

Supplementary material

Interview Questions

Part one: Telling your story so far of navigating diagnosis (photovoice optional)

Here you will provide an overview of your experiences of navigating diagnosis so far, using photovoice or other creative methods, to share your story with us. If you have chosen to use photovoice or other creative methods you can show your slides at this point. As you show your photos/artwork/writing we might ask questions like:

- *What is happening there?*
- *How does it relate to your identity / experiences of trying to get an autism diagnosis?*
- *What do you want to show?*
- *What can we do about it?*

If you elect not to use photovoice or other creative methods you might want to just tell us a little bit about yourself and give an overview of your experience of navigating diagnosis so far.

Part two: interview questions

Here we have some specific questions to direct the conversation. We might not follow them in the exact order, and might ask other questions not on this list as we organically explore the things you are saying. The bullet points are prompts - additional/follow-up questions along the same lines of the main question, which we may or may not use if we want to go into depth on a particular topic.

Topic 1: Thinking about and seeking diagnosis

Tell us about what made you seek out an autism diagnosis?

- Did someone prompt you, was it your own view or did you see it in others?
- How long did it take for you to seek diagnosis from first thinking about it as an option?
- Are there other autistic / neurodivergent people in your family (officially diagnosed or self-identified or suspected by you)? When did these diagnoses happen and how are they related to your diagnostic journey?
- Did you ever read about the experiences of people in the media getting a diagnosis, and did this have any influence on you at all?

Why are you seeking a diagnosis now?

- Did you have a 'lightbulb moment' when you realised that you might be autistic?
- Were there barriers until this point? What were they?
- How did you feel growing up without a diagnosis?
- Do you think it's better or worse to be diagnosed as an adult rather than as a child?
- If you could go back and get diagnosed earlier would you?

So where are you now in the steps towards diagnosis?

- Are you on a waiting list for diagnosis? How long have you been waiting?
- Have you felt that the diagnosis process has been appropriate for adults? Why / why not?
- *If applicable* - Was your assessment done in person or online? Do you think that made a difference to the outcome?
- *If applicable* - What was your experience of the ADOS (Autism Diagnostic Observer Schedule)?

Did you do your own research before/during the diagnostic process?

- Did you look at diagnosis questionnaires, the list of symptoms needing to be ticked?
- Do you feel able to identify with questionnaires like the Autism Quotient?

How was your experience of going to see your GP to seek referral?

- How supportive and/or knowledgeable was your GP?
- If you are seeking diagnosis privately - why?

Have you spoken to others (e.g. family, friends) about your possible diagnosis, and if so how did that go?

- How open are you with others about the fact you are thinking about or seeking diagnosis?
- Have you experienced any negativity if you've spoken about self-identifying as autistic?
- Have you experienced any bias during the diagnosis process? e.g. due to gender identity, race, age etc.?

What support have you received during this whole experience of navigating diagnosis?

- How important is the support of your friends/family to you when it comes to seeking diagnosis and identifying as autistic?
- Has seeking diagnosis impacted your personal relationships?
- What support is currently missing for you?

How do you feel about possibly getting told you're not autistic?

- What are your next steps if your assessment suggests that you are not autistic?

What do you think will change for you with a diagnosis?

- What are your hopes for post-diagnosis life?
- What support would be helpful for you after receiving a diagnosis?

Topic 2: Views about being autistic / autism

Do you prefer 'autistic person' or 'person with autism'? Why?

Do you currently self-identify or call yourself autistic? Or are you waiting for a formal diagnosis before you call yourself autistic?

- Is being autistic an important identity label for you?
- What things prevent you from self-identifying as autistic?
- What things encourage you to self-identify as autistic?

Do you think that formal diagnosis is the only way to be recognised as autistic? Why / why not?

Have there been any times when you've felt negative or rejected the idea that you might be autistic? If so, can you tell us more about that?

- Have you ever thought about wanting a 'cure' or wishing you weren't autistic?

Autism is classed as a disability. Do you see yourself as disabled?

- Do you know what you are legally entitled to when you have an autism diagnosis?
- Have you tried to get accommodations through work/education (if applicable) without a formal diagnosis?
- If you get a formal diagnosis, will you try to get accommodations?

How do stereotypes about autism fit with your own experience?

- Have these stereotypes influenced your diagnosis experience at all?
- How do you feel about the way autistic people are often deemed "quirky" or "odd"?
- Do media portrayals fit with your experience?
- Has anyone ever said to you things like "you don't look autistic"?
- Alternatively has anyone ever agreed point blank or told you "I see that" or "You look autistic" if so how do you feel about that?

Topic 3: Community and identity

Has realising that you are autistic changed the way you see yourself?

- Has this self-realisation as autistic changed the way you think about previous events in your life? In what ways?

Have you linked into any autistic communities before or since identifying you might be autistic?

- If yes, what were your experiences?
- If no, why not? Are there any barriers?
- Do you think that connecting with the autistic community is useful? Why/ why not?
- Do you have any worries or concerns about connecting with the autistic community?
- Are you keen to connect with other autistic people? Why / why not?

Wrapping up questions

If you could advise other people who are currently thinking about getting an autism diagnosis, what would you say to them?

If you could advise the people who have the power in diagnosing autism, what would you say to them?

Do you have any final comments or thoughts you would like to share?

Additional quotes for themes and sub-themes

Theme / sub-theme	Example quotes
<p>Everything shattered</p>	<p>“And then my breakdown happened in at the end of 2018 beginning of 2019. [...]The only thing that I didn't do well was, was like look after myself and after two years of doing that, I was just completely and utterly burnt out. And I just couldn't get back to the office after the Christmas break.” (Skye)</p> <p>“And then just before the pandemic happened, [my] mental health, got worse again. [...] I had to go back on antidepressants. So, I wound up on fluoxetine and it wasn't working, and then they tried me on sertraline and that really, really, that was a terrible experience. [...] I was like, why is this happening? And then my mum was like, “well, have we considered the fact that it's not for your brain type?” And I was like, what on earth does that mean? [...] Then the pandemic happened and then I started to feel more autistic about things, so that might sound silly. But it was like because it was suddenly locked in as like a specific space with lockdown and stuff.” (Scarlett)</p> <p>“It came to second year of uni. That was when like the pandemic started to hit and all that. And I remember I was travelling back home on the train and I was getting so overwhelmed with all the noises and all the people and I was like, Oh my God, this is unbearable and was kind of looking around everyone. And I was like, why is no-one else being this, why is no-one else stressed out about this? And I was like, I should maybe Google it. And Googled that and realized, and I had spoke to my mum, and she was just like, “I mean, yeah, like, you could be”.” (Rebecca)</p>
<p>Being seen</p>	
<p>➤ Communities as an invaluable source</p>	<p>“I just don't do social media at all, but I have found on Twitter the neurodivergent community. And that's been also a great resource for me for getting all of these people people's views on things and all of the things they struggle with and, and there's so much that resonates with me there that that gets posted and there's so many useful documents that I just follow up from there.” (Skye)</p> <p>“TikTok has a very specific algorithm. So, if you interact with videos, are you see things, then that's what you're gonna see. And it suddenly became like this barrage of people talking about their stims and their experiences. And I was like hang on, these things aren't universal? Like this isn't just something everybody does?” (Scarlett)</p> <p>“I mostly follow people who are either autistic or have ADHD [on social media]. Or are in related kind of areas. A lot of people that I've come across are in a similar kind of boat, just really getting to understand their own neurotype as adults. And it's interesting again seeing other people's journeys and really validating” (Bea)</p>

	<p>“I think I generally surround myself by positive people. My sister is my best friend, and we share the same wholesome friendship group. The majority of us, well, I think all of us, are neurodivergent anyway. If they're not autistic, then they're ADHD, and if they're not, then they're dyspraxic. [...] So, nobody's a neurotypical in our circle, and we've got quite a close knit circle. We speak every day, and we all speak very openly about our 'disabilities' for want of a better word. So yeah, my friends and family have all been really, really supportive, and that's been really helpful.” (Mia)</p>
<p>➤ Validation matters – understanding difference</p>	<p>“That was the first time [after doing my own research] that I saw some of these things spelt out, and somebody saying no, it's OK to be like that as well. And that was like a massive, big relief to, you know the first time, that somebody said no, the way you are is OK.” (Skye)</p> <p>“Essentially the [TikTok] algorithm took over eventually and showed me my special interests and it seems that I had a lot of ND folk talking about their own experiences and talking about their special interests. And I was like these people are my people and I thought, OK, this isn't bad. It was like seeing positive representations of neurodivergent people, and specifically women, grown women, not young children, and so all of a sudden I was seeing things that I could go yeah. OK. I see it now.” (Maggie)</p> <p>“I think I've always had this assumption that if it's not working, if what people say works doesn't work for me, I must be doing it wrong. So in some ways that's it's relieving quite a lot of that shame or that negative self-talk. Which is quite freeing.” (Bea)</p> <p>“I think that it [diagnosis] will also help me make sense of my own interest in autism in general as well. Like, the research that I'm doing for my dissertation is about neurodivergence and I would feel a lot more comfortable to be able to communicate to other autistic people that I'm working with that I am autistic. I think I would find that the hardest without the diagnosis. Speaking to people who were diagnosed as if I was too would make me feel, like I don't know, just weird. I think that yeah, it will help me feel, I don't know, more authentic in some way.” (Mia)</p>
<p>➤ A time for sense-making</p>	<p>“But it's been the self-identification that's unlocked all of that, not the formal diagnosis, which was just like... for me, it's like, of course I'm working so much with information and seeking out information all the time and I definitely have the capabilities that you know, intellectually, to just read up stuff and, and put stuff together, put information together, and work through it. And then I've had therapy for the last three and a half years which has been very helpful for exactly that process. So yeah, it's been a massive change in the way I see myself, in the way I also see things in the past, interactions in the past. And I'm much more comfortable with myself now and just being able to put that shame down. It's fine. I'm OK.” (Skye)</p>

	<p>“I’m not feeling terrible about it. I feel quite hopeful that it will help me understand myself better. I have always struggled with this concept of self-care because all the things people tell me I should try just don’t really do anything for me or, aren’t, I don’t find they replenish. And I’m kind of understanding that actually I just need different things. And what I’ve got to do is find those things that are really replenishing. And if that’s a weighted blanket and then a dark room, it might be. That’s not everybody’s bag, but that’s OK... it is helping me kind of find my own way. And giving me the permission to do that.” (Bea)</p> <p>“Since kind of realizing that I could be autistic, I realized that I don’t need to fit into that neurotypical standard of like being really sociable and going out and drinking and all these different things. Like it’s totally OK for me to just not take part in those things and self-identifying as well, along with that has kind of given me the opportunity to tell people, look, I don’t want to do these things or I’m not interested in that.” (Rebecca)</p> <p>“I think that this was quite significant to my own autistic journey because I realised how much I had depended on alcohol as a social lubricant. And since stopping drinking I noticed how much more difficult it was to socialise. I’d always thought myself as quite a sociable person but without drink it became very difficult and I didn’t want to socialise as much. And I realised that I wasn’t as much of an extrovert as I maybe thought I was.” (Mia)</p>
<p>➤ But the ongoing battle on stigma and prejudice</p>	<p>“For my mum, it’s very, very different. I mean, she’s, she’s got so much... God, she’s so ableist... I guess she’s pushed herself so hard to fit in and denied any of the struggles, and now I’m like going out there and I’m no, this is me. This is important. This matters.” (Skye)</p> <p>“I think this image [of an angry face] sums up so much for me, it’s sums up the reaction I had when people first said, “are you autistic?” Excuse me, I’m gonna swear now. But like f**k off, of course I’m not. I’m not a freak, weirdo, slash, whatever word you want to put in there because I had internalized a whole load of stuff around being autistic. And it was always boys. And so, I really struggled to identify with that at all. And my response was anger or fear or disgust or whatever. It certainly was not positive. But then that kind of was the same reaction I would get from other people. So as soon as I would go to the doctors, that’s the picture I would see on their face. And I would talk to, I don’t know, my colleagues who had worked with me for years and were like, “you’ve never said this before” and it’s like, “why didn’t you know it before?” Didn’t know it. Been an adult long time. Didn’t know it. “Well, then that can’t be true”. Or “well, you’re just getting on the bandwagon. Everybody reckons their autistic these days” and all of this sort of thing. And so, it’s a really familiar facial expression that I kind of come back to time and time again.” (Maggie)</p>

	<p>“When I explain something that’s happened and I’m like, oh well, I actually think it’s to do with, with like the autism. Or I’ll like sort of give up halfway through sentences. I get like brain fog or trip over my words a lot and then I’ll stop and I go well, it’s just the autism and sort of move on. Because it’s the way it’s like sort of reset my brain and she [a friend] just looks at me and rolls her eyes and she is sort of very negative about it. I never expected it.” (Scarlett)</p> <p>“I guess imposter syndrome, internalized kind of ableism type stuff that I kind of need to sort out myself [is a barrier]. And I think there’s also like a worry that it [diagnosis] won’t go the way that I hope it will, or people won’t take it as well as I hope they do. I’ve already had an instance where my dad is already like, “you’re not autistic, you do all this, you go to university, you live by yourself”. And that was just telling them that I think I could be autistic. So, I was like, how is he gonna react if I actually get a diagnosis or not? So, he doesn’t know much about it anymore, but yeah, a lot of the barriers are kind of just people’s views on it, I guess, and my own views.” (Rebecca)</p>
<p>Understanding not judgement please</p>	
<p>➤ Stop pathologising us</p>	<p>“I mean with homosexuality that used to be a diagnostic label as well in the past and now it’s not. I wonder whether we do need an official diagnosis for autism.” (Skye)</p> <p>“I do find that things are pathologized as soon as you say, well, I’m autistic... And this picture [of toys lined up] is similar to another one that I’ve seen, where if you put it in front of some people who are neurotypical and say neurotypical children did this, they’re like, “oh, isn’t that amazing? Look, how organized they are? That’s so cool that the way they’ve done this and blah, blah, blah”. But as soon as you put it front and say, an autistic child did this, it’s all “Yeah, I can see. Isn’t that terrible? They just can’t play, can they?” And just all of this. Oh my gosh, why is it awful? And just it drives me mad and actually it makes me angry. Don’t pathologise me, don’t pathologise people like me because how would you like it? I would love us to start pathologising neurotypical behaviours because then they would kind of understand how it feels.” (Maggie)</p> <p>“I think it’s like almost like a form of advocacy in a weird way to be like I am autistic and not a person with autism because it removes this whole idea that autism is curable or that it can be healed or can be lessened in a way. So yeah, I always try and use autistic person just because I don’t think it’s something that you can remove from yourself.” (Rebecca)</p> <p>““I find it easy to read between the lines”. Strongly agree. I LOVE reading between the lines.</p>

	<p>[...] It's not a "special interest" though. I don't get "upset when I can't pursue it". But writer's block does make me cry and hit my head against the wall. That's different though. Everyone feels like that." (Mia)</p>
<p>➤ Our internal trust and expertise</p>	<p>"If you even think for fraction of second that might be who you are, you probably are. Like Neurotypicals aren't out there thinking, "I'm autistic". You know what I mean? ... When you're thinking about going forwards and getting an autism diagnosis, that means you've already hit the level of self-awareness. So, if you've got that level of self-awareness, go for it. [...] What I'm saying and like my friends at work is, it's like they're looking for that missing piece of them for suddenly click together and I can see them holding the piece to go with it. Even though I hate the puzzle piece." (Scarlett)</p> <p>"I think the thing just before my assessment or while I was doing my assessment, was what if? I'm pretty much convinced myself that I was autistic. Through all the reading and stuff I've done. And then I had a, what if they say no? What if they say I don't have autism? What then? And I guess thankfully I haven't got to consider that any further, but it was a... I was like actually, in some ways, I suppose if you're that convinced then going for the diagnosis, I guess it's not necessary." (Bea)</p> <p>"Now that I've sat with it a bit more, I'm kind of like, no, but I think I must be [autistic] because nothing else seems to fit, really. And so, I think I would. I don't know how to appeal it [if they said I wasn't autistic] or if I would try the process again because obviously it's really long. But I think that I would be maybe a little bit disappointed but look at different avenues for all these things." (Rebecca)</p> <p>"I would still be the same person regardless, basically [if I was told I wasn't autistic after assessment]. So I guess it might feel quite invalidating, but it would also, I don't know... it would just make it feel quite difficult to trust their assessment. Because I would still be coming out of that assessment with the same feelings and concerns that I went into it with." (Mia)</p>
<p>➤ We need less stereotyped, more intersectional representation</p>	<p>"But most stereotypes I sort of don't resonate with. Like I just, I see them, I see why they are stereotypes. I see how it is quite a common thing but I think because I'm a woman with autism, that they're always centred around men. And I don't really see that, I don't think." (Scarlett)</p> <p>"I think when I first was asked the question, "do you think it might be autism as well?" You know you've got all the media portrayals of white boys. Nerds or, you know, really extreme. You know very significant support needs and, and people who are nonverbal and, I</p>

	<p>guess I didn't really identify with many of those portrayals, or many of those sort of images I'd seen" (Bea)</p> <p>"I think it's Paddy McGuinness's wife, is recently diagnosed autistic and I found that really interesting. And because she is... like I don't think she's the highest like a high-profile celebrity but she's there and it's quite interesting because I think she's a model or something like that and I remember kind of saying on like my private Instagram where I rant, I was like seeing people, I think it's really important that celebrities do. They don't have to reveal their diagnosis, but if they do, I think it's important." (Rebecca)</p> <p>"I don't really feel like I've seen a representation of autism in media or in stories that feels like me. But then sometimes there's just aspects of characters that are relatable. We watched Atypical and I know that some people felt that that was stereotypical in a bad way. [...] But I think that you can't have an accurate representation of autism because we're not homogeneous. You can't represent every autistic person in one character. So I think that sometimes the 'autistic community', is a little bit harsh on media representations and art. Because it's like, what do we want? They can't represent everybody. It would be nice to see more diverse representations across different texts, I guess for sure. And the stereotypes around maths and science... [My partner] is a maths and science autistic, but I am not. I want to see more arts and cultures autists." (Mia)</p>
<p>➤ Assessments consist of performance and poor metrics</p>	<p>"I would like them [clinicians] to really delve deeper into masking because an assessment is actually a relatively short space of time and you only see a snapshot of somebody. And when you see that person, maybe four or five times so that you can get a better sense of them. You are still seeing a masked version of them. You need to see them at different times, sometimes. You know not just 10:30 or whatever, but if you see them at different times, you'll see them when they're tired. You'll see them when they're excited." (Maggie)</p> <p>"And then about two weeks later, I did the ADOS. Which is the kind of conversational assessment with some weird tasks that were very weird. And I tried very hard not to go researching it before I did it because I was kind of like, well, I suppose if it's gonna test something, I need to go into it blind. And I didn't want to be like doubting myself as to whether I'd managed to cheat or something. I'm sure it has been validated in some way, that I hope it's not hard to cheat. I'm not sure why anybody would want to but I tried not to look into it too much, but I did look at a bit of research about how effective it was, or how sensitive it was to picking up autism in adults, and particularly adult women." (Bea)</p> <p>"I did the AQ and it basically came back that I was like 'borderline' autistic. But I take it with a pinch of salt because I think that the questions are so inaccessible for autistic people to answer. And I hate</p>

	<p>Likert scales. And yeah, just the fact that it's measured in terms of agreement and not in terms of frequency, when obviously you can feel something sometimes and it's different at other times and it's situational. Like "I prefer to do things with others rather than on my own", like doesn't everybody like to do a bit of both? And it is totally dependent on what's happening." (Mia)</p>
<p>Here's a leaflet, off you go</p>	
<p>➤ We want (local) connections</p>	<p>"So, I went to a board game club. It was fun, but I only went three times. [...] I loved it because I was like connecting with all these amazing people and, and just synapses everywhere. And it was great, and I enjoyed it. And then I remember finding out that completely by accident that ohhh it's an autistic group and I was like no, it's just a board game group. They're like, "yeah, but it's for autistic people". Like when people go "she's deaf". It was like literally said like [whispers] "for autistic people". So odd and I was like oh well, maybe I shouldn't go anymore then. So I stopped going because it was like, oh well, I'm so sorry, I didn't mean to kind of come in and encroach on your safe space. If you see what I mean. So, I didn't go again and then they moved it to [place] and now I can't blooming go anyway because that's not where I live." (Maggie)</p> <p>"More like access to communities [is needed], I guess if that makes sense. A lot of the things that I've had to find, I've had to find online. So like Discord or TikTok or I think [group] was recommended to me from like my learning support but for people that aren't in education or have these other places that they can go to, I think more access for communities and community support and social groups and that would be really good." (Rebecca)</p>
<p>➤ We want to know what support is available to us</p>	<p>"I got the impression it [post-diagnosis support] was a mix of things including work adjustments, which I guess is what a lot of people ask about. And, to be honest, that was where I started out. Like I said, you know, I was panicking about how on earth I'd manage my increasing workload as I go through my career. And so yeah, work adjustments is what I do need some advice about." (Bea)</p>