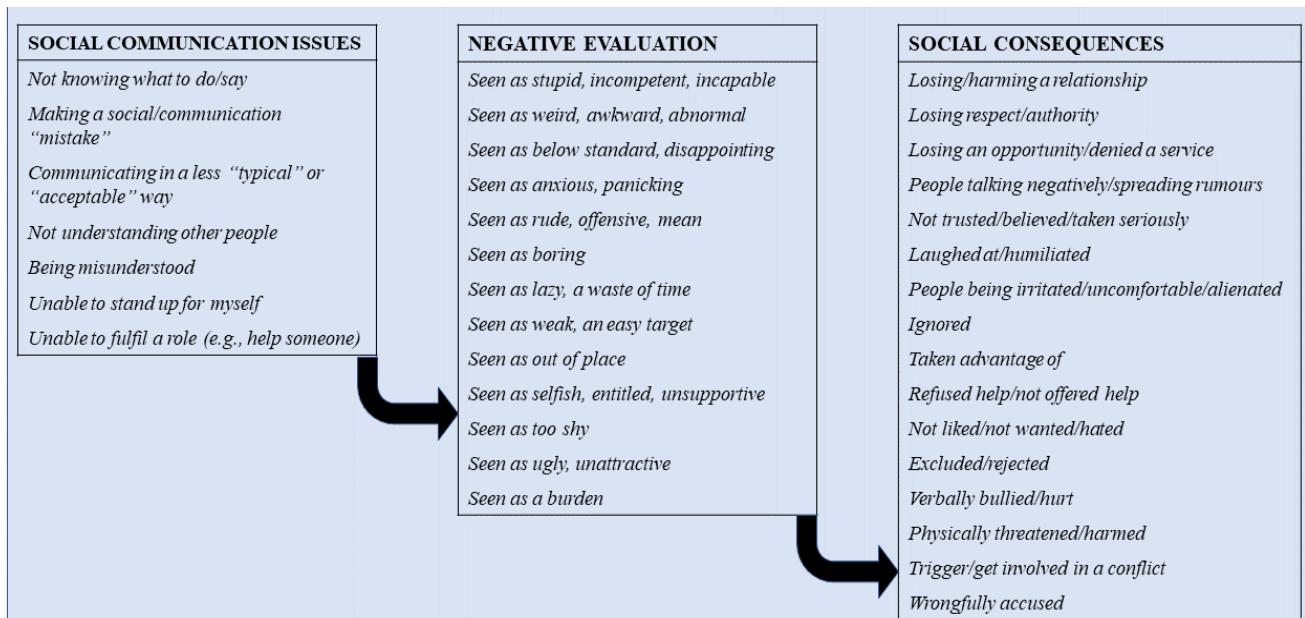
Qualitative Results: Experiences of Social Anxiety

We carried out detailed analysis of the comments you made in the survey. A key aim was to work out what additional factors might be important for autistic people. We set out these results in three parts below, with each subheading highlighted in blue.

1. Possible Similarities between Autistic and Non-autistic People

Participants explained that sometimes their anxieties about social situations related to making mistakes and being judged by others. This involved a fear about not performing well in a social situation, (2) then being seen negatively by others, before (3) suffering negative social consequences of this. Different participants expressed this process in different ways, and some

participants highlighted that it was only some parts (rather than all three parts) that bothered them. See the diagram below for this process that participants told us about. We have kept to participants' words as much as possible here.



It is important to bear in mind that the process shown above is similar to social anxiety in neurotypical people. However, the assumption in mainstream approaches to social anxiety is that these anxieties are disproportionate. By contrast, many autistic participants in our study argued that this process reflects their day-to-day social reality rather than being a fear ungrounded in reality. As one participant stated, "after fifty years of bullying and exclusion, I know that this fear is not irrational or unfounded." This is a really important point, as therapy for social anxiety generally works on the assumption that the fear is disproportionate or "irrational". This suggests that a different approach to therapy is needed.

2. Differences between Autistic and Non-autistic People

Autistic people also told us that other factors caused distress for them about social situations. These factors seemed different to the fears of being seen negatively by others (which are seen as key to social anxiety in mainstream approaches). Some of these factors were "individual factors" (i.e. the things we bring to a situation) and others were "environmental factors" (the difficult, inaccessible, inhospitable nature of social environments). These factors were more specific to autistic people, and much less reported by neurotypical people with social anxiety. We give full details about these autism-specific factors that can trigger social anxiety in the table below. On the left side is the label we have given to a particular factor; on the right is a quotation from a participant as an example of that factor.

INDIVIDUAL FACTORS TRIGGERING SOCIAL ANXIETY

<i>Sensory differences</i>	I can't filter out traffic, background chatter, bright lights, the buzz of electricity, so I struggle to focus on conversation and interaction anywhere that isn't quiet.
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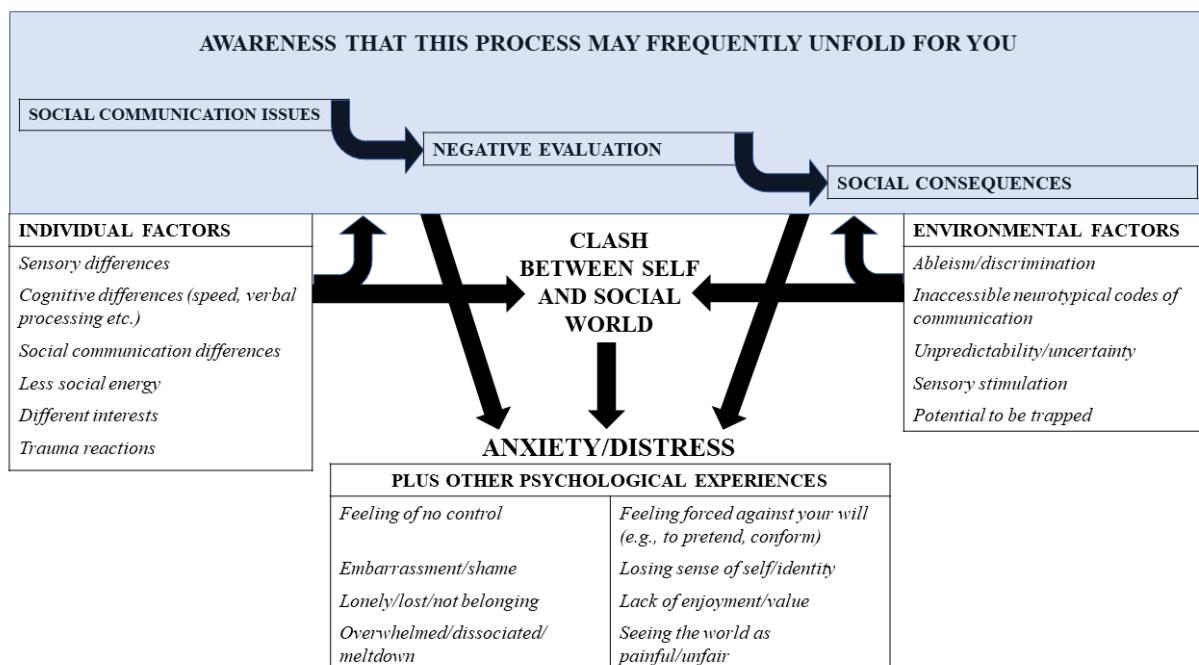
<i>Cognitive differences (speed, verbal processing, etc.)</i>	I have trouble when talking to professionals, e.g. doctors, because I find it difficult to think at the same time as speaking and listening and keeping track of what I need to say or ask. And then I end up leaving without asking the question I need to.
<i>Social communication differences</i>	I live in a parallel universe that is joined imperfectly with the other - so I feel as though I'm communicating across some kind of cosmic glitch.
<i>Less social energy</i>	I find it very difficult to manage situations where a lot of social interaction is taking place. I become exhausted very quickly and need to have time alone to reboot.
<i>Different interests</i>	I'm often very aware of my own boredom and disinterest in what's going on. It is not often that my taste in media, hobbies, etc. intersect with the people around me, and I have learned the hard way that people won't tolerate me expressing my thoughts about those things for very long and doing so can lead to situations (especially confrontational ones) which are far harder to handle.
<i>Trauma reactions</i>	I usually feel like I dissociate from social situations. It's like I have a well-trained social brain that handles the situation and acts nice to people, but that is not actually the real me. I think it is the trauma from being rejected and bullied so much when I was younger.

ENVIRONMENTAL FACTORS TRIGGERING SOCIAL ANXIETY

<i>Ableism/discrimination</i>	The worst situations are where I have to face someone who works in government or some other institution that has some influence and control or "authority" over me and may impact my existence negatively when they don't understand the way I communicate or behave.
<i>Inaccessible neurotypical codes of communication</i>	It's the unreasonable rules of the neurotypical majority. Doesn't help when other people say "what rules?" as though there aren't any.
<i>Unpredictability/uncertainty</i>	The unpredictability of people, their behaviour, their movements. There are too many variables to predict. I'm concerned because it could take me out of routine.
<i>Sensory stimulation</i>	The immediate environment, is it too light? too loud, smells bad? Overwhelming sensory issues can wipe out what could have been a pleasant interaction.

<i>Potential to be trapped</i>	I need an escape route. Formal situations are the worst because I can't get away, I don't have control. That's when I might have a meltdown.
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The factors in this table combined to make social situations distressing for autistic people. In addition to anxiety, participants felt there were other psychological experiences resulting from the incompatibility between themselves and the social world, including loneliness, meltdown, a lack of enjoyment and feeling forced against your will. We have arranged all the factors already described into a diagram below.



Our analysis indicated this was a “distinct” form of social anxiety, specific to autistic people. this differs to mainstream approaches to social anxiety which purely focus on fears of being seen negatively by others. If people want support with experiences shown in the diagram, therapists may need to adapt their typical approach, as the nature of the anxiety is different. We give more suggestions about therapy below.

3. Autism-Specific Social Anxiety: Examples

To illustrate the “distinct” form of social anxiety shown in the diagram above, we provide some quotations from autistic people about what makes them feel anxious:

“Human beings and human sounds. When you're forced to interact with someone you can't hide behind your headphones, you actually have to listen to them. This means every other sound in the vicinity is coming at you and triggering you. Children are the worst - repetitive and sudden movements, lack of spatial awareness, screeching and yelling, stomping, drumming sounds, etc. My toleration levels are so very low now that I'm terrified of having a complete meltdown in public.”

“I find it hard making predictions about people. It's difficult gauging motivation so preparing for my turn in the conversation is exhausting. The worst thing is knowing I haven't sufficiently

communicated that time, meaning I'm going to have to do it again soon. This happens all the time. My concerns often come true and it generally means I can't access the same things others do because of my social functioning.”

“I don't really know what exactly makes me anxious; I have felt at times that the more people there are, the more social input there is and the more interactions I have to manage/script? I also felt that my sometimes painfully high empathy plays a role; mainly as a kid I interpreted my anxiety around groups as me being able to 'feel all the kids inner worlds' which was just really intense. I also feel like I have complex PTSD from being bullied so much and in general having bad social interactions my whole life (at that time they seemed out of the blue to me, as I always try to be nice to people and help them which is so confusing). And I don't like people looking at me, especially multiple people. I think this might be because it messes up my mask which is a little different for everyone.”

“Socialising is not something that I have ever experienced any benefits from. Though other people insist that it makes them feel good, I don't experience any benefits. Socialising is not accessible for me. I have auditory processing disorder, so I cannot understand what people are saying. If they are talking on the phone or are wearing a mask, or any other way that I can't see their mouth moving, then I cannot understand anything. If I can see their mouth moving, I can guess a few of the words and guess the rest from context (I am often wrong). This requires a lot of focus and mental effort. Then there are the hints, facial expressions, body language etc. All of which I cannot interpret no matter how much I study. I also cannot effectively communicate via speech. If I am expected to speak, in order to be able to say anything I either have to have a social script extensively prepared and practiced, or I have to try to repeat words they said to answer questions. I cannot use speech to actually communicate what I want to say, I just end up saying words that have little meaning. This is incredibly stressful, as people expect me to be able to speak and I cannot. There are always consequences if I cannot perform socialising how other people expect and want. People think I am being rude if they inaccurately assign meaning to the sound of my voice or my face or body positions. They misinterpret what I am trying to say. People get angry very easily. People don't check if they are correct before they accept their assumptions as fact and act on them. I am constantly forced to defend myself in social interactions, as people become aggressors very easily. The more anxious I get, the more dangerous it becomes. I lose the ability to speak at all, I lose the ability to process what people are saying, I lose the ability to think. I get physically ill and this lasts for hours or days.”

PART TWO: THERAPY FOR SOCIAL ANXIETY

Approximately 40% of autistic participants completing our survey said they had accessed therapy specifically for social anxiety. Often this was CBT, which is the most commonly available and most researched therapy.

Strikingly, only 10% of autistic adults found CBT helpful, whereas 65% found it unhelpful. Indeed, some autistic people said that CBT was harmful; as one person said, “CBT was extremely damaging and made me feel even worse after each session”. There was limited evidence about other therapies.

Autistic participants identified many reasons that made therapy less effective for them, which can be seen below. We have arranged different reasons into broader themes, and given examples from participants on each occasion.

THEME 1. ANXIETY IS BASED ON EVIDENCE.

They tried to tell me that my anxieties are irrational, but they are all evidence and experience based.

Real differences in my social skills cause anxiety.

Past experience has taught me that I am quite likely to say or do something rude, and that is anxiety-provoking. CBT seemed ill-equipped to help me deal with the consequences of my social differences.

Real negative social experiences, trauma and discrimination cause anxiety.

I don't like it when you're asked to look for evidence (or lack of) to explain how you feel because I have swathes of it, e.g., when people try to frame your worry as just a feeling not based in evidence, because most of mine is based in trauma.

Therefore exposure-based therapy does not necessarily work.

My anxiety levels never decreased or changed whilst using CBT and I felt therapists laid the blame on me rather than actually trying to find out if there was something else at the root of why it wasn't working. Exposing myself to things never made them any easier because I'm neurodivergent.

Therapy does not address underlying causes (Autistic differences? Trauma?).

CBT doesn't address underlying causes so much and doesn't acknowledge the fact the world needs to change.

And it just ends up blaming the individual.

What I haven't liked about therapy is that NO ONE is properly trained in trauma. Some think they are but they aren't. I would ask basic questions like 'why do I freeze in social situations' and would just get a glib answer.

No it just blamed me for thinking the wrong way and using unhelpful strategies. I have tried to do better but can't keep it up.

THEME 2. THE PROCESS OF THERAPY DOES NOT FIT.

The therapist couldn't understand that not everyone has the textbook cycle of anxiety so you can't always do the same thing with people.

Modifying behaviours is sometimes inappropriate.

Many of my old coping mechanisms were completely undone by it because I was told that I was relying too much on comfort items or stimming, things that are absolutely essential to some people with Autism. I had to work out new coping strategies and allow myself to use some of the old ones again. Focused far too much on undoing strategies that I needed to function in

	the way I had been, rather than improving upon them.
<i>No actionable tips with coping and adjusting life to my needs.</i>	Therapy was only asking about what happens, didn't try to come up with a plan to help together or learn strategies. It didn't make a difference for anxiety of talking to people and not knowing what to say in a conversation.
<i>Therapists speak in ways that are not accessible.</i>	Every session the therapist would ask me what I wanted to bring to the agenda. He never explained what that meant despite me asking several times. He asked me what my goals were and I told him my goals were to not experience such severe anxiety symptoms [...]. He didn't seem to like that. I think he wanted my goals to be something like 'make eye contact' or 'join a club', but he never said what he wanted me to say for that question.
<i>Therapy felt one-sided.</i>	The therapists were trained to stay silent and throw questions back at you. Little/no advice was given.
<i>Social and communication differences impact the therapeutic process.</i>	When I arrived, I would just start to talk about the first thing I could think of, and then I'd go into that in minute detail even if it didn't feel that important. It's difficult to stop and redirect my thinking when it is going into too much detail down one track while speaking. I think this is to do with the effort of processing speech. This had a detrimental effect on my therapy as we often didn't cover what would have been the most useful topics.
<i>Identifying and explaining feelings is hard.</i>	It is hard for me to identify how I'm feeling, or to think things through in front of another person. It just means that I have to take things away before I work out what I feel and then it's hard to bring it up again.

THEME 3. THERE WAS A LACK OF UNDERSTANDING OF NEURODIVERSITY (IN THE THERAPY AND/OR THERAPIST).

It wasn't designed with autistic people in mind. Therefore, it didn't work.

<i>There were too many neurotypical assumptions.</i>	It seemed impossible to get them to take either my autistic traits or the consequent discrimination seriously. Essentially, they were just one more bully to have to deal with, attempting to make me conform to "normality" by doubling down on my masking, and using psychological tactics which were no match for the neurological origins of many of my problems. When all you have is a hammer, everything looks like a nail, as we engineers say.
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<i>Autistic ways of thinking are not respected.</i>	I have felt patronised, minimised and judged by therapists who critique my "black and white thinking".
<i>Therapists did not recognise neurodiversity (which might have been the most helpful thing).</i>	It was useless as these so-called experts had no idea I was autistic even though I went through 450 hours of counselling.
	The effects of therapy were somewhat temporary. I found being diagnosed with autism more helpful.

In addition, a small number of autistic participants indicated that therapy had been helpful. We have also looked at reasons for this, and completed the same sort of analysis for unhelpful aspects.

THEME 1. POSITIVE THERAPEUTIC RELATIONSHIP.

<i>Trust and respect</i>	Just talking to someone, particularly if there is no one else - if you like and trust the person it's enormously helpful.
	She understood autism and trauma. She was deeply respectful towards me as a valid, well intentioned, good human being.
<i>Person-centred adjustments to therapy</i>	She realised that I had trouble judging my own feelings, and instead switched her questions to asking about causes and sources.

I can rearrange the room, sit how I like, take things with me, I don't have to look at the therapist.

THEME 2. WHAT I GOT OUT OF THERAPY.

<i>Awareness and understanding of myself</i>	It was helpful to unpick patterns and helps me to understand why I think/behave/respond the way I do to different situations.
<i>Reframing</i>	It helps me put words on my thoughts and give me new ways of looking at different issues.
<i>Self-acceptance</i>	It hasn't necessarily reduced the anxiety itself, so much as helped me understand it better and adjust my reaction to it. I can make better decisions about putting myself in situations that might cause anxiety. Our sessions are not about "fixing" difficulties.
	I talk about being autistic and the impact it has had on my experiences frequently, and I think it's helped me to learn to be more forgiving towards myself.
<i>Strategies adjusted to my needs</i>	She's equipped me with exercises I can do in stressful situations and scripts I can use so I don't need to tell everyone I am autistic. She discusses resources with me so I can explain to

people what I need them to do if I'm in meltdown. It was also she who suggested fidget toys.

Suggestions for Therapists

Below we share with you some suggestions that we are planning to send to therapists. This would be a first step to developing more appropriate therapy for social anxiety. If you have any feedback about these suggestions, please let us know.

- Therapy needs to take into consideration the individual and environmental factors that cause social anxiety in autistic people (such as the factors reported here). These are different to factors for neurotypical people. There also needs to be a broad understanding of neurodiversity, discrimination and trauma. To achieve this, we recommend (1) education of therapists about these factors, and then (2) discussing factors with clients in therapy. This might involve the therapist providing information/resources to the client, as well as joint discussion about key factors based on the client's expert knowledge about themselves.
- Therapy needs to be truly validating. Therapy needs to recognise the challenges and well-founded anxieties autistic people experience about social interaction. We would encourage therapists to become more aware of their own relationship with neurodiversity, so that they don't impose their norms and assumptions on clients.
- We need to work out with clients what a good outcome for therapy is likely to be. It may be that a client will always struggle with social situations – what is a good outcome for them going to be? It might include some reduction in social distress, but also finding some acceptance towards oneself and finding practical solutions to particular stresses relevant to the individual's day-to-day life.
- Therapists need to consider how appropriate it is to encourage clients to change behaviours. If certain behaviours are backfiring, we might hope to help someone with that. However, our goal should be to add to a person's coping strategies rather than taking them away. What looks like an unhelpful behaviour to a therapist may have a different function for the autistic person. It may be a stim or a way of coping with sensory overwhelm or getting by in a neurotypical world. Ultimately, we want to help people weigh the pros and cons of behaviours, so they can live in the healthiest way.
- Some autistic people in our sample wanted therapists to be clearer and more direct in their communication. Therapists need to be clear what is meant by "goals" for instance, and explain what goals might be achievable in therapy. If the client is looking for some advice about coping strategies or social situations, the therapist might need to be more active than they would with other people.
- We need to be mindful that therapy is itself a social situation. Therefore, all the factors described in this report that cause social anxiety for autistic people might show up in therapy. If we are aware about this, it may give opportunities for noticing and learning about different factors. If we are not aware, there could be problems.

- Practical adaptations to therapy may be helpful, e.g., changes to lighting, availability of fidget toys, not needing to wait in a waiting room, online sessions, an awareness that it is okay not to make eye contact, etc.
- Our analysis suggested that the Clark and Wells model is only partly relevant to autistic people. Also, many autistic people said CBT was not helpful. As CBT according to this model is the most common therapy for social anxiety, services need to be careful about offering this to autistic people. However, we do not recommend a blanket approach where this therapy is never offered. This might act to exclude people from a therapy that might help some autistic people. Therefore, we encourage therapists to honestly explain the options, and help clients understand the model and approach so they can make an informed decision about it.
- Be aware of autism and neurodiversity. People accessing services may not know they are autistic. Sometimes, the most helpful thing for people is a diagnosis. Referring a person for an assessment may be an important part of therapy.

These suggestions for therapists represent things we feel therapists could do now to help people. In the future, we hope to develop more tailored therapies to the difficulties experienced by autistic people.

Thanks very much for reading!

Best wishes,
Dr Alex Wilson