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Improving Talking Therapies for Autistic People

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A report for the North East and North Cumbria Integrated Care Board

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Executive Summary

Background

Autistic people are more likely to experience common mental health conditions such as anxiety and depression. Whilst there is a substantial evidence base for psychological therapies for anxiety and depression and well established NHS Talking Therapies services, there is limited evidence on what works best for autistic people in this context. In particular, there is limited guidance on what adjustments and adaptations may work best for autistic people accessing psychological therapies services. Many autistic adults will have received a diagnosis recently and other people will be waiting for an assessment so will have added uncertainty about how what may help them to access services effectively. In this project, we aimed to understand the experience of autistic people (and those waiting for an autism assessment) when accessing Talking Therapies and improve the offer to autistic people through service redesign and training with clinicians.

Methods

We used mixed methods in the project including qualitative analysis of semi-structured interviews with autistic people and clinicians in Talking Therapies services and quantitative analysis of Talking Therapies training needs and evaluation of the impact of training and service redesign.

Results and Findings

We identified a number of themes from our interviews with autistic people and clinicians which has helped us to better understand the challenges to supporting autistic people in Talking Therapies. Both autistic people and clinicians reported that Talking Therapies services need significant adaptation (including clinician training) in order to meet the needs of autistic people. We designed training which clinicians reported had a positive effect. We also made changes to a Talking Therapies service to how they identified autistic people who accessed their service which led to approximately 5% of clients being identified as autistic (or having similar needs that require adaptations to therapies).

Next steps

We will work to develop a large-scale research funding proposal to NIHR to build on this work and help evaluate the usefulness of these service changes particularly the impact they have upon autistic people's experience of Talking Therapies. As part of this research and wider service development, the protocol for identifying autistic people could be tested in a wider number of Talking Therapies services and the training programme could be used in other services (following further refinement and depending on resources).

Introduction

Autism is a neurodevelopmental condition characterised by impairments in social communication, a restricted, repetitive, and stereotyped pattern of behaviours, interests, and activities and/or sensory differences which affects 1.1% of the U.K. population. Autistic people are more likely to experience mental health conditions, particularly common conditions such as depression and anxiety (Hollocks et al, 2019).

Effective treatments for depression and anxiety exist. UK National Health Service (NHS) clinical guidelines (https://www.nice.org.uk/guidance/cg123) recommend low-intensity and high-intensity psychosocial interventions based on the principles of cognitive behaviour therapy (CBT) as evidence-based treatment for mild to severe depression and anxiety. However, autistic people have social communication and neurocognitive differences which can mean mainstream psychosocial therapies may not be readily accessible to them and therapists do not ordinarily receive additional training in how to work specifically with autistic people. The autism National Institute of Clinical Excellence (NICE) guidance (https://www.nice.org.uk/guidance/cg142) suggests that autistic people should receive therapies based on general NICE guidance; however, autistic people report significant barriers to accessing healthcare (Mason et al, 2019). A systematic review of perceived barriers and facilitators to autistic people accessing psychological therapies (Adams & Young, 2020) identified the most frequently reported barriers as a lack of therapist knowledge about autism and therapists being either unwilling or unable to tailor their approach to meet the needs of autistic people. A recent large-scale survey of autistic people's views on reasonable adjustments in healthcare published by members of the current research team reported similar findings (Brice et al., 2021).

Both the NHS England long-term plan (https://www.longtermplan.nhs.uk/areas-of-work/learning-disability-autism/) and the Department of Health and Social Care's Think Autism Strategy (2018; https://www.gov.uk/government/publications/think-autism-strategy-governance-refresh-2018) cite improving mental health services for autistic people as a key priority.

In England, psychological therapy for anxiety and depression is primarily provided through Talking Therapies services (previously known as Improving Access to Psychological Therapies - IAPT) which in 2020-2021 received 1.69 million referrals. Talking Therapies services have a common structure throughout England using a stepped care model with a trained and supervised workforce that provides evidence-based psychological therapies with a requirement of detailed pathway reporting and routine outcome monitoring on a session-by-session basis (https://www.england.nhs.uk/wp-content/uploads/2020/05/TT-manual-v4.pdf).

There are several projects that have developed interventions for autistic adults that can be implemented in Talking Therapies services. A feasibility trial of psychological therapies for anxiety experienced by autistic people (Personalised Anxiety Treatment for Autistic Adults - PAT-A) has been undertaken which has demonstrated acceptability of a suite of anxiety interventions based on a formulation of autistic people's anxiety needs (Parr et al., 2020). Guided self-help for mild to moderate depression experienced by autistic people has been developed and initially trialled with a fully powered, NIHR funded RCT underway (Russell et al, 2020).

The context described here presents a clear need to better understand autistic people's use of mental health services such as Talking Therapies and to consider implementation of specifically adapted therapies. However, there are currently no data on autistic people's use of or outcomes in NHS Talking Therapies (TT) services and there are no accounts of processes to obtain such data. There are also no data on how autistic people's experience of TT services or of TT therapist's experience of providing therapy to this group.

This project aims to be the first to examine the process through which autistic people access TT services and their clinical outcomes compared to people who are not autistic. It will also help us to think about the best ways of supporting people who are waiting for an autism assessment when they are accessing Talking Therapies.

This is an early phase study that explores how to make service design changes to Talking Therapies services and explore comparative outcomes for autistic people as well as developing a blueprint for data linkage methods within the Secure Data Environments to create processes to analyse the interventions, pathways and outcomes of autistic people in wider Talking Therapies services. As so little is known about autistic people's use of these services, we will also explore barriers and enablers to autistic people's use of Talking Therapies services from the perspective of autistic people and clinicians.

Setting

The setting is an NHS Talking Therapy service part of CNTW (Cumbria Northumberland Tyne & Wear NHS Foundation Trust). As this is an early phase study, we are less concerned about the representativeness of the Talking Therapy services. Talking Therapy services are required to record data on all steps of referral, engagement, and clinical outcomes [for example, amongst a very wide range of data they record referral sources, patient characteristics and presenting complaints, waiting times, sessional attendance, session by session data on core clinical outcomes measures using GAD-7 and PHQ-9 (Dagnan, Boothroyd, Dagnan & Muncer, 2019) plus additional measures for specific anxiety disorders, outcomes against national standards and using reliable change indicators]. Data are collected at every clinical contact, the amount of data available on each contact is significant.

It was likely that the participating service would have a significant proportion of autistic people sufficient for meaningful analysis. Talking Therapy services generally have high rates of referral; to put this into context, in a separate exercise involving the an NHS TT service over a 10-year period we identified 130,000 referrals, of which around 80,000 were unique (i.e. not counting re-referrals). Autism in the UK is typically reported a present in around 1.1% of the population (Brugha et al., 2011). Thus, we would expect at least 10 in every 1000 referrals to TT services to have autism although this number should perhaps be higher given the higher rates of depression and anxiety in this group. However, we do not know whether barriers to being referred to Talking Therapy services exist and this study will establish an initial description of referral rates.

Methods

A mixed methods approach was taken using qualitative and quantitative approaches to help understand the challenges for autistic people accessing NHS Talking Therapies services.

Semi-structured interviews with autistic people and clinicians

The qualitative element of this proposal will recruit participants from NHS Taking Therapies. Autistic people who have used Talking Therapies will be recruited from autism support groups. In order to map the experiences of key actors in a project-pertinent manner, semi-structured interviews were undertaken with two purposively-sampled groups of participants: (a) autistic people who had engaged with Talking Therapy services over a range of durations, and (b) therapists working within the involved Talking Therapy services. These interviews were transcribed verbatim, and analysis was undertaken using the systematic model of reflexive thematic analysis (RTA) outlined by Braun and Clarke (2022), which involves adherence to a trusted six-step process: Familiarization; Coding; Generating themes; Reviewing themes; Defining and naming themes; Writing-up. For each participant group, the RTA was coordinatively conducted by two members of the research team, one of whom was the original interviewer, in order to enhance analytic credibility through triangular consensus validation. This process was carefully monitored throughout with reference to the key concerns relating to trustworthiness in qualitative research articulated by Yardley (2000; 2017).

Training needs analysis

In order to help design training within Talking Therapies services, a survey was developed using Microsoft Forms which aimed to explore clinician’s views about working with autistic people including gaps in their understanding in relation to autism and adapting psychological therapies for autistic people

Training, design, implementation and evaluation

A brief (2hr) training session was designed using information from the interviews, training needs survey, existing literature and discussion within the project group. This consisted of initial autism awareness and general principles of reasonable adjustments to support effective access to services and also how to adapt psychological therapies for autistic people. The training also included an update on service changes to help identify autistic people within the service and on electronic records. Two sessions were delivered virtually to cover all staff working within the service (including administrative staff).

Participants completed the following measure at pre-training only:

1. Demographic sheet - which identified the name of the participant, their age, time working in TT and experience of providing therapy for autistic people.

Participants completed the following measures pre-training, immediately post-training and at 3-month follow-up.

2. The Therapy Confidence Scale–Autism; (Cooper et al, 2018; Dagnan et al., 2015). This 14-item scale describes the confidence of therapists in working with autistic people. The items are reproduced in Dagnan et al. (2015) and describe stages in engaging people in therapy, from forming a therapeutic alliance, carrying out assessments, formulating, adapting interventions and enabling a positive end to therapy.

The TCS-A has a single-factor structure accounting for 62% of the variance, Cronbach's Alpha for the scale is 0.93, test– retest reliability is 0.83, and the scale has been shown to be sensitive to change following training (Dagnan et al., 2015). Based on 67 people who completed the scale at pre-training in this study, Cronbach's Alpha for the scale was 0.93.

3. A five-item General Therapy Self-Efficacy Scale (Dagnan et al., 2015) using five items adapted from the General Self-Efficacy Scale (GSE; Schwarzer & Jerusalem, 1995) where the general statement of problem was adapted to represent a general clinical problem. We used the scale to provide a measure of general clinical efficacy to determine any generalisable effects of training provided in this study. Dagnan et al. (2015) reported properties of the scale from 107 mainstream

therapists, and the adapted scale has a Cronbach’s Alpha of 0.69 and an adjusted item-total correlation range of 0.31-0.51.

Based on the 67 people who completed the scale pre-training in this study Cronbach’s alpha for the scale was 0.77.

The participants in the training days were sent an email asking them to complete the baseline questionnaires prior to the training sessions, the email contained a link to a Microsoft Forms based questionnaire. Immediately after completing training participants were sent a further email asking them to complete the post training questionnaire, again with a link to a Microsoft-forms based questionnaire. After 3 months a further email was sent out to training participants asking them to complete a further follow-up questionnaire. For each data collection period two follow-up reminders were sent out at weekly intervals to all staff with a reassurance to those who had already returned the questionnaire.

Service redesign process

It was identified that NHS Talking Therapies do not routinely identify autism as a condition experienced by participants engaging with their service. A project group was set up with a local NHS Talking Therapies service to redesign the landing page for new clients accessing Talking Therapies which identified whether the client is autistic so this can be flagged and appropriate adjustments/adaptations are introduced. Service data were reviewed three months after the introduction of the new protocol for identifying autistic people to review the rates of autistic people identified within the service.

Ethics and approvals

The project has ethical approval from University of Cumbria and approval as a service evaluation from Cumbria, Northumberland Tyne and Wear NHS Foundation Trust.

Results

Thematic analysis of autistic people's views of accessing NHS Talking Therapies

Thematic analysis of the interviews with autistic people accessing Talking Therapies yielded four global themes: (a schematic diagram is included in the Appendix)

1. Pre-Therapeutic Context
2. Therapeutic Relationship
3. Rigidity and Quantification
4. Training and Adaptation

These are outlined in detail below, supported by direct data where they are illustrative, and particularly where variable interpretations of the same ostensive phenomenon are at stake. Headings are organised around major subthemes.

With respect to this particular analysis, it should be noted that the participants provided rich, long-wave accounts of getting an autism diagnosis, and their broader mental health difficulties. While these are addressed in terms of context-provision as part of theme 1, they are beyond the purview of TT services themselves. As such, they are addressed in the core analysis as and when made relevant in that way by participants themselves.

Pre-Therapeutic Context 1: Pathway to autism diagnosis

Most of the participants addressed below were diagnosed relatively recently (the oldest diagnosis having been made in 2017), and all were adults in their twenties at the time of diagnosis. The periods from initial referral to diagnosis were highly variable, and in some cases marked by significant waiting periods (over two years in one case). What was consistent across all participants, however, was that their path to an autism diagnosis began with referrals to various services or agents for other mental health or behavioural issues. For example:

> PC1: *“I had some really bad trouble that led to me ending up in hospital and having to speak with the crisis team and during like the conversation with the crisis team, I felt like they kept trying to force me into a box that I didn't feel quite fit. So afterwards I decided to do some of my own research about like how I've been feeling, what was going on inside my head…I started trying to like figure out when it started, things like that and the one thing that kept popping up was autism…So I got in touch with my doctors and they referred me to the adult autism assessment team…and I was on the waiting list for two years-ish…I had a couple of appointments with them and then they diagnosed me officially [four months later].”*

All participants similarly identified key ‘gatekeepers’ who had variously facilitated or impeded their autism referral or assessment. These included school and university counsellors, GPs , support workers and, in one case, TT therapists. While most were seen to have ‘done their best’, there was a prevailing concern among some participants that the less helpful gatekeepers simply did not know enough about autism to register that it might be in-play.

> PC2: *“[Th]ey said that I was being referred [to TT] for CBT. However, I know that normally CBT only gets six weeks and I worked with my therapist for 12 months…[and]…really she really went into the deep depths of trying to understand what my triggers were. But again, she didn't think I was autistic. She just thought that I had a lot of inbuilt stress or traumas.”*

This inferred lack of knowledge about autism among gatekeepers had also led to some unfortunate therapeutic choices. PC4 was, for example, sent for group CBT by university mental health services (for anxiety) despite already being under assessment for autism at the time, and found it to be a particularly unpleasant and isolating experience.

> PC4: *“I went to group CBT and there was lots of people who had anxiety [and] I had anxiety, but it made me feel bad because I felt like I was just way more extreme than everyone else. I felt a bit embarrassed. Like they were talking about like having panic attacks in class and stuff but for me it was like way more extreme, and I just felt a bit embarrassed. I thought it would be like useful to see how other people dealt with things, but made me feel like ‘Ohh, it*

> *must be something really wrong with me compared to what everyone else is going through'."*

Accounts were also given of how families and friends had, often (though not always) in a well-meaning way, told participants that they 'couldn't be' autistic, largely due high-functionality or effective masking:

> PC4: *"I'd been chatting with [friends], it all seemed a little bit unclear because obviously I was much older and I was a woman and it didn't maybe…I think a lot of people were a bit like 'OK, well, someone's told you to get an assessment, but I don't really know why - doesn't really make sense…you wouldn't be at university if you had autism' sort of thing."*

> PC2: *"29 years of my life where everyone just went with 'You're articulate, you can express yourself'. Like, yeah, that's cause of 29 years of training."*

> PC3: *"…my mam sort of didn't believe me and she said 'I think you've got ADHD' because I can't really sit still unless I'm hyper focused. But that is another autistic thing."*

> PC5: *"My mum is, or was, a social worker and so whenever I brought the idea of, 'I might be autistic' – 'No, no, you're not'. Slap it down. Slap it down, slap it down."*

Pre-Therapeutic Context 2: Benefits of autism diagnosis

All participants, irrespective of the degree to which they had expected their autism diagnosis, or length of time over which they had been expecting it, ultimately found its receipt to be positive on multiple levels.

> PC3: *"I wouldn't change a thing about being autistic. Some days I would. Some days I honestly would. But then when I got diagnosed, it only clicked like six months later. Like, this is what you need."*

Firstly, the diagnostic process and final diagnosis (often supported by fact-finding work) were routinely claimed to have enabled participants to make sense of their own biography in a new light, to reclaim their narrative as 'relatively normal' *for* an undiagnosed neurodivergent individual, and to understand their mental health problems in a new context.

> PC1: *"[After diagnosis] I did a lot of my own research on stuff… mostly on social media. I followed a lot of creators who were also diagnosed autistic and female, so then I could figure out their stories and how it connected with mine."*
>
> PC2: *"[Diagnosis helped me] work through what autism is within myself, so that I could learn myself better."*

Secondly, the formal diagnosis was seen to have helped greatly with social and physical contexts, particularly home and work, where the boundary-making they needed was no longer seen as an artefact of their personalities, but rather a reasonable accommodation for an autistic person. In short, it liberated them from the uncomfortable binary of either accepting unwanted proximity or being seen to be 'strange'.

> PC1: *"…having my family like understand, you know, autism and how it affects me. Having that sort of understanding that wasn't really there before because it was just sort of like 'Ah it's just [P1], she's just got some quirks'. But then they would like, keep trying to still force me to be [makes air quotes] normal. Whereas now I feel like I can sit them down and explain 'Hey, look, I really physically cannot do that. It's not the case that I won't… I really cannot do that'."*
>
> PC3: *"I do CrossFit and [after the diagnosis] they're like, 'Oh don't hug [PC3], give her a high five if she's done a good job', and I love that!"*
>
> PC3: *"I've had a lot of like 'Ohh, you don't look autistic' and I'd be like 'Yeah, I know - you don't look normal'."*

This overlaps a final issue in the participants' accounts of this matter, which was that a formal diagnosis functioned as a passport into stronger informal and formal support systems for autism itself and other attendant issues:

> PC1: *"About a week after I got diagnosed, everything shut down with COVID but after everything started reopening, I started signing up for like support groups…on social media. And I've definitely got a lot more of a support structure in place to help when things get a bit difficult…* I've made a lot of friends through the support groups that I signed up with.*"*

> PC3: “*Because of my epilepsy and I need carers - I got more help with care when I was diagnosed with autism even though my epilepsy is uncontrolled.”*

Pre-Therapeutic Context 3: TT referral

Some participants had received TT therapy prior to their autism diagnosis, and others were already diagnosed with autism at their first point of contact. Due to most participants having had multiple points of contact with TT, however, all had been referred into TT services at least once after being diagnosed.

The participants were first referred to TT for a range of co-occurring mental health conditions, with depression a constant for all, and anxiety for most. All also observed that TT services had only been first offered to them when their mental health issues had hit an acute stage, with very significant impacts on their family, social and/or working lives.

> PC2: *“[T]he screening woman that I spoke with, who picked up my referral, asked me questions that weren't to script… The question is always ‘have you thought about killing yourself in the last two weeks’ or I can't remember the exact wording, but it's very bluntly. ‘Have you thought about this?’ But she asked me have you got a plan to help you, if you want to kill yourself and I went well, what do you mean by that? Was like, well, if you got a will, have you got arrangements put in place that if you die everything will be arranged? ‘Oh god, yeah, I've had that for years! I if I cocked it today, no one would be left in the lurch. Are all of my financial assets my dog, my house? That is all pre prepared and planned for and she went ‘Yeah, that that is a sign that you're probably trying to kill yourself’.”*

While all participants’ first referral to TT was through a GP or counsellor, some participants had multiple points of contact with TT services (as noted above), with self-referral a routine feature in subsequently. At their first point of contact post-diagnosis of autism, however, participants noted that autism itself was a key consideration within Talking Therapies:

> P1: *“[T]hey just turned around and said, ‘Well, we can't help with that [autism] because we're not trained in that, and the only thing I can help you with is anxiety and depression’.”*

Given the aforementioned degree to which an autism diagnosis had helped them contextualise and make sense of their own mental health, this was found to be a point of particular confusion and highlighted potential challenges in different expectations of autistic people and clinicians in Talking Therapies.

Therapeutic Relationship 1: Autism salience

Following directly from the observations above relating to referral/admission into TT services, the participants highlighted how during their direct therapy (of any kind), the salience of their autism in their lives and mental health seemed to go largely unrecognised - therefore largely unaccommodated - by their therapists, at least at first.

This manifested in three strongly overlapping ways. Firstly, autism was sometimes not picked-up as relevant to the therapeutic context, which meant that the participants felt it was functionally ignored. Secondly, autism was acknowledged, but not as relevant to the mental health condition(s) for which the participant was receiving therapy. Finally, a relationship between mental health issues and autism was acknowledged, but the therapist seemed to have limited knowledge/training around what that might be or how to handle the matter in practice.

> P5: *"The person that I was working with was young and she was blank faced, confused, most of the time. She started off with the 'We don't work with autistic people'."*

Therapeutic Relationship 2: Tricky therapeutic interaction

Following from the previous subtheme, participants were clear that their therapists seemed not only under-trained about the facts of autism and autistic people's experience of mental health but also about how autism might impact upon the interpersonal, therapeutic domain itself. Again, irrespective of the therapeutic technique being applied, which was usually CBT in the first instance (see below), participants viewed their therapists as struggling to adapt to their specific needs from the outset. This manifested in a range of actions, such as assuming shared understandings, using abstractions rather than anchoring the discussion to concrete examples or using 'set' and often inflexible questions with a pace that was difficult to follow.

> PC1: *“[T]here's a lot of times where I've gone in and they've just mentioned something as if I'm supposed to know what it was, and just understand it. So [I needed] an explanation of how something worked or what they meant by certain things that they've said…Sometimes it's a mixture of medical jargon and I've just not understood what it was, and sometimes it was a case of where they’ve described something, and I've not understood.”*
>
> PC2: *“[T]he initial appointments were hard but that's because she was working on the script, because that's what she's told and trained to do, and that's what they get assessed against of ‘Did you work through this, this, this?’… Me, being me, I was very open about ‘So why are you asking me these questions in this order? Because they don't make sense!’…the script isn't made for how my brain works.”*

Note that these matters are also further addressed in terms of the adaptations made by therapists later in this analysis. The therapists were (on the whole) not seen as inherently ‘to blame’ for these problems, however. Rather, these issues were universally viewed as a service challenge, in terms of a lack of training and inflexible treatment offers. Indeed, some participants voiced active sympathy for therapists who were clearly trying their best. This did little to generate confidence in the therapy itself, particularly where participants felt they needed to educate their therapist (rather than it being viewed as a collaborative approach).

> PC4: *“A lot of times it would be like maybe the therapist has had, like, one session on autism and now they have a lot of questions, so then they're asking me for things or saying like so is this how you say it? Or ‘So this would be a special interest, would it be?’ and it just felt a little bit…strange.”*

As also addressed later in this analysis, however, all therapists were ultimately seen to continually strive to adapt, often successfully over time, and were consequently well-liked by the participants.

Therapeutic Relationship 3: Positive interactional latencies

While, for a variety of reasons explored in this analysis, participants voiced frequent scepticism regarding the efficacy of much of the therapy they received for handling co-occurring mental health conditions, all were nevertheless positive about (a) their therapists (ultimately), and (b) the provision of a ‘safe space’ in which to talk about their mental health. This was considered rather better than nothing at all, which is broadly what they would have received unless prepared/able to pay for private therapy.

> PC4: *“[T]he person I got, she was very nice and sometimes with these things like which you maybe don't get as much of in the NHS, it's about like if you get on with the person, sometimes just a person level and I felt like she was… I really liked her and thought like ‘Ah, I'm really lucky’.”*

In these terms, and particularly when TT therapists were able to offer more flexibility about how they delivered treatment, the sessions were also described as providing an opportunity to articulate everyday challenges and talk-through difficult events.

> PC2: *“[The therapist] just enabled the conversation to go wherever my brain was going at the time, so it meant that I was actually much more engaged with what we were talking about because I could just go with this … we went wherever the conversation ended up. But then we talked about lots within the 45 minutes appointments.”*

> PC4: *“I think it was useful knowing there was someone who I could go to about things that were happening to me because there isn't really that to go to and we did do some exercises together like drawing circles round, like who's in where and stuff.”*

Rigidity and Quantification 1: Outcome measuring

An overwhelmingly negative aspect of participant experience in TT related to the manner by which therapeutic progress and outcomes were measured using quantitative instruments (the PHQ-9 and GAD-7 are standard, though these were not explicitly named by participants). Some of the participants explicitly articulated a struggle to conceptualise their feelings in numerical terms at all:

> PC1: *“And it was basically a piece of paper with a bunch of different questions with on a scale…Do you feel depressed? Do you feel anxious? Have you had suicidal thoughts? Stuff like that. And then they have, like, scores based on*

> *those answers, but the problem is I really struggle to quantitate my feelings, so I've never really known what to put on those answers.”*
>
> PC1: *“I ended up just putting what I thought they were expecting me to put…because I felt like that was just easier. And I knew what they wanted me to put because I could remember what I put the week before, and I could remember what I put the week before that. And then I would just think, alright, so this week I am like 0.5 points better, so I'll put [motions filling in] that there and I'll put this there and I'll put that there.”*

While this problematised the sense of the instruments in practice, some of the participants were more transparently concerned about the potential impacts on their place within the service if they were seen to improve too much or too little on these scales. This, in itself, could become a source of anxiety which may be present for other people who are not autistic.

Consequently, the same participant attempted to manipulate scores to represent sufficient improvement to remain with their therapist, who was well-liked.

> PC4: *“I want to [show] it was useful, but it was not… it felt like probably…the bare minimum that I needed…I think I wanted to be able to keep putting that I was getting better because I was maybe worried. I was probably worried…they would do what they did last time and stop [the therapy] again because I was too sick or something.”*

Conversely, another purposely over-scored their progress exactly in order to be discharged, after deciding that the Cognitive Behaviour Therapy (CBT) with which they were being provided was ineffective.

> PC1: *“I was discharged early because I kind of fudged the questionnaire numbers…and basically, because I felt like the CBT wasn't even doing anything, I just gave them the answers that they were looking for rather than what I was actually feeling.”*

Rigidity and Quantification 2: Over-structured encounters and CBT

Following from the above, the manner in which TT therapists took a highly-structured approach to direct interaction with clients was universally criticised by participants as not sufficiently autism informed and so was perceived as inappropriate and alienating.

> PC2: *"I think CBT is the kind of go to, you know, a lot of it is the default, everyone ends up having it."*

All of the participants who could name the therapies they had received had undergone at least one programme of CBT, and they had not found it helped them in the way it was supposed to.

> PC3: *"I would go every 2 week and always have to fill out a form on my feelings, it was a 30-minute session and I just got handed leaflets all the time."*

> PC4: *"I have done CBT before and usually it seems not very applicable."*

Participants did not always find it easy to explain why CBT didn't make sense to them in this respect, but typically the problems were rooted in a rigid and scripted approach.

> PC1: *"[I]n CBT it's a case of they've almost got like a checklist to work down. It's like, 'OK, we've discussed this with thing, we've discussed that thing, we've discussed…' and I felt like we weren't allowed to discuss anything outside of these checklist items."*

While some saw the overall structure and predictability of CBT as attractive, participants viewed the prescribed structure as having a negative impact upon participants' available time to think, explain or express ideas, and to restrict the modes of available expression to right-now verbalisation.

> PC1: *"[A]utistic people do tend to just sort of … if someone will say something [unclear], we'll just agree. Because we don't know how else to describe it. So, we'll just agree, which isn't always what we need."*

> PC2: *"A lot of people who are autistic…they don't know how to get the words out. They don't know that these words even exist to be able to explain how they're feeling. So just because someone goes 'No', that that doesn't work because they don't know how to explain why it doesn't work, so it's not just… because I've had a couple of friends get dropkicked by the service because they were just classed as 'argumentative' and 'unwilling to participate'…And it was not that they were unwilling to participate - they don't know how. They*

> *don't know how to tell you…why it doesn't work, so it's again, it's working off-script and trying to help the person find the words that they need, because if you don't understand why it's not working, nothing will ever work."*

Training and Adaptation 1: Broad training

As briefly described above, a pervasive concern among all participants was that their TT therapist had apparently received little or no training relating to autism itself, its relationship with mental health or how it might impact upon therapy. Participants advanced a number of suggestions about the particular kinds of training that might help in the future, with some broad-stroke areas emerging. The first of these related to developing understanding of the links between autism and mental health,

> PC1: *"I think one of the most important things is understanding what autism is and like even just having a very general overview of what it is and how it can affect a person and because so much mental health is related to autism for autistic people. So, understanding like autism could be causing these feelings rather than it just being the depression or just being anxiety would help people be able to put things into context as well."*

This was noted to require a greater understanding that autistic people might experience the physical environment differently to other clients:

> PC3: *"I think for me massively is know… ask what they're sort of sensitive to like bright lights. If there's a flickering light bulb in room, you won't get me sitting there…That's another thing I've got to focus on."*

The same participant also drew attention to how therapists might be trained to take better account of how an autistic person may communicate and interact (e.g. a certain 'blunt honesty' among some autistic clients).

> PC3: "*And so if you just like… if they just ask and it's more like would you like to tell someone face value how it is… I know it might seem really hard, but we are honest. There aren't many autistic people I know that aren't honest… like we are very blunt. So yeah, I'd say that and then accommodate to them."*

Training and Adaptation 2: Positive adaptations

Finally, the participants were all able to point to ways in which their TT therapists, across the course of their work together, had made constructive adaptations. While these were not always described in terms of their instrumental therapeutic utility, they were all seen to have made it easier for the client to relax and/or communicate at the very least. Firstly, using understanding checks and not pressuring the participant for ‘quick answers’ within the session were deemed to be key:

> PC1: *“She would always make sure that I understood everything. She would ask me what would like sort of help, which obviously at the time I wasn't entirely sure on, and she was also incredibly patient when I seemed to get like stuck on certain things that other people maybe wouldn't have gotten stuck on.”*

Similarly, being prepared to return to and rephrase questions where necessary, rather than simply ‘sticking to script’ was seen as immensely useful:

> *PC2: “She did her best and anything that was clearly not…. Anything she asked me and I didn’t give the answer that she was expecting, she’d then go back and reframe the question.”*

Participants reported that treating autism and mental health as inextricably interlinked things for an autistic client, in practical terms, rather than separate abstract entities, would be helpful:

> PC1: *“[S]he did always try and tie things back into the autism. So, while she wasn't trained in that, she did have a good enough grasp of what autism was…and actually like listened when I tried to explain my experiences with it. So then try and like tie in the obviously the behavioural therapy, homework tasks to the autism as well as the depression and the anxiety.”*

Thematic analysis of Talking Therapies clinicians working with autistic people

Thematic analysis of the interviews with TT therapists yielded four global themes: (a schematic diagram is included in the Appendix)

1. Experience and Trepidation
2. Service incompatibilities with autism
3. Therapeutic Environment
4. Training and Adaptations

These are outline/d in greater depth below, with reference to direct data where illustrative, and particularly where variable interpretations of the same ostensive phenomenon are at stake. Headings are organised around major subthemes.

Experience and Trepidation 1: Perceived failings in the past

Underpinning all of the participants' accounts of working with autistic clients was a concern with 'past failings'. Largely attributed to a lack of autism-specific training leaving distinct gaps in their substantive knowledge and therapeutic skills, participants identified cases where they had either not helped, or even made a client's situation worse. This related to incidences where undiagnosed (or undisclosed) autism had not been recognised at all:

> *PT2: "I've had autistic clients in the past [and] haven't served their needs particularly well when they haven't said it out loud. I haven't picked it up."*

It also related to cases where the client was known to be autistic, but the participant struggled to help them with their specific mental health problem(s):

> *PT8: "[There] was one that I think I particularly failed…he had been diagnosed with autism. He was extremely serious in this presentation, was very serious. He'd come with all his notes. He was very, very sort of organised, lovely guy, but…I just never felt he got off the ground. I didn't know what I was doing. I didn't feel as though I made any change."*

For all participants, a history of such problems emerging when working with autistic clients was viewed as something of a double-edged sword. On the one hand, most admitted to a sustained trepidation (sometimes outright anxiety) when beginning this order of work.

> *PT3: "[T]hat's the worry…the potential that maybe we could do more damage than good, and obviously that never feels good when that's your practise."*

Conversely, in the absence of effective training, trial and error was viewed as having been a 'necessary evil' in learning important adaptations.

> *PT2: "So, in that case…well I have learned from it, but I don't think my expectations were realistic at that time. I was setting [the client] up to fail in some ways, and…encouraging her to put herself in situations that would be stressful for her with the intention of helping with her depression."*

Generally, however, it was seen as the case that it was much easier to work with autistic clients when the autism diagnosis was well-established with the client:

> *P10: "[T]he person I'm working with at the moment, who's had the diagnosis for a few years, I'm finding it easier to work with him…he's aware of it and kind of has acknowledged it and understands it quite well. And so that's allowed us to kind of manage you know, his autism in the sessions quite proactively."*

Experience and Trepidation 2: Experienced obstacles

When unpicking the issues that had coloured their experiences of working with autistic clients, and/or were a source of apprehension about doing so in the future, participants articulated three core/general concerns. The first was that autism has a wide variety of complex presentations, and adaptations learned from trial/error with one autistic client will not necessarily be transferrable to another.

> *PT1: "[O]ne person with autism is probably different to every other person. They'll be similar, they'll be similarities within it. But then, a lot of difference from the same and the same level as well."*

The second concern related to atypical emotional responses, including inferred 'distress intolerance', that proved difficult to read or predict.

> *PT5: "[S]o, on the one hand, [the client] is saying, I don't think it's a problem. I've dealt with this, and then she's very distressed. So I was very confused thinking 'Okay clearly there is…something here'…. I constantly felt wrong-footed with her emotional responses which were different to the words she was saying."*

Finally, and closely linked to emotional expression, some participants had found the interpersonal/communicative manner of some autistic clients challenging to comprehend, particularly around establishing 'what the problem is' prior to any therapy even beginning:

> *PT6: "[I'm] thinking 'I'm really struggling to understand what you're telling me'. Like they're literally speaking a different language to me...Sometimes I'm feeling baffled and they're probably feeling baffled and confused, and it just feels like there's a pane of glass between us and, and we're really, really struggling and that's quite frustrating for both of us."*
>
> *PT10: "I guess it's the communication thing, isn't it? Being able to describe what the problem is, which I think can be quite difficult for [for autistic clients] sometimes."*

Service incompatibilities with autism 1: Adapting the model

A major concern endemic to all participants' accounts related to the structural organisation of TT services and the current challenges they with suitability, for autistic individuals experiencing mental health conditions s, and the consequences thereof for therapist and client.

Under these circumstances, many established therapeutic assumptions regarding what will likely prove beneficial for an individual could be difficult to apply when working with autistic people without sufficient adaptation.

> *PT8: "The assumption that this [autistic] person needs to be out in the world doing things with other people, that assumption from me was unhelpful for them, I think."*

Nowhere did participants more keenly articulated this than with respect to social anxiety, which was widely seen as particularly difficult to separate from autism itself.

> *PT5: “[Something] I find quite challenging is sometimes…understanding where autism stops and social anxiety starts, so this sense of being different and not being able to read situations and therefore not being able to predict people's responses. So social situations feel very stressful.”*

> *PT3: “[One client] will sit quite small, and sometimes that is part of social anxiety and sometimes that's related to, I guess, the autism. [What] she talks about is feeling often overstimulated and worried about what people think of her in a social situation, it's really difficult as a therapist to pull apart to a certain extent, to know which bit we're treating and also to know from a kind of conceptualization type whether the patient would even know the difference and whether that [even] matters.”*

A further key concern around the core nature of the TT services, and their capacity to help autistic clients, stemmed from the very manner by which ‘progress’ and outcomes are measured from session to session, i.e., by ‘moving the numbers’ on statistical instruments such as the PHQ-9 and GAD-7. The therapies used were seen to broadly have less statistical impact in this respect with autistic clients, either because the service itself was not always able to provide therapy in the context of autism or (as addressed below) the use of the instruments themselves was challenging for autistic people. Ultimately, however, it was generally surmised by participants that TT was providing a valuable service, even in the context of potential challenges of actively helping autistic clients’ mental health in a measurable way.

> *PT2: “Some clients just needed a safe space to explore the way that they feel.”*

> *PT10: “That was an important part of the sessions for her, just talking about how it felt to be her. Probably more of that than CBT, to be honest in those sessions.”*

Perhaps more importantly, TT was seen as valuable because there were simply no other available services

> *PT6: “I do think some of this work is sounding…more long term, with TT being required to somehow take the strain because there's no other service taking the strain for supporting people with autism.”*

> *PT9: “[I]t's very easy to say discharge and signpost, but then we can't get through to the service that they need, or you know [it’s] not available in their area.”*

Service incompatibilities with autism 2: measures

Regarding the aforementioned use of measures of therapeutic progress/outcomes, participants did typically voice faith in their overall efficacy. Regarding autistic clients, however, there were key reservations about how well they could reflect what might appear as visible progress to a therapist. The first concerned an often-encountered resistance to reducing experience to numbers, and particularly the use of ‘small’ 0-3 scales such as those in the PHQ-9 and the GAD-7.

> *PT5: “A lot of autistic people say they hate [the questionnaires] because you've got to pick a zero, one or two or three, and they're like, ‘But I'm in between, I don't understand’.”*
>
> *PT8: “It just felt too hard for [the autistic client] to categorise himself within that spectrum of numbers. So, I think I've had extremes [reported].”*
>
> *PT12: “[Autistic] clients have said…’If you give me a scale of one to ten, I need to know what one means, what, what 2 means, what 3 means 4,5,6. Because if you give me that [but] you don't explain to me what that actually means, I'm not gonna have a clue. I'm gonna feel so overwhelmed by it.’…If you're not that explicit, then I think people just tick a box and it doesn't really mean anything. It's pointless.”*

Service incompatibilities with autism 3: Time - ‘Slow down to speed up’

Perhaps the most ‘structural’ aspect of the TT service that participants identified as obstructing effective work with autistic clients was time within the system itself, which impacted practice in a number of ways.

Therein, autistic clients were seen to benefit most when they could take stock and answer questions without feeling rushed. TT structures rarely permit these things to be fully realised, however, given direct contact time available, and the kinds of therapies used, which are typically highly structured and time limited.

> *PT12: "We're seeing more and more people with autism [and] they require longer sessions."*
>
> *PT8: "…with TT, I think that it's quite a rigid like 50 minutes…I think that gets in the way sometimes. Well, it does a lot for me, you know, I do feel that those quality of the sessions is for me…hampered by, you know, stack them high… there's flex [in the system], but I think but flex requires prep, and prep requires time."*

Most participants viewed time to be a particular problem when conducting (usually telephone-based) assessments in general, given a 30-minute allocation for each.

> *PT12: "When you do the…training there's a full module on how to assess people in TT, and you're encouraged to do Socratic questioning, but we all know that we don't really have that much time to do that properly when assessments are half an hour."*

While some participants maintained that these problems were magnified with autistic clients, others argued that the opposite might be the case:

> *PT1: "It's not a very long assessment and it just does what it does to look at what the symptoms are at the time and allocate…Probably because it's simple and straightforward, it might be helpful for autistic people."*

On the matter of available time for reflection, consolidation and preparation, however, there was a great deal more unanimity among participants.

> *PT10: "I think there's not nearly enough time for reflection in TT. We're probably working with more complex people than we were intended to be working with, and I think they all take time to reflect and prepare for."*

Therapeutic Environment 1: Remote interactions and physical spaces

A key issue raised by some participants, and one relating to both assessment and therapy, was that their autistic clients tended to favour face-to-face interaction to virtual spaces, and virtual spaces to using the telephone.

> *PT11: "When I've had [assessments] through for people who have been autistic, [they] will ask for face to face. So, I've done some face-to-face assessments because they preferred them to being over the phone."*

In line with prior observations regarding the variability of presentations in autism, participants had also worked with a few clients for whom the exact opposite was true.

> *PT2: "…working with [an autistic client] on the phone rather than face-to-face…was helpful for that particular person because they struggled with the face-to-face interaction."*

The latter raised few structural problems within TT itself, although participants cited the general lack of nonverbal cues when using the telephone as a therapeutic obstacle by some. The latter, however, created some distinctive obstacles. Firstly, and somewhat inevitably, scheduling and organising face-to-face work was more inherently time-consuming within an already time-pressured system (see above).

> *PT1: "[A client] that I assessed the other week, she ended up having to wait longer to be seen face-to-face…because it's harder to [get] assessment slots into someone's face-to-face treatment diary…everyone's out of the habit of booking [and] we have so little face-to-face time."*

Secondly, some participants maintained that autistic clients could particularly benefit from the presence of family members or other sources of support during assessments or therapy.

> *PT2: "if we know that [a client is] autistic to start with, we could think about making reasonable adjustments at that point…we might think about…a face-to-face assessment…or having somebody else present."*

Although this presence was ultimately taken to be of variable therapeutic benefit, largely on a case-by-case basis, scheduling issues inevitably become yet more complex when additional attendees are required at a face-to-face appointment.

The final problem raised by participants around face-to-face work with autistic clients related to the physical spaces in which the therapy itself was available. These were, in some cases, viewed to be particularly unsuitable (even unpleasant) for individuals highly sensitive to the vagaries of their immediate environment.

> *PT10: “You work in some terrible places, and…I think ‘Oh my God, this is horrible’. You know, people just kind of don't seem to notice. But I think for autistic people it’s a bigger issue.”*

Therapeutic Environment 2: Therapeutic techniques

Discussions of therapeutic technique were dominated by concerns around the how to make CBT effective for autistic clients. Not all participants said this; however, with some participants identifying autistic clients for whom CBT had indeed worked well.

> *PT7: “I'm thinking of this particular person who engaged extremely well. I think some of his autistic characteristics actually made him do better with the therapy. He attended every time, he attended bang on. If I asked him to do something, he did it and…those are the main things you need to do well with the CBT-based approach, in my view.”*
>
> *PT4: “I think you can…go wrong with the application of CBT…you need a practitioner who has an awareness and understanding that there may be differences in lateral thinking and processing as well as context blindness.”*

Ultimately, however, there was a generally held concern that any approach which tried to ‘restructure’ the way that an autistic client thought about the world could shake confidence and exacerbate anxieties.

> *PT7: “I suppose my greatest fear is making the [client] feel worse than [they] did in the first place…[C]ognitive restructuring, I’m now realising, is the one I feel on very shaky ground [with] and actually I would hesitate to engage in that intervention with someone with autism.”*

The use of psychoeducational elements in therapy were also reported to have been very productive in working with autistic patients.

> *PT5: “Often [I spend] more time around processing emotions, identifying, labelling [and] understanding there might be more time on psychoeducation than we might do with other people without autistic needs.”*
>
> *P6: “…just having that general understanding of what sort of areas might be difficult for [autistic clients] and then, importantly, taking the emphasis off ‘What’s wrong with me?’ That psychoeducation thing of ‘Well, you know, it's*

> *quite normal. You would find it hard in social situations because you have autism' and building up the strengths… Being compassionate to self and focusing on these are my strengths as someone with autism, this is what I'm really good at which other people aren't good at? That's certainly I think a good position to have."*

Training and Adaptations 1: Training benefits and deficits

As highlighted elsewhere in this analysis, there was a unanimous concern that training around autism and working with autistic clients in TT is lacking.

> *PT3: "[M]y experience was that we didn't really get the training before we got the [autistic clients] through the door. So, it was kind of, this is something I'm dealing with. And I suppose as therapists, we [were just] expected to make adaptations to kind of fit."*

Some participants did note that autism had recently become a higher priority on their own training, however, with demonstrable benefits for not only working with diagnosed autism but also recognising potentially undiagnosed cases.

> *PT2: "I've had some training recently…well two lots of training about the same time on autism, and then I don't know if I I'm seeing it more because I know about it, but I do feel like I've had at least two, four autistic people on my caseload at a given time over the last year or two. So I think generally speaking, the diagnosis itself is getting wider and perhaps there is more awareness than there was before, but me having done this training and having more awareness meant that I wasn't just seeing people who…had a diagnosis as being autistic, but I was also able to identify people who might be autistic, and then go through the questions to think about whether that was a meaningful label for them."*

Among the participants for whom autism training was still seen to have been minimal, it was particularly the 'unknown unknown' aspects of autism – knowing where to even begin - that most eroded their professional confidence:

> *P6: "I think most, many therapists know, myself included, we don't have a clue. You know, we don't have a clue what to do, where to start. It can be*

> *quite anxiety provoking…[if] autistic people are gonna end up in TT services, cause there's no other autism-specific service, then…actual training would be good."*

In terms of 'known unknowns', meanwhile, the areas in which participants specifically understood that they needed improved knowledge and skills for practice, consensus coalesced chiefly around interpersonal communication techniques, ad-hoc adaptation skills and how to separate mental health conditions (not least social anxiety) from autism itself.

> *PT3: "I feel the training that would be more suitable would be about how to deliver CBT or IPT to somebody who either believes they're autistic or has that diagnosis and how that differs."*

> *PT8: "I'm very careful about the language and whether…this spectrum is severe or not…and the more severe the symptoms, the more lack of confidence I have in doing it right or doing anything you know, sometimes I feel as though I just struggle to get the conversation going and I'm not quite sure what to say or how I should get things moving so I think."*

> *PT10: "…having a bit more of a framework to think about in terms of…timings, ways of working, what help, what might not be so helpful. Ways of wording things. Because I think I probably use quite a lot of metaphor, which is probably confusing [for autistic clients], isn't it? So yes…I would love to do some more training on [this]."*

Training and Adaptations 2: Experiential adaptations

While the quality and quantity of direct training within TT was viewed largely negatively, most participants did impress that they had made adaptations successfully with autistic clients, largely through aggregated experience over time and independent research, often augmented by trial-and-error.

> *PT6: "I'm certainly a lot more confident than I was and I think that probably, certainly within TT, I've probably now enough of a sense of what's helpful and how to do things, and also I have got access to some resources both from*

> *CPD and from my own interest in autism…after having worked since 2016. So that's what, seven years?"*

The first order of adaptation routinely described related to maintaining a focus on clients' own concrete concerns and breaking questions down into smaller components. For example:

> *PT9: "[I] look at the language I'm using... It's very easy to say I would, but the reality…when you're actually doing it is harder. But trying to keep it fairly concrete, you know?"*
>
> *PT12: "[I]t was about, you know, breaking that [question] down. So, what is it about cleaning the teeth that is really difficult?...Is it the smell? Is it the taste? Is it the touch? Is it the, you know, the sensation having the toothbrush in? Is it the sensation of the toothbrush? Is it other idea having something in your mouth?"*

Also relevant to the previously discussed issue of psychoeducation, a second order of adaptation commonly described was the normalising and/or validating of autism itself during discussions about other things, and using understanding-checks to avoid misplaced assumption.

> *PT5: "[I]f you've got somebody in the room who thinks in a very, very different way to you it's even more important to keep checking…that you're on the same wavelength."*

The third order of adaptation related to carefully monitoring the autistic client's interactions with the physical environment, and then making constructive changes ad-hoc.

> *PT2: "[A client] that I worked with and had a sensitivity to the light being on, the bright sort of regular office light that you have on and we had the lamp, so we turned off the big light to put on the lamp and that was a reasonable adjustment to support the needs that they had…so, you know, there might be some relatively simple things that we can do that's gonna meet the needs of that person…make adaptations just to make sure that they can engage in the process, really."*

Finally, and centrally, there was a broad consensus among the participants that while training in the past had not been of great use to them (certainly over the longer term) in terms of helping them make adaptations, TT supervisors had been a strong and supportive resource, in some cases being trusted to find additional resource in the system where it would most benefit a client.

> *PT3: "I don't know if this is TT or if this is my service [but] if I went to my supervisor and said, 'You know, I've identified that I'm working with somebody who either identifies as potentially having autism or has the diagnosis, and what we've agreed is that actually more time or an extra session or more frequently or a longer session', I'm pretty confident that…they would say 'Yeah, absolutely. Let's, let's meet that need'."*

It was concurrently observed, however, that supervisors within TT were themselves often under-trained regarding autism.

> *PT7: "…the difficulty can be that I think sometimes the supervisors don't feel entirely confident and as highly trained as they might like to be in autism, what it is and how to work with it."*

Finally, the value of group supervision was raised as a potential augmentation to current practice, in terms of helping learn about challenging issues such as autism.

> *PT8: "[T]hings like group supervision might be good, you know, because obviously we have individual supervision, [but] group supervision, where you can bring a case and you can discuss it and people can understand together, you know…what you did right, what you did until what happened, you improve it and exposure to that would probably be really good for therapists and for us all to learn more."*

Training needs survey descriptive analysis

There were 31 participants from NHS Talking Therapies who responded to the training needs survey. The demographics are in Table 1.

Table 1: Training needs survey demographics

Gender	
- Female	27
- Male	3
- Prefer not to say	1
Age	46 years 4 months (mean); 26 years 9 months - 62 years 5 months (range)
Times worked in NHS Talking Therapies	8 years 2 months (mean); 1 year 6 months – 14 years (range)
Time worked in mental health	14 years 2 months (mean); 4 years – 32 years (range)
Profession	
- High intensity CBT therapist/clinical psychologist	15
- Psychological wellbeing practitioner	5
- Counsellor	6
- Trainee high intensity CBT therapist	4
- Primary care mental health worker	1

The participants reported that about half (n=17; 54%) were aware that a client was autistic before they assessed them for the first time. A third (n=10; 32%) reported assessing autistic clients over more appointments than would be typical and half reported treating autistic clients for more appointments than would be typical (n=17; 54%). 18 (58%) reported that they felt they had worse outcomes for autistic clients. 26 (84%) reported they did not have access to appropriate (i.e. specific to mental health) autism awareness training and nobody reported that they had access to supervision in relation to autism. Most respondents (n=25; 81%) noted barriers to accessing talking therapies for autistic people. Of these, the most commonly reported barrier was a lack of clinical knowledge about autism (n=23; 75%). Other common barriers reported included: interpersonal communication differences (n-21); autistic clients having difficulty identifying their own emotional states (n=21); communication preferences to not use the telephone (n=13); sensory differences (n=10). Respondents also reported that:

- as clinicians they didn't always know what reasonable adjustments should be offered or that it was sometimes difficult to provide reasonable adjustments (e.g. fixed lighting in a waiting area);
- sometimes the pace of talking therapies sessions was too quick;
- there were difficulties providing talking therapies in the usual way (e.g. difficulty challenging thoughts; difficulty engaging in new interventions that raise arousal);
- existing measures/questionnaires could be overwhelming and it was not always clear how assessments could be adapted with autistic people in mind.
- they had been asked to make reasonable adjustments and that these were met where possible (e.g. changes to length, timing and location of appointments; changing written resources such simplifying self-help resources to be less wordy, more visual prompts and written progress plans; video calls rather than telephone; allowing more time for processing information/checking understanding; meeting sensory needs such as quitter environments and using fidget toys; reducing eye contact).

Nearly all participants (n=30; 97%) said that they worked with people waiting for an autism assessment whilst they were accessing Talking Therapies and of these 23 (77%) said they would take the same approach as if the clients had an autism diagnosis. Over half said they would like training on areas of practice such as identifying therapeutic approaches that would be effective for an autistic client, how to structure sessions, adapt communication and help an autistic client to understand their own emotional states better.

Service redesign

A project group was set up with members of an NHS TT service) including clinicians and administrative staff alongside autistic people and clinical academics. The aim was to consider how to identify, at as early a stage possible, whether a client accessing the service was autistic or waiting for an autism assessment. It was agreed that all Hub staff within the service (initial administrative assessment point within the service) would ask patients "I*s there anything else we need to know ahead of your assessment such as significant health issues or autism for instance*?'. If the patient answers positively the 'Autism' label can be put on as a Referral Label by the Hub staff. The label can also be added by practitioners (in assessment or treatment). Hub staff were also asked to tick the Autism box under Long Term Conditions and add a non-clinical notes when the label is added. Within the assessment, staff also documented the impact of autism including how it appears to impact on the presenting mental health condition and any things the practitioners might need to consider when working with the client. There would then be an opportunity to offer the client computerised CBT, telephone, online video and face-to-face when appropriate and documents their wishes.

The new process was introduced in June 2023 following this training. After three months, 57 clients were identified as autistic out of 1207 clients accessing the service for the first time (4.7%). Of these, the mean age was 31 years (range 18 – 66 years) and there were 31 (59%) females and 17 (32%) males. Whilst this is initial data it is in line with the gender split within national NHS Talking Therapies data for the general population (Psychological Therapies, Annual report on the use of TT services, 2021-22 - NHS Digital) and the mean age of people accessing NHS Talking Therapies is 40 years (Socio-demographic differences in use of Improving Access to Psychological Therapies services, England - Office for National Statistics (ons.gov.uk))

Training evaluation quantitative analysis

A two hour online training course was developed which included an outline of this process alongside initial autism awareness and principles of reasonable adjustments and adaptations to talking therapies on the basis of the interview and survey feedback and delivered to all staff within the NHS TT service. An evaluation questionnaire was developed and given to staff participating in the training before, immediately after and three months after the training. 45 staff completed the measure before and immediately after and 17 completed at follow up as well. The comparisons of the two scales from pre to post training are shown in table 2. The data are analysed using paired sample t tests. In response to the item 'The training was engaging and relevant to my job', nine (13%) respondents replied 'neither agree nor disagree', 27 (39.1%) replied 'agree' and 11 (15.9) replied 'strongly agree'.

Table 2: Comparison of pre- and post-training confidence and therapeutic efficacy scores

	N	Mean	Std Deviation	Mean Difference	SD	t	significance
Confidence-Pre	45	36.13	9.32	9.91	6.41	10.30	<0.001
Confidence-Post	45	46.04	8.30				
Efficacy-Pre	45	17.33	3.01	1.33	1.96	4.55	<0.001
Efficacy-Post	45	18.67	3.17				

At 3 months post training participants answered the question 'I have applied what I have learned during training' one person (5%) replied, 'disagree' five (25%) replied 'neither agree nor disagree', 11 (55%) replied 'agree' and three (15%) replied 'strongly agree'.

Table 3 shows the responses for those people who completed questionnaires for all three time points, the data are analysed using repeated measures ANOVA. Figures 1 and 2 show a positive profile, with confidence and efficacy scores increasing significantly from pre to post training and the levels of confidence and efficacy maintaining to the 3-month assessment.

Table 3 Comparison of pre- and post-training confidence and therapeutic efficacy scores

	N	Mean	Std Deviation	Mean Square	df	F	significance
Confidence-Pre	16	37.00	10.11	684.10	2	35.47	<0.001
Confidence-Post	16	48.62	7.98				
Confidence 3 months	16	48.00	7.60				
Efficacy-Pre	17	16.65	2.94	21.08	2	15.38	<0.001
Efficacy-Post	17	18.41	2.81				
Efficacy 3 months	17	18.71	2.57				

Figure 1: Mean scores for confidence at pre- post and 3 months from training

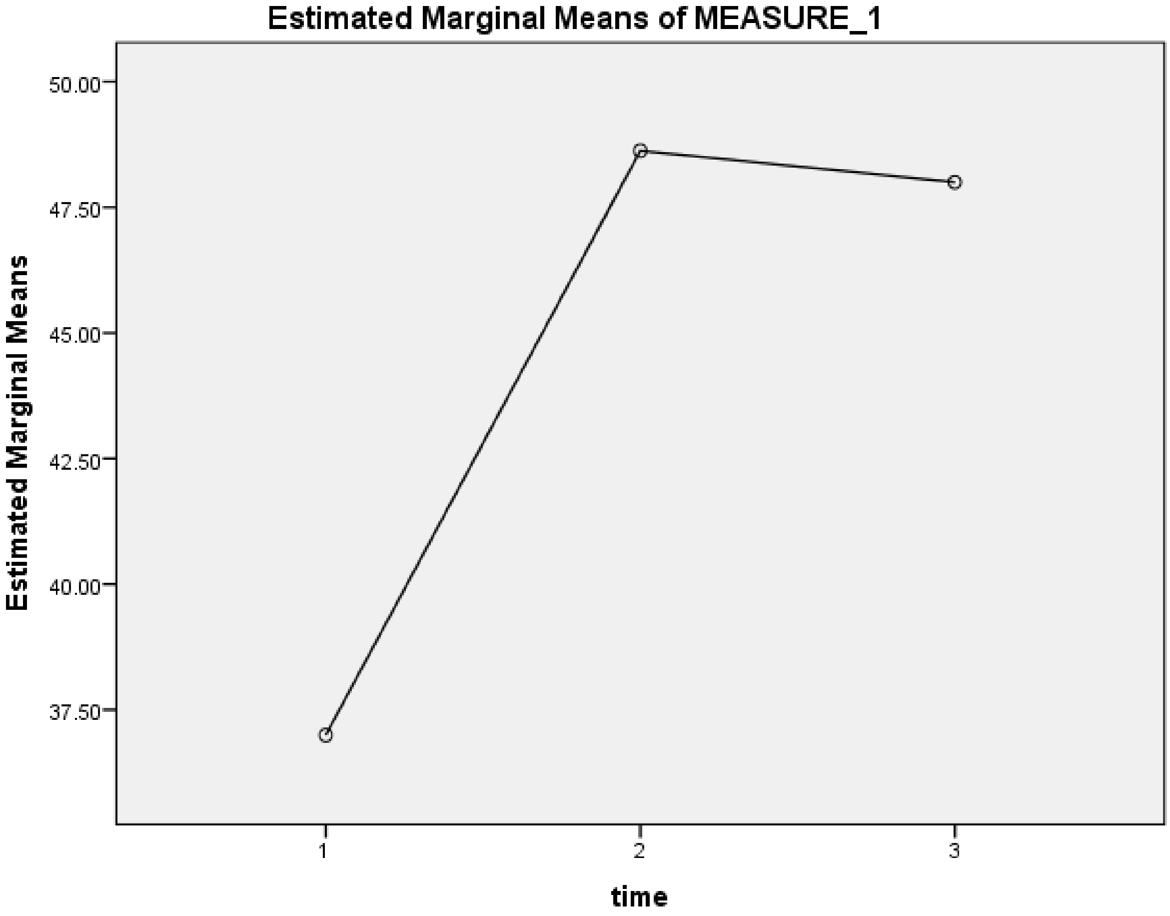
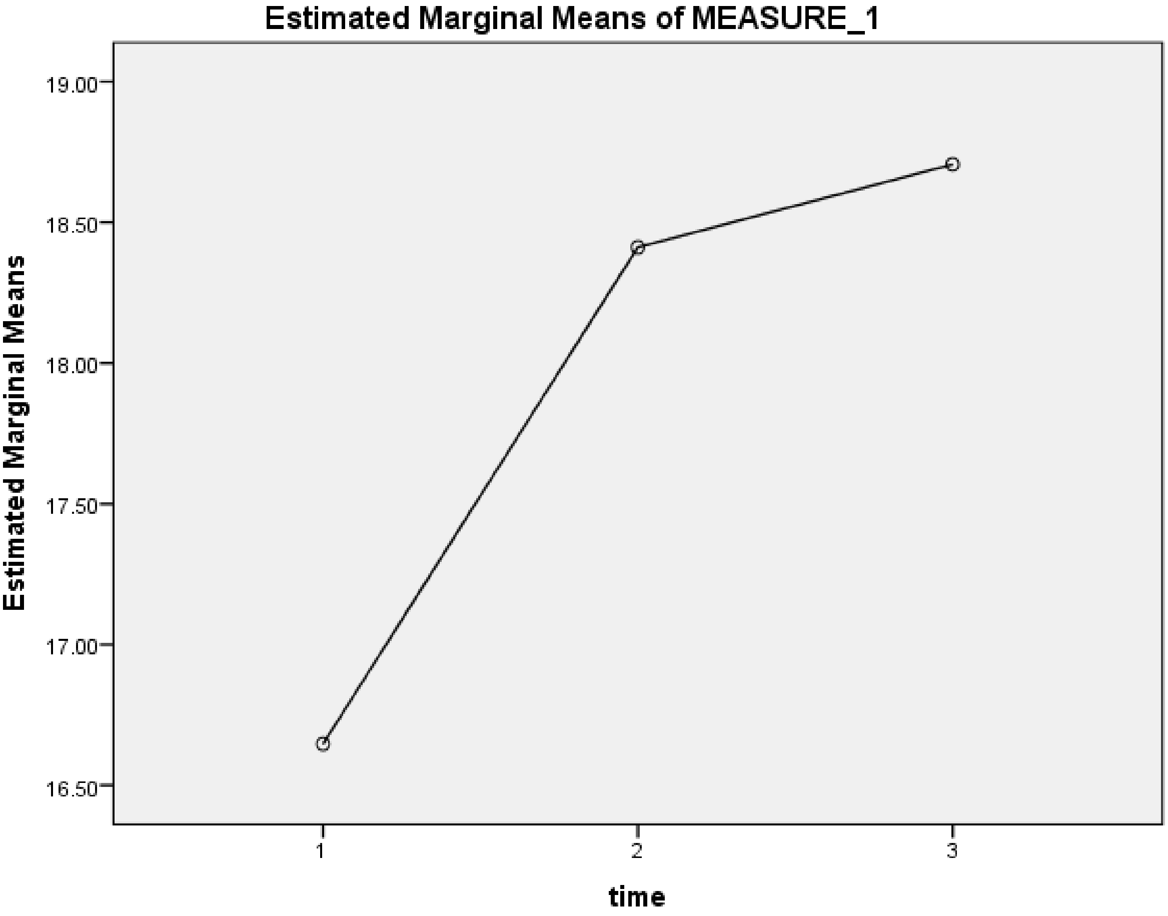


Figure 2: Mean scores for efficacy at pre- post and 3 months from training


Estimated Marginal Means of MEASURE_1
Estimated Marginal Means
19.00
18.50
18.00
17.50
17.00
16.50
1
2
3
time

Summary of findings

Autistic people are more likely to experience mental health conditions and are more likely to experience barriers to accessing healthcare (Mason et al., 2019). This project aimed to explore and improve the experience of autistic people (and people who may be waiting for an autism assessment) when accessing NHS Talking Therapies services (formerly known as Improving Access to Psychological Therapies). In doing this, we aimed to explore the views of autistic people and clinicians supporting autistic people and understand some of the ways that we can both identify autistic people coming into services and also help adjust/adapt services to meet their individual needs. One of the themes raised by autistic people in this project is that autism was not always well understood by clinicians and not seen as salient to how autistic people accessed services or how autism impacted upon mental health conditions (e.g. anxiety and depression). Autistic people reported how difficult this was as they had expectations that an autism diagnosis would help others to support and understand them (as their autism diagnosis had helped them to understand themselves better). However, they did appreciate the support that was available within NHS Talking Therapies and were keen to keep working with therapists they liked. Clinicians working with within NHS Talking Therapies talked in this project about some of the structural limitations with their services which provided barriers to effective access, challenges in adapting therapies to meet the needs of autistic people and limited training they had in relation to autism. Overall, the shared views of autistic people and clinicians indicated that whilst support offered from Talking Therapies was seen as potentially valuable, changes were needed to improve access and make therapies more effective for autistic people. These views helped to guide the project work undertaken with local NHS Talking Therapies to change the way in which autistic people were identified when they first accessed the service, identifying potential reasonable adjustments to help improve access and training for clinicians about how to adapt therapies within the context of autism. To support this, a training needs analysis was undertaken so that clinicians could identify gaps in their knowledge and skills related to working with autistic people (e.g. uncertainty about how to structure sessions, adapt communication and help an autistic client to understand their own emotional states better). On the basis of this, we developed a training approach that provided an initial overview of how autistic people may experience mental health conditions (e.g. how they may experience distress in social situations which may be different or happen alongside social anxiety as may be experienced in the general population). We were able to deliver this training to the whole team who responded positively and measures indicated notable increases in confidence related to working with autistic people immediately after the training (and at three month follow up). The training evaluation showed a generally positive response to the training with positive feedback on the impact of the training and positive gains in confidence in working with autistic people a small but significant increase in general therapy efficacy. Given the introductory and relatively brief training offered int this initial study this seems a very positive response. We have continued to work with a project team in the NHS Talking Therapies service looking at developing further training. We will focus this training on a more in-depth approach to understanding how autistic people experience common mental health conditions. We will also look at training with a more technical view about ways to adapt therapies for specific mental health conditions (e.g. social anxiety) in the context of autism.

Alongside the training, the project team agreed a structure and process (including a specific question staff ask at a first point of service contact) for identifying autistic people at an early point of accessing the service. In the three months following implementation of this structure, the service identified approximately 5% of people in this way and they would subsequently have a flag within the system for clinicians to then think about adjustments needed according to that individual's needs (supported by the use of some brief documents that help to identify potential adjustments). This is higher than the prevalence of autism (approximately 1%, Brugha et al, 2011); however, as autistic people are more likely to experience mental health conditions then we would expect there to be an over representation of autistic people in NHS Talking Therapies. There is a higher proportion of females to males in this group which is consistent with the demographics for NHS Talking Therapies in general but is contrary to the gender prevalence in autism where there are more males than females (Brugha et al., 2011). However, in surveys involving autistic people accessing healthcare we have found a broadly even split between male and females (Brice et al, 2021). As such, this may be representative of the numbers/demographics of autistic people accessing NHS Talking Therapies. Further data collection will help to confirm this and the project team will continue to review this. The protocol for identifying autistic people (and other people with similar needs) can be shared and we have had some initial discussions about how this can be done (including with colleagues form the NHS England Autism Programme team who have asked if they can use this wider). Whilst the identification of people is positive, it has not been within the scope of this project to explore whether they received adjustments/adapted therapies and the impact this has had upon outcomes. We plan to use the positive findings from this project to explore this further through a larger National Institute of Health Research funded project. We are in the process of pulling together a bid for a specific Learning Disability/Autism call from the Health & Social Care Delivery Research stream in NIHR. We have had positive discussion with national clinical academic partners, NHS Talking Therapies, NHS England and autism/learning disability organisations (National Autistic Society, Autistica and Learning Disability England) about forming a consortium to take forward this research. In addition, one of the initial goals of the project was to explore the potential use of the (then) Trusted Research and Evaluation Environment (TREE) to generate data that could be used to understand the outcomes of large-scale services such as Talking Therapies and eventually to allow understanding of the impacts of interventions across systems with multiple TT providers. During the period of this project the nature, priorities and processes of the TREE have changed such that discussion of this aim has not been possible. There are numerous examples of the use of data linkage with an impact upon autistic people (e.g., Widnall et al, 2022; Sohal et al, 202). As part of this exploration, we have started to consider the demands of ensuring that people whose data is included in larger scale data linkage and analysis are aware of the potential use of their data. We assume that, at times, this research and planning work will focus on specific, disadvantaged, populations and that the challenges of communication about this to such groups does not yet seem to have been considered locally or nationally. We consider that researchers and service planners should proactively make information about data use in research publicly available. Accessible information should be shared and made relevant to people and their contexts through a range of channels to make awareness of data research practices actively and consistently available. Public and patient involvement and engagement with research using sensitive data should be inclusive, from its design through to reporting. This requires targeted and meaningful outreach, particularly for groups such as autistic people and those with learning disabilities. Part of the communication should be to increase understanding of the safety and security processes used to protect sensitive data for use in research and service planning. However, public trust in this cannot be assumed and a full understanding of public concerns around these processes and the specific concerns of disadvantaged groups should be generated and acted upon in developing national and local communication around the use of large-scale sensitive data. This is another area that we will follow up in the next steps following this project.

Next steps

Members of the project team established as part of this project will

- Develop a bid for a large scale funded national research project to build on the findings from the current project including large scale data linkage
- Develop indepth follow on training to map out specific therapyadaptations and how they may be used in practice
- Follow up flagged people within the Talking Therapies service to explore outcomes
- Assess what adjustments are being used in NHS talking therapies (a small scale project is currently underway to explore this)
- Share the protocol used for identifying autistic people with other Talking Therapies services as part of ongoing research

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Appendix

Figure1: Thematic analysis schematic diagram of autistic participants' views

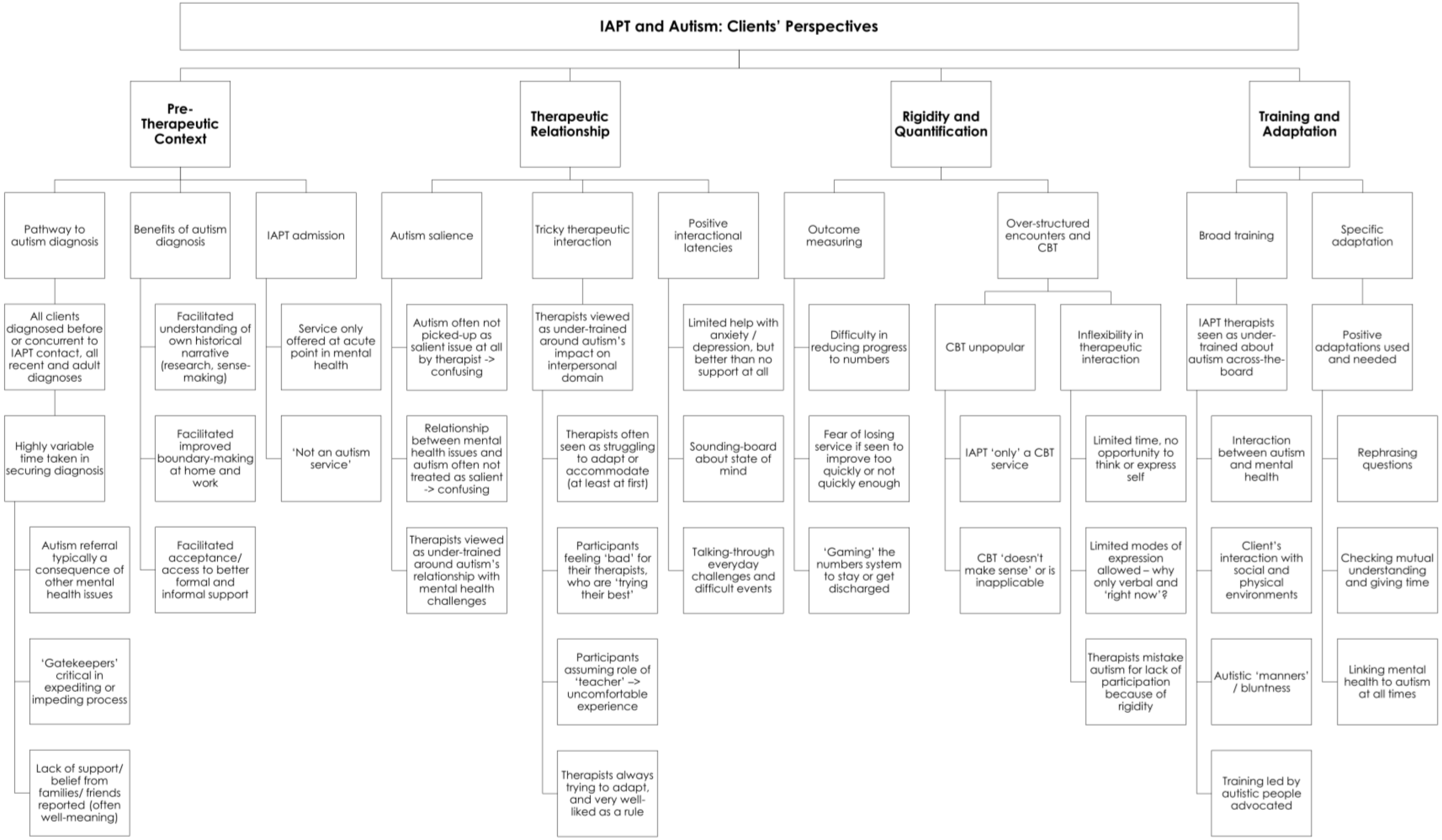

Figure 2: Thematic analysis schematic of clinicians’ views