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Anxiety Problems Experienced by Autistic Children: Child and Parent Perspectives

Autism

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Abstract

Autistic people are at increased risk of psychological distress, particularly anxiety problems. Childhood anxiety problems can lead to various negative lifelong outcomes, including disrupted education and reduced quality of life. Working closely with an Expert Reference Group and co-researchers with lived experience of autism and parenting an autistic child, we explored the experience of autistic children's anxiety to inform autism-specific intervention development. We interviewed nine autistic children with anxiety problems and 10 parents. Interviews were analysed using Interpretative Phenomenological Analysis and Template Analysis. We report five themes: (a) Buffering the constant impact of anxiety; (b) Walking the cliff edge; (c) We're on our own here; (d) Being understood is the safest path and (e) Pursuing a journey of learning. These themes illustrate how anxiety problems can affect autistic children and their families. Key learnings for intervention development include (a) the potential value of delivering support through an established relationship with a safe, trusted adult; (b) the possible amplifying effects of the combination of environmental factors with sensory sensitivities on anxiety and (c) acknowledging the difficult balance for families between helping the child to manage in a neurotypical world, and finding ways to adjust the environment to better meet their child's needs.

Lay Abstract

Autistic children are more likely to experience problems with anxiety than non-autistic children, which can have lasting effects on their well-being and development. Understanding what anxiety problems feel like for autistic children and their parents can help create better support and interventions. In this study, a research team including autistic individuals, parents of autistic children and clinicians explored these experiences. We interviewed 10 parents and nine autistic children with anxiety problems. The interviews revealed five main themes: (a) *Buffering the constant impact of anxiety*; (b) *Walking the cliff edge*; (c) *We're on our own here*; (d) *Being understood is the safest path* and (e) *Pursuing a journey of learning*. These findings highlight the complex and ongoing impact of anxiety problems on autistic children and their families. We found that helpful support for these children may come from a trusted adult with a preexisting relationship, recognising how external factors and sensory sensitivities can make anxiety worse, and considering the experiences of children and families within systems that are not designed for autistic people. This study offers important insights that can guide the development of more effective and compassionate interventions for autistic children experiencing problems with anxiety.

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Introduction

Autism is a mode of being characterised by distinctive sensory experiences, particular styles of thinking and attention, and a range of social and communicative preferences (Murray et al., 2023). The combined profile of these dimensions is individually complex. Yet, autistic people share an increased risk of experiencing anxiety problems (Stark et al., 2021), with up to 62% of autistic children affected (Vasa et al., 2020), often from an early age (Chan et al., 2023). As with non-autistic children, anxiety problems can have profound negative implications for children and their families, reducing quality of life (Adams & Emerson, 2021). This impacts children's emotional well-being, social relationships, and ability to engage in school and home life (Neilson & Bond, 2023).

The National Institute for Health and Care Excellence (NICE) Clinical Guideline 170 recommends that interventions that are well-evidenced in non-autistic populations are adapted to meet the needs of autistic people (NICE, 2013). For anxiety interventions to be appropriately and sensitively adapted to meet autistic children's needs, more understanding is needed about what it is to be and to care for an autistic child with anxiety problems (Adams et al., 2019), and how the environments that autistic children experience interface with their anxiety problems (Kester & Lucyshyn, 2018). Existing adaptation guidance focuses on compensating for autistic differences, such as through inclusion of visual aids (NICE, 2013; Uddin et al., 2026), rather than drawing on phenomenological insight that environmental mismatches, including sensory overload and social demands, contribute to autistic children's anxiety problems (Neilson & Bond, 2023). To date, the experiences of primary school-aged autistic children with anxiety problems have not been adequately captured in the academic literature (Billington et al., 2025). A detailed understanding of these experiences will increase the likelihood that treatments for anxiety problems are developed in ways that meet the needs of both children and their caregivers.

This paper presents findings from a qualitative study that explores the experience of anxiety problems in autistic children and their parents. It formed part of a wider project in which we co-developed a new psychological therapy for anxiety problems in autistic children (Cullingham et al., 2025). Our aim in this study was to understand the meaning and experience of anxiety problems for autistic children and their parents, to inform the process of adaptation and co-development.

Method

Design

Qualitative data were obtained from interviews with parents and children, employing a multi-perspective sequential qualitative design to triangulate insights across participant groups and strengthen the broader applicability of the findings.

We analysed the data in two sequential stages. First, using a bottom-up Interpretative Phenomenological Analysis (IPA) approach to develop sensitised experiential categories (Smith et al., 2009), followed by Template Analysis (TeA; King, 2012) to refine and extend these categories across the remaining interviews. This is an established approach (e.g., see Dennis et al., 2013; Nizza et al., 2024) which combines TeA's more top-down, flexible structure with IPA's experiential focus to support analysis across larger datasets.

Positionality

Although the research team included neurodivergent members and people with lived experience, the overarching framework initially reflected a traditional clinical understanding of autism. Over the course of the project, the team moved towards a more neuro-affirming perspective as interpretation and discussion shaped their understanding. This evolving stance supported a focus on autistic children's lived experiences and how these made sense within their relationships and contexts, which is reflected in the analysis.

The final analysis was grounded in an interpretivist, neuro-affirming position that recognised both the reality of children's experiences and the interpretive processes through which children and those around them make sense of those experiences.

Collaborative Working

A team of researchers, including an Expert Reference Group (ERG), co-constructed all elements of this study and the wider project (Cullingham et al., 2025). The ERG comprised autistic researchers, clinicians who support autistic people with mental health difficulties, autistic adults and parents of autistic young people with anxiety problems, as well as a young autistic person with experience of anxiety problems. The ERG was chaired by two members of the research team, one with experience parenting an autistic child with anxiety problems and one with clinical experience. An autistic

researcher who is a parent of autistic children had a dual role on the ERG and the research team (see Cullingham et al., 2025 for further details on the ERG).

The ERG were integral to the study, supporting recruitment (reviewing documents, sharing advertisements), improving accessibility (reviewing interview schedules), and contributing to the analysis. ERG members regularly met with the researchers to finalise themes at the person and group level and to discuss relevance and meaning. Their input ensured themes were grounded in lived experience and that the analysis reflected the emotional and relational complexity described by families.

Recruitment

Convenience sampling was used; social media and email advertisements were circulated through charities, schools, the research team, the ERG, and parent support groups. Interested individuals contacted the research team directly. All participants provided informed consent/assent and received a £10 gift card.

Eligibility Criteria

Children and parents were eligible if the child was aged 5 to 12 years, had a confirmed autism diagnosis, experienced anxiety that significantly affected daily life, and was able to communicate in English, with adjustments and support if needed. Children with severe or profound intellectual disabilities were excluded, as the nature of their intellectual disabilities involves high adaptive-support and a qualitatively different lived experience and caregiving profile, meaning families' interpretation and sense-making of anxiety would likely differ substantially from those represented in this study. Children with mild or moderate intellectual disabilities were included, as their lived and caregiving experiences were considered broadly comparable to the wider sample.

Diagnosis Confirmation

To confirm that children had been formally identified as autistic, documentation from a registered health professional or an Education, Health and Care Plan (EHCP) was required. A formal anxiety disorder diagnosis was not needed, as many autistic children struggle to access clinical support for mental health difficulties. Anxiety problems were confirmed on the basis of elevated scores on either the parent report or child report Anxiety Scale for Children with Autism Spectrum Disorder (Rodgers et al., 2016) and via an interview with the parent(s). Scores ≥ 20 indicate significant anxiety; child report scores ranged from 21 to 54 ($M=31.1$), and parent report scores ranged from 18 to 50 ($M=34.9$).

Sample size

The parent and child interviews were each considered a coherent, standalone sample within the recommended sample size range for informational depth within qualitative studies (e.g., see Malterud et al., 2016).

Participants

We (VT, ES, and TC) interviewed ten parents of autistic children with anxiety problems (aged 36–52 years) and nine autistic children with anxiety problems (aged 8–12 years). The sample was predominantly White British; two parents and two children reported other ethnicities (not specified here to preserve anonymity). See Table 1 for further participant details. All but two of the children were attending mainstream schools with adaptations. One child attended a specialist autism provision, and one child was on a significantly reduced timetable in a mainstream school.

Interviews

Parent interviews explored experiences of raising an autistic child with anxiety problems, and child interviews focused on children's own experiences. Interviews were virtual or in person and lasted from 25 to 60 min, with parent interviews typically being longer. Three child interviews were in person; the rest, including all parent interviews, were virtual. All but two children opted to have a parent with them. Interviews were conducted by researchers experienced in supporting autistic children with anxiety problems. Children received simple information sheets, and assent and parental consent were obtained. The approach was informed by Cridland et al. (2015).

Methods to support comfort were developed with the ERG. Parents shared information about their child's communication needs and interests during consent. Visual supports linked to children's interests were used with three children, and one child used the Microsoft Teams chat function, as they were not able to access spoken communication. Topics of interest were discussed first to build rapport. Interviews followed a child-led style, prioritising comfort, using flexible conversation, and avoiding pressure to discuss anxiety. Conversational scaffolding helped check whether children were ready to talk about anxiety, and interviewers normalised discussing fears by sharing simple examples of their own, such as spiders, when appropriate.

Data Management

All interviews were audio-recorded, securely stored and transcribed. Transcripts were pseudonymised, and children were provided the opportunity to choose their pseudonyms.

Table 1. Anonymised Data of Study Participants.

Child Participants		
Children in IPA analysis	Pseudonyms Ages of children in years Gender Description of types of worries.	Bob, Joe, Ava, James, Imogen 9, 10, 10, 11, 11 3 Boys; 2 girls One child worried about many things, but particularly the transition to high school. One child struggled with many different forms of anxiety, particularly around sleeping alone. One child expressed a lot of fears about people accepting her. One child worried about something bad happening to their family. One child worried a lot about how people perceive her fitting in.
Children in TeA analysis	Pseudonyms Ages of children in years Gender Description of types of worries.	Sydney, Frankie, Carly, Noah 8, 8, 10, 11 3 boys, 1 girl One child worried at bedtime about scary movie characters coming to get him. One child worried at bedtime and about spiders. One child had a very intense and specific fear of a potentially dangerous object. One child worried that people would think negatively of him and that he would get something wrong.
Parent Participants		
Parents in IPA analysis	Pseudonyms (relationship to child) Relationship to child Ages (gender) of child/children in years discussed in the study	Carol, Katie, Lauren, Robyn, Olivia 5 mothers, 0 fathers 7 (Male), 10 (Male), 11 (Female), 11 (Male), 11 (Male), 12 (Male)
Parents in TeA analysis	Pseudonyms Relationship to child Ages (gender) of child/children in years discussed in the study	Cheryl, Dawn, Evan, Josie, David 3 Mothers; 2 Fathers 8 (male), 8 (male), 9 (female), 10 (male), 10 (male)

Note. Pseudonyms and corresponding data have been presented as unlinked to preserve anonymity.

Analysis

Phase 1: Person-Level Themes (IPA)

Five child interviews and five parent interviews were purposively selected to ensure breadth and depth and then analysed sequentially using IPA. The first researcher (VT) immersed herself in each transcript by listening to the audio and repeatedly reading the text, recording descriptive, linguistic, and conceptual exploratory comments. These were then developed into preliminary person-level themes. A second researcher (TC), familiar with the dataset, reviewed the notes, and both researchers met to discuss interpretations and agree on the final person-level themes. Reflexive notes were recorded after each meeting, and weekly qualitative supervision from a third researcher (ML) provided additional interpretative challenge. Person-level themes were then reviewed with the Expert Reference Group (ERG) to ensure experiential resonance.

Phase 2: Group-Level Themes (IPA)

Two researchers (VT and TC) iteratively refined the child and parent group-level themes, ensuring they reflected the idiographic detail of the person-level analyses. The third researcher (ML) reviewed the developing structures, and themes were finalised only when consensus was reached across all three researchers and endorsed by the ERG.

Phase 3: Template Development and Application (TeA)

The child and parent group-level themes were used to create separate initial templates for the TeA. Two researchers (VT and TC) developed and applied these templates to the remaining interviews, with supervision and interpretative support from the third researcher (ML). Templates were reviewed with the ERG and adapted as new insights emerged, with regular consensus checks across the research team.

Phase 4: Integrative Synthesis

Once both TeA datasets were complete, the child and parent templates were compared to identify areas of convergence, complementarity, and divergence. This integrative stage generated a set of overarching themes representing a higher-order synthesis of both perspectives.

Results

The five overarching themes were as follows: (a) *Buffering the constant impact of anxiety*; (b) *Walking the cliff edge*; (c) *We're on our own here*; (d) *Being understood is the safest path* and (e) *Pursuing a journey of learning*. Each theme incorporates evidence from both samples (parents and children). See Supplementary Table 1 for parent and child themes.

Buffering the Constant Impact of Anxiety

Parents and children described how anxiety problems were experienced by the family as a constant intrusive challenge. 'I have always felt very worried all of my life' (Bob). This was 'hard' (a word emphasised by several respondents) because avoiding anxiety-provoking situations was an overwhelming and exhausting task.

For children, the persistence of anxiety was 'annoying' because it kept returning, and 'frustrating' because it prevented them from doing some things they wanted to do ('I'd just be sitting at home worrying' instead of taking part in an activity, for example). They found the experience of anxiety 'stressful' (Joe said that 'I cried a little bit and it's hard to breathe'), and difficult to contemplate when reflecting upon those experiences ('they (fears) are usually stupid and irrational', Carly). Some of the children were able to give powerful descriptions of how their worries manifested:

I have visions of – it looks like . . . what it looks like is, I'm just like . . . I'm kind of shivering sometimes and I don't know what's going to happen. (James)

They really go round in my head and I can't sleep and I was like 'oh I want this out of my head please!' (Frankie)

However, most child respondents struggled to offer the kind of description above, with most reflecting on how difficult it was to understand and describe anxiety. Parents described how sometimes, the day after a meltdown, their children did not remember these experiences. It appeared that they were buffered from the full extent of the impact of anxiety problems by their parents, who carried the load of trying to protect their child, something which took tremendous effort and anticipatory planning, day after day. For example, Carol described the pressure of always 'being three steps ahead', and both Katie and Josie visualised all of the people around the child as treading 'on eggshells'. Parents reflected that everything had to be planned,

and that they missed 'just being spontaneous'. They described their commitment to this task as unwavering. Indeed, families in our study appeared to organise their lives around the child's worries, and it tended to be the mother who was the central bulwark of the family's defences against these worries. Parents shared that they frequently felt pressure to remain calm to support their child, yet the effectiveness of the strategies they employed was experienced as uncertain and inconsistent:

I found that every day is really different and what might work one day won't [on] another, and it's much more variable than I think for someone neurotypical. (Dawn)

I think it's really easy to become complacent and I think that that's when things get worse, and it's almost like you have to be on your guard all the time. (Cheryl)

Parents were sometimes tearful, describing the strain of this aspect of their relationship with their child. Josie described it as 'very draining'. The work that they put in to protecting their children from anxiety, alongside the unseen labour of preparing and supporting them for every eventuality, was extensive and depleting parents' psychological resources: 'I just don't have any days that are easier' (Josie).

Walking the Cliff Edge

It was not possible to anticipate and avoid all sources of child anxiety. Often, it seemed that potential triggers for anxiety were hidden from view, with the potential for significant danger lurking just out of sight, reminiscent of a cliff edge, which was nearby but obscured by fog.

Children described how anxiety arose in situations where things were unpredictable, and anxiety could escalate quickly. For example, James complained that 'If a change just happens out of nowhere, then I don't know what to expect. I can't handle change'. Imogen pointed out that the change did not have to be an unanticipated addition: 'When things get cancelled it really, really, really upsets me and worries me . . . especially if I've been preparing for something special, then all my preparation is wasted'. She described the anticipatory preparation as if it were a way of making something appear, and that a cancellation was painful because it made that thing 'disappear'. Anxiety also arose in places and situations where the children felt unsafe ('I'm never going again! Never!'). For seven of the children, something was experienced as unsafe *because* of its unpredictability. Frankie simply stated, 'I don't like sudden changes to the plan'.

Sometimes the children's worries escalated beyond the immediate situation. Imogen described this as if it were a more general aspect of her character – a tendency to focus on the worst possible outcome. Several other young respondents described how their anxieties had

incorporated perceived threats to the safety of their families. The family's safety appeared precarious, and the child was often focused on how they could fend off the impending catastrophe. James described 'really intense' worries about 'bad things' happening to loved ones. Ava reflected on how difficult it was to shake this kind of feeling, even when her family tried to reassure her:

Like if you [Mum] were in danger and they [sibling] were like 'Let's go and watch YouTube, Mum's okay, blah-de-blah-de-blah', then I'd be like, 'You're acting suspicious, darling!'

For parents and children alike, when avoidance strategies failed, the severity of their child's anxious distress was horrific and often overwhelming. Imogen stated, 'I just cry and scream until it stops' and later referred to the challenges she had regulating her feelings in those moments, emphasising 'just how hard it is in a state of distress to just calm down or to just wait a second or to just breathe'.

Carly described needing to escape as the feeling was so overwhelming 'because my mind usually just goes like AHHHHHHHHH RETREAT RETREAT'. Parents described hair-pulling and self-harm, repeated meltdowns, extreme eczema flare-ups, and alarming risks taken to escape stressors. Cheryl described how difficult it could be to remain hopeful under such constant pressure:

It's been so intense for so long that there has been evenings where she's cried a lot and instead of helping her, I've cried because I've just got to a point where I don't know what to do.

Collectively, it was as if both parents and children were trying to find their way in the face of hazards which were difficult to identify, to gauge and to avoid. Dawn reflected that there was a tension between her 'mother-bear instinct' to immediately step in and fix problems for her son, and what the problem of anxiety might actually call for, which she thought was helping him 'to work it out for himself'.

We're on Our Own Here

This theme reflects some of the secondary consequences for the family of attempting to manage the child's anxiety problems, and of doing so within a system which currently offers very limited support for autistic children. For example, Joe said, 'I didn't feel like she [therapist] actually helped that much', when discussing specialised anxiety support he had received. Even when children were provided support, the demands placed upon the family were extensive. Dawn described this:

With my daughter, she might have a session with her psychologist once a month. The other 30 days of the month, the support primarily comes from us, as a family unit. Not just as parents [. . .] – she talks to her brother, they care for each

other. So you're really [. . .] providing a hell of a lot of that support at home, but you're just kind of left to get on with it [. . .] There seems to be a gap there, to me, that could helpfully be filled by something.

The sense of being unsupported was not restricted to the sphere of specialist services. Parents described having to anticipate situations not just from the point of view of their child, but also for the benefit of others, who might not understand the child's needs or reactions. Joe described comparing his worries to others. This additional social dimension underscored how the families saw themselves as living outside of normative expectations:

That's the hard thing with a child who doesn't always react in a way that maybe all my friends' children do. You start feeling that [. . .] people will judge you as a parent, and you know, that kind of never goes away – even though I am a rational, professional person. [. . .] You still feel it sometimes that it's, 'Oh why can't I just do like everyone else is doing?' (Carol)

Yes. I think my sister thought that for a short time, but she stopped being afraid of it, but only for a very short time with her but for some reason with me, I have had it for a very long time. (Joe)

We can see that both the child's anxious responses and the parents' worries (e.g., about a child who reacts differently, a child who can't sleep alone) appear to contribute to this feeling of being set apart from other families. Other systems around the family, particularly schools, were also experienced in complex ways. Schools were often a source of the child's anxiety but also were sometimes the only source of respite for parents, leading to mixed feelings for parents about their reliance on school.

Schools could be inconsistent in their support, and children could at times struggle to attend. There was also a sense that children tended to cope with attending school by 'masking' how they felt ('he has learnt that if he smiles and sits still and be quiet, people leave him alone'), until, upon returning home, the distress overwhelmed them. Frankie and Joe spoke about not liking people looking at them: 'I don't like it when people are looking at me while I am doing stuff' (Frankie), while Ava, James and Imogen all spoke about the experience of masking their autistic selves at school. Ava coined a term to describe this, fusing 'hiding' and 'secretive' together: being 'hidetive'. Imogen reflected on how this kind of behaviour prevented peers and teachers at school from witnessing her distress but placed additional burdens on her Mum:

I masked completely how I felt at school [. . .] And then I would come home and Mum would just get the worst experience ever, and I would be crying, screaming about things that had happened in my day that had gone really badly wrong, and I am still scared to cry at school. I don't want to do that. (Imogen)

As Imogen's account demonstrates, it is exhausting and isolating when one does not feel able or safe to disclose one's discomfort. In this example, the family is then managing the consequences of a day's masking, trying to support and soothe their exhausted and distressed child. Both the child's and the family's distress are left unseen by the wider system, perpetuating the feeling of isolation.

Being Understood Is the Safest Path

In this theme, young people and families reflected on how understanding was the key to coping as a family, where an autistic child has anxiety problems. As we have seen already, children have described how it was difficult to make sense of their experiences of anxiety. At times, it was hard for the children to talk about anxious feelings. They found that they sometimes doubted their own insights. For example, Ava said that 'I don't even know what it [anxiety] is! . . . I don't even know what's going on in my own head!' and Bob described how his 'head just explodes' when he tries to think about his experience of anxiety. In the context of this perplexing threat, children recognised and appreciated that families, and particularly mothers, were playing an important role in managing the impact of anxiety. In part, as Ava illustrates here, this was because her mother was perceived to understand the child and her worries best:

- Int.: Is it easier to talk to CAMHS [referring to a therapist at Child and Adolescent Mental Health Services] or to your Mum?
 Ava: **[Gesturing – pointing to Mum].**
 Int.: Is that a big point at Mum?
 Ava: Mm..
 Int.: Yeah. Why is it easier to talk to your Mum?
 Ava: Because she gave birth to me, and I have known her the longest time.

Because parents were generally seen to *understand* (more than most people) the child's worries and feelings, they could be relied upon to provide helpful insights, and 'a safe place' when it was needed. Sydney felt safe 'knowing that [the monster] is not going to come because Mummy is going to wrestle him', for example. Underpinning all of this was the idea that parents could be trusted to *make the effort* to understand. Other children described how important it was that parents knew what was going on for them ('I just know that I just want them [parents] to know at the time'; Joe) and that this combination of knowledge and understanding allowed parents to act as 'temporary worry disablers' (James).

Parents recognised that autism refracted and focused anxious experiences in important ways. The intensity and constancy of anxiety, as described in the second theme, were important aspects of this. In addition, some specific

aspects of autism interacted with child anxiety in important ways. One of these was sensitivity to certain sensory experiences, which could boost or trigger children's anxious feelings:

He's almost constantly in fight and flight, so we're just trying to dampen it down. If we can . . . at least with the sensory if we can get that down a little bit and he's not so reactive to everything around him, erm then his anxiety comes down a little bit but we've got this vicious loop that if his anxiety goes up his sensory stuff goes up and then y'know you're, kind of like, swatting at flies for a while. (Olivia)

Another anxiety-amplifying aspect associated with being autistic was the child's concerns about changes in plans, rules or routines (as described in the second theme). Parents also had to be mindful of some children's strong positive preferences:

We cut carrots into sticks and there has to be an even number, so everything is even numbers. You can't have odd numbers you just . . . I have done it before like cut something a mistake that it is an odd number and he just won't eat any of it. (Josie).

It is important to underscore that parents in our study saw autism as a fundamental part of who their child was but did not frame anxiety in the same way. For example:

If we could just get his anxiety sorted out he would be such a different – he wouldn't be a different child, because he is fantastic as he is, but it would just make everybody around him's life that little bit more easier, as well as him being a lot happier [. . .] He is a happy boy, but he could experience so much more things couldn't he, if we could just get a handle on it? (David)

We've got an absolutely amazing child who is so loving, so caring, that he is so much fun and, you know, if you start engaging with him on the things that, you know, he likes, Pokémon – I am loving playing Pokémon with him, you know – it is to really celebrate and enjoy the differences. Find what is different but enjoy it because there are a lot of things to enjoy. (Evan)

When highlighting the importance of understanding the child's needs as an autistic person, some of the parents described professionals who had demonstrated this quality. They were represented as rare and special (e.g., a teacher with a psychology degree who was like 'gold dust'). Such professionals had the potential to make a huge difference, but parents described how it could still take considerable time to develop the necessary relationship with the child.

Parents highlighted that 'standard' interventions and services could be unhelpful, precisely because they did not draw on an understanding of autistic children's needs and experiences:

I think it's really hard to understand where a child is coming from if you don't understand autism. (Robyn)

The families that were on there [**intervention for behaviours of concern**], we kept saying that, 'This won't work for our children', and there was no . . . they weren't willing to adapt it at all to us. (Lauren)

This central role for being able to situate the child's anxiety problems in the context of *their* autism (and not just autism in general) links to a final theme, which outlines the families' strong positive orientation towards learning and change.

Pursuing a Journey of Learning

Children and parents described a continual process of trying to understand anxiety and how to navigate a neurotypical world. Children masked (as described in *We're on our own here*) and experimented with different strategies, often hoping anxiety could be permanently solved or removed. However, when anxious feelings inevitably returned, it became clear that no strategy offered lasting relief. As Imogen noted, 'Nothing has actually worked to always get rid of them'.

Children described temporary improvements followed by the return of worry, which left some feeling hopeless about the future and unsure how to manage anxiety problems long-term: 'We don't get anywhere . . . I can't keep living like this' (Ava). This ongoing cycle of trying, adjusting, and beginning again formed a shared family sense of being on a continuous learning journey.

Parents wanted to be able to do more to help their child to cope *now*, so that they would be more able to cope by themselves when they were older. Parents described how they were constantly learning in their efforts to do this. For example, Cheryl was upset to learn of her daughter's feelings of hopelessness, but this just seemed to strengthen her long-term resolve to find ways to help:

A few months ago she said, 'Nobody can help me. Nobody understands and it's just going to be like this forever', and it really made me think that although I'm doing things in the background to try and help her, she doesn't see it and she doesn't understand it. So when I do things like mind mapping with her she knows that I'm trying to break it down and I'm trying to understand and I think that in turn has helped her to open up a little bit more.

Parents described navigating a delicate balance between changing the world and changing the child to fit the world. This was motivated by protection and love as they sought the best ways to support their child in an environment that often fails to meet their needs. In some situations, particularly with teachers and schools, parents described the effort that went into building support around the child ('generally what I end up having to do is manage everybody else so

that they don't trigger him'; Katie). There were also contexts where the focus shifted to what children might benefit from learning in the longer term. For example, Robyn worried that her child tended to be very hard on herself and tended to show this to her peers:

I also need to make sure she manages her behaviour. I mean to me, obviously, but more importantly to the people that don't love her and know her, who won't tolerate it, you know? I don't want her to come out thinking she's a terrible person because she is actually showing that side of herself to too many people who then reinforce that idea that she's not a very nice person.

Unable to control how other people might react to her daughter's disclosures and self-criticisms, Robyn focused her attention on encouraging her daughter to share these worries less frequently. These concerns were sometimes held in tension with other concerns expressed about (and from) the children, with regard to the emotional costs of 'masking'. Imogen said:

I am worried that people won't like my personality or like the way I look. Mainly . . . like I think they are not going to like the way I act and so, like say they are like 'Oh my God I really love this', I am like 'Oh yeah, I love that too'. Even if I don't, even if I am like meh, I will be like 'oh my gosh, yeah, I love that!', because I want to be like them and I want to fit in.

Parent participants in this study were motivated and central to supporting their children with their anxiety problems, which was valued by child participants.

Discussion

This qualitative study formed part of a wider project to inform intervention development for autistic children with anxiety problems. We explored parent and child perspectives, using IPA and TeA in combination, to provide deep idiographic insights and to extend these across the full dataset. The five overarching themes describe how anxiety problems are experienced within families. They highlight components that may be helpful when developing interventions for anxiety problems in autistic children.

Across parent and child accounts, there was a strong desire for anxiety to be alleviated and a shared depiction of parents as a source of safety in an anxiety-inducing world. Parent and child accounts broadly aligned but were different in nature. Children tended to focus on getting rid of anxiety, and parents on understanding the experience. Children's accounts were briefer and less linear, with meaning emerging across multiple interactions and modalities such as typed responses or gestures. This may have reflected the intangible and overwhelming nature of anxiety.

In themes such as *Buffering the constant impact* and *Walking the cliff edge*, anxiety was described as elusive and intangible. Families often existed in a state of

hypervigilance, investing substantial energy in predicting and managing anxiety and in helping others understand their child's needs. Nuanced understanding of autistic children's internal experiences was viewed as protective, as reflected in *Being understood is the safest* path. Nonetheless, a cross-cutting narrative emerged that no matter what parents or children did, anxiety repeatedly returned. When it did, children experienced extreme distress, and parents had few tools to ameliorate it. These episodes left families feeling powerless and reinforced the sense that anxiety was unmanageable, unchangeable, and potentially dangerous. In *We Are on our own here* and *Pursuing a journey of learning*, families described feeling unsupported by systems and services and often left hoping for the impossible. Targeted anxiety interventions can successfully reduce anxiety symptoms in autistic children (Wood et al., 2020), indicating that direct anxiety management may help mitigate this cycle.

Systemic factors, especially school environments, strongly shaped how anxiety was experienced. Consistent with prior work (Jones et al., 2020; Kasztelan Chapman et al., 2025), parents and children identified school as challenging as it was structured around neurotypical norms, increasing sensory, social, and cognitive demands and contributing to cumulative daily stress (Tsou et al., 2024). Parents described weighing their perception of their child's present needs against future demands when working with schools, facing the difficult choice of pushing for environmental adjustments or encouraging tolerance of distress to build skills for a neurotypical world. These findings support efforts to create autism-aware environmental adaptations in school environments.

Children frequently described masking, hiding their distress, and trying to fit in, suggesting early internalisation of stigma and shame around their autistic identities, which contributed directly to their anxiety. Botha and Gillespie-Lynch (2022) highlight the importance of positive autistic identity for well-being, and our findings extend this to younger children by showing how stigma and fear of getting things wrong impinge upon their perspectives. Parents interestingly described a parallel process of wanting to hide away parts of their reality to try and fit into neuro-normative standards or be prepared for the backlash when they did not. Parents described the daily stress of helping others to see their child's needs, alongside the pressure of preparing their child and themselves for potential judgement. The distress described is consistent with Butiu et al. (2026), who found that stigma was associated with high levels of parenting stress among parents of autistic children. The findings indicate that anxiety problems, as experienced by autistic children, need to consider broader contextual factors alongside the child and parents' perception of what it means to be autistic and their relationship with autistic identity.

This study supports the reframing of what it means to adapt anxiety interventions for autistic children. Adaptation

has primarily focused on helping autistic children access interventions designed for non-autistic populations by adding visual supports or simplifying communication (NICE, 2013; Uddin et al., 2026). Our findings suggest the need for a different starting point, one that aligns with a neurodiversity-affirmative approach (Porras Pyland & Rodriguez Tackett, 2026). Effective adaptation requires attending to autistic identity and to the ways autism and anxiety interact. Interventions should attend to autistic self-concept and reduce internalised stigma that contributes to masking, as well as considering systemic factors and environmental adaptations to better suit autistic ways of being. This shifts the question from how to overcome autistic communication or social differences so children can access existing programmes, to how to build interventions that integrate autistic ways of experiencing and navigating the world. Such a neuro-affirming approach acknowledges baseline anxiety, sensory and social stressors, and the cumulative impact of environments designed around non-autistic norms.

Children identified parents, typically mothers, as their most trusted source of support. Children described worries of separating from parents, akin to separation anxiety, a common form of anxiety experienced by autistic children (van Steensel et al., 2011). Parents framed this more positively, emphasising the child's sense of safety and connection rather than fear of separation. Both groups identified that beyond being a safe place, parents held deep knowledge of the child's internal experiences and daily stressors. Parental involvement is well documented to enhance child anxiety treatment outcomes (Rodgers et al., 2022; Wood et al., 2020). The qualitative accounts help to deepen the understanding of why that is. Children articulated that they preferred parental support to therapeutic support, as no professional understood their experiences as deeply as the parent who had been consistently present. Parents also noted that therapists were not present during the most challenging moments. Interventions that sit within established relationships and provide tools to caregivers may therefore be particularly effective, such as parent-led models which can be acceptable and beneficial for managing child anxiety problems (Creswell et al., 2010). Notably, parents of autistic children often experience high levels of parenting stress (Tönis et al., 2026), and those in this study expressed feeling unsupported. Therefore, parent-led approaches should explicitly consider parental stress and address factors contributing to overload, including the tension between meeting autistic needs and helping children face their anxiety problems. If done in this way, parent-led interventions may have the potential to positively impact both parents and children.

Children, as well as parents, were highly knowledgeable about what supported their well-being, underscoring the importance of ensuring that all interventions, whether parent-led or direct to child, actively incorporate the parent and child's opinions on what is effective.

Reflections and Limitations

The sample was predominantly White British, financially secure, and academically advantaged, which limits generalisability. Global majority families often face additional barriers including stigma, mistrust, and structural inequities (Alam et al., 2024). Although some valued aspects of autism support overlap with our findings, such as autism-specific information and trusting professional relationships (Alam et al., 2024), the study did not consider race or intersectionality, which is likely to be highly relevant for ethnically minoritised autistic young people and their families (Nelson & Lichwa, 2025). Mothers were overrepresented in the parent sample, which may contribute to the theme of mothers acting as the primary emotional and organisational bulwark. However, this pattern is consistent with wider evidence that mothers often carry a disproportionate share of caregiving labour in families (McLaughlin et al., 2026). These dynamics may differ in single-parent households or families with same-sex parents. Younger children were underrepresented, likely due to wait times for autism diagnostic assessments. Future research should prioritise earlier and more diverse recruitment.

Future Research Directions

The findings from this study reiterate the challenge of school environments for autistic children. Although beyond the scope of this study, the findings highlight the need to deepen our understanding of how environmental supports and individual coping strategies can be effective for autistic children. Ideally, through creative, co-produced methods that can capture internal experiences in ways traditional tools may miss (Billington et al., 2025). In addition, further research into ways to support autistic children with anxiety problems to participate in research is needed.

Conclusion

The findings from this study contribute to the literature on autistic children's mental health by offering new insights into how anxiety problems are experienced within this group and their families. The results point to a conceptual shift in what it means to adapt and co-create interventions to support autistic children experiencing anxiety problems. Promising future directions for intervention development are co-produced, neuro-affirmative in nature and include environmental accommodations alongside well-evidenced anxiety management strategies. Interventions that are delivered within trusted caregiver relationships may offer particular benefit.

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Ethical Considerations

This study formed part of a wider study, *Childhood Anxiety in Autism Managed by Parents*, which received ethical approval from the Health Research Authority (HRA) and Health and Care Research Wales (IRAS; Project ID 307932) and was reviewed under REC reference 22/HRA/1600. Governance approvals were provided through Manchester University NHS Foundation Trust (MFT), the study sponsor. All procedures complied with national guidelines for research involving human participants, and informed consent/assent was obtained from all participants or their legal guardians.

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Supplemental Material

Supplemental material for this article is available online.

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