

Appendix C

Table 3

Primary quotes illustrating analytic themes and subthemes

Themes and subthemes	Example quote
1. Lonely, difficult service experience	<i>'People might feel like they want to kill themselves [...] It is terrible when you have to wait a year, because a lot of people have gone and done it. It is just sad when that happens, it really is, especially when you can do something about it; someone can help you and you can resolve the problem.'</i> (Autistic adult, M, UK) ¹¹
1.1 Barriers at every step	<i>'I cannot tell you how many intakes we went to and after maybe an hour or 2 hours or tons of paperwork, they would go, "Oh yeah. We do not have that expertise. We really cannot do the autism." And I was like could somebody have told me at that initial phone call you cannot do the autism? Because that was 3 hours of our life we are never going to get back. I cannot tell you how many of those intakes I walked away from in tears'</i> (Parent, F, US) ³
Difficulties accessing support	Recognizing need for support: <i>'I recognise that I often don't realise just how bad things have become. In the last year I have started thinking about suicide, even though I don't want to die, and that has been the thing that's made me realise how bad things might be.'</i> (Autistic adult, F, UK) ⁷
Services being based around neurotypical norms	<i>'They are all set up for what I would call, and I don't know what your typical patient with anorexia is like, but it is not our daughter; she has got complex needs and none of them, you know none of the workshops we attended addressed those extra needs.'</i> (Family member (Family member, UK) ¹
Clinicians' lack of awareness and stereotyped attitudes	<i>'They thought that I was stubborn and lazy and unwilling to help myself, and they let me know it. They ended up asking me not to come back, because my case was too "complex"'</i> (Autistic adult, F, UK) ²⁰ <i>'In this field it's really frustrating because people want to take a cookie cutter approach and that's impossible because what one person with ASD is capable of doing another person with ASD is not capable of doing or vice versa. And then you throw in any other kind of diagnosis and it's just going to make it that much more complicated.'</i> (Counsellor, F,US) ²⁴
System/ organisational barriers	Financial barriers: <i>'The only therapy that has been paid for, not by me but by the system [is CBT] and that is absolute rubbish. It doesn't help me.'</i> (Autistic adult, UK) ¹⁶ Lack of training: <i>'Certainly in the department we all recognised that we really don't have an awful lot of training, and not a lot of training in adaptation for CBT working with this group'</i> (Therapist, UK) ²

<p>1.2 Negative consequences</p>	<p><i>'They never told me 'you were wrong'. There were comments like, 'You just want to be special,' or not really knowing how to relate to the sensory things I tried to explain ... It made me feel like I was either a freak or making things up or it was all in my head.'</i> (Autistic adult, F, UK)¹⁰</p>
<p>iatrogenic harm and distrust in the service system</p>	<p><i>'I dread having to come into contact with any sort of medical thing to do with autism... or mental health because they're just a nightmare, they just make you much worse.'</i> (Autistic adult, UK)²⁹</p>
<p>Tension in personal relationships</p>	<p><i>'The support doesn't really meet my needs and so my mother has to do more for me and her health hasn't been too good really. So sometimes I try to suffer in silence so that I do not let her in my flat so [that] she cannot see what a mess I am in, and that I haven't food in to eat.'</i> (Autistic adult, M, UK)⁶</p> <p><i>'It is difficult with engagement because sometimes the family want the person to come more than the person'</i> (Therapist, UK)²</p>
<p>Inappropriate use of medication</p>	<p><i>'... my GP tries to keep throwing antidepressants at me but [I] think [I] just need to understand myself better [and] get other conditions diagnosed.'</i> (Autistic adult, UK)⁵</p> <p><i>'The answer was often medication of some sort and for some that was appropriate and suited them, but I think for many the medication was given just because we didn't have anything else to do'</i> (Therapist, M, UK)¹¹</p>
<p>2. Complexity needs flexibility</p>	<p><i>'I don't tend to find myself following a particular model because it's very rare that one will satisfactorily fit, so it's more idiosyncratic, and it will depend on the person's ability'</i> (Therapist, F, UK)³⁵</p>
<p>2.1 Impact of being autistic on treatment</p>	<p><i>'If there was someone who both understood the condition and me, I feel progress would be made.'</i> (Autistic adult, M, UK)⁷</p>
<p>Interaction between autism and mental health difficulties</p>	<p><i>'Emphasis needs to be placed on figuring out which behaviours are anorexia based, and which are autism based. If someone is refusing to eat their dinner, it could be because their eating disorder is telling them that it will make them fat, or, the food could be touching, is an autistic sensory issue. The behaviours are exactly the same, but the causes can be so different. Knowing all of this, if doctors and therapists and dieticians can be flexible regarding autistic patients, they're going to see much better outcomes'</i> (Autistic adult, UK)²⁰</p>
<p>Communication</p>	<p><i>'I could keep up with the nurse for one or two sentences at the most and then I felt that my brain could take no more, I would stop trying to follow what she was saying and simply close down. I remember hearing nothing, but still see her mouth going up and down.'</i> (Autistic adult, UK)²⁶</p>
<p>Working with emotions</p>	<p><i>'... [it's] just Asperger's with me [...] - [I] learnt to hide my emotions and feelings to survive school and home without being hurt, so only [got] visibly upset in the last moment when [it became] unbearable. Because they cannot read my face [doesn't] mean [I'm] not having those emotions before ...'</i> (Autistic adult, UK)⁵</p>

	<i>'They'd ask me questions, how you feel about this, how you feel about that, and the harder I thought about it, the more I couldn't figure out what I was feeling like . . . That was kind of useless.'</i> (Autistic adult, US) ²⁵
Thinking styles	<i>"It can be really hard to shift, cognitive process issues, not being able to move from one topic to another"</i> (Therapist, UK) ¹⁰
Sensory sensitivities	<i>'On the unit I found it extremely difficult to sleep, the buzzer on the door of the unit used to really irritate me and sounded really loud, but it didn't seem to affect anybody else. The beeping noise of the fire alarms will keep me awake at night. I found myself in a situation where every night I spent in hospital my sleep was broken. There is also a constant humming noise, that when I felt anxious it sounded louder than it did when I wasn't feeling so anxious, I think it might be the air- conditioning or the heating system, not too sure'</i> (Autistic adult, UK) ²⁶
Need for predictability	<i>'Set the expectations about what happens in therapy. You should just make those expectations clear from the beginning'</i> (Autistic adult (Autistic adult, US) ²⁵
2.2 Need for a comprehensive and flexible approach	<i>'It can be anything and we try and be as flexible as we possibly can to give individuals that come through the door the opportunity to engage with what we're offering, so there are no strict and rigid rules and regulations. We're as flexible as we can be'</i> (Therapist, F, UK) ¹¹
Being bespoke and evidence-based	<i>'Just know who you're talking to. Know that a lot of people with autism are very smart and a lot of them have great skills and a lot of them have great potential, and just figure out how can you specifically tailor to this specific person's needs and interests. And how can you make it relatable and memorable. And what's relatable to him may not be relatable to her and vice versa.'</i> (Autistic adult, US) ²⁵ <i>'So, in a way, probably what we're talking about is a kind of tool-kit of interventions that can be customised to a particular patient, where the skill of the therapist, actually, is critical.'</i> (Therapist, M, UK) ³⁵
Adjusting timings and expectations for outcomes	Timing of sessions: <i>'NHS [National Health Service] counselling is good for people who can immediately connect to another person. If you have autism it takes time, and by the time you are starting to make some kind of connection you have run out of sessions.'</i> (Autistic adult, F, UK) ⁷ Expectations for recovery: <i>"What a change looks like in their mind, it might be 'I have to be 100% better and nothing's better until I've reached that point' but actually our whole job is pointing out the shades of grey ..."</i> (Therapist, F, UK) ³⁵
Bridging formal and informal support	<i>'I think if we could allow [family] opportunities to come and have [support] skills topped up... and more family members trained in that kind of information. I think that is what would make the biggest difference to our service users'</i> (Therapist, UK) ²

3. Collaboration and empowerment	<i>'But we have to try to find a way, a clinical bridge, you know, a way in to communicating with these clients, because, you know, they need our help and the onus is on us really to find a way of helping'</i> (Therapist, F, UK) ¹¹
Building therapeutics relationships	<p><i>'I could tell that she was clearly reading the notes and reflecting on the sessions and just, 'you said this,' or 'I know you talk about doing that'. She'd often ask me stuff that I'd said the week before . . . and that was really really lovely. It shows that she actually was quite interested and that we got on and I really, really appreciated that.'</i> (Autistic adult, UK)³⁴</p> <p>Need for continuity of care: <i>'... you make progress ... but then that psychologist tries to leave, passes on everything to someone else, and then it all gets lost and forgotten about.'</i> (Autistic adult, UK)⁹</p>
Listening to autistic voices	<p><i>'I have had my share of ineffectual medications and therapies, including ignorant psychiatrists and counsellors who made things worse rather than better because they seemed to decide what the problem was and what was best without actually listening to me. However, I have also had some very good counsellors and GPs who have listened, been good at talking to me in a way I can engage with, and worked with me rather than simply talking at me.'</i>(Autistic adult, M, UK)⁷</p> <p><i>'I accept you for who you are and I'm going to try and understand where you're coming from and your experience to the best of my ability because it's your experience.'</i> (Therapist, F, US)²⁴</p>
Enabling independence, self-advocacy and self-care	<i>'My treatment has given me more compassion for myself as a human being'</i> (Autistic adult, M, UK) ⁷

Note. First order quotes (participants' direct quotes) are presented to illustrate the analytic themes and subthemes of the thematic meta-synthesis. Details about the participant are provided, including participant group, gender (where available) and location, and study IDs are used to link them to the original paper (see Table 1).