

‘Playing a guessing game’: Recognising and responding to anxiety in children with intellectual disability

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Abstract

Background: Children with intellectual disability are at greater risk of developing anxiety than the general population. Limited research has examined the challenges associated with recognising and responding to anxiety in children with intellectual disability, and its perceived impact.

Aim: This study aimed to explore anxiety in children with intellectual disability, from the child and parent perspective to better understand how parents and children recognise and respond to anxiety.

Method and Procedures: Six children with an intellectual disability (age range: 12–17, four boys) and their mothers participated in a semi-structured interview online. Interviews were transcribed verbatim and interpreted using thematic analysis.

Outcome and Results: Mothers elaborated on the difficulties with recognising signs of anxiety due to the impact of the child's primary diagnosis and the overlap of symptoms with co-occurring conditions. Mothers and children discussed the ‘contagious’ effect of anxiety within the household and how this influenced mothers' approaches to managing their child's anxiety. They reported that anxiety limited the meaningful activities in which children and families could engage.

Conclusions and Implications: These findings highlight the importance of supporting mothers to recognise their children's anxiety and to assist them with strategies on how best to respond and cope. These findings have implications for future research, and practitioners working in this field.

KEYWORDS

anxiety, child, intellectual disability, interview, mother

1 | INTRODUCTION

Intellectual disability involves difficulties in intellectual and adaptive functioning across conceptual, social and practical domains, which have an onset during the developmental period (American Psychiatric Association, 2013). Individuals with intellectual disability are significantly more likely to have a mental health condition than the general

population at all stages of life (Hughes-McCormack et al., 2017). The prevalence of anxiety is particularly high, with 7%–34% of children and adolescents with intellectual disability being diagnosed with an anxiety disorder (Buckley et al., 2020)—much higher than the rate of 3.6% reported in the population of children without disabilities (Emerson & Hatton, 2007). Moreover, elevated anxiety is a common feature of neurodevelopmental conditions associated with intellectual

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disability, such as Fragile X syndrome (Wall et al., 2019), Williams syndrome (WS; Kozel et al., 2021), 22q11.2 deletion syndrome (22q11.2; Schneider et al., 2014) and autism (Zaboski & Storch, 2018). Rates of anxiety are higher still in these populations, whereby 37%–60% of children with WS (Kozel et al., 2021) and 34%–36% of children with 22q11.2 have a clinical diagnosis of anxiety disorder (Tang et al., 2015; see Edwards et al., 2022; Glasson et al., 2020, for review). Despite this elevated risk, little is known about how anxiety in children with intellectual disability is recognised, and responded to, by their parents—and especially the children themselves—and its impact on their lives. The current study addressed this gap and sought to understand these issues by eliciting the views and experiences of parents of children with intellectual disability and the children themselves.

Anxiety disorders are characterised by excessive fear and worry with related behavioural disturbances that typically persist beyond developmentally appropriate periods (American Psychiatric Association, 2013). Anxiety is conceptualised as a constellation of clinical features that are physiological, cognitive, emotional and behavioural in nature. Physiological manifestations in children and adults include muscle tension, hyperventilation and other somatic complaints, while emotions include fear, worry, irritability and dread. Cognitions typically feature predictions that are catastrophic or expectations that one will fail to cope. Avoidance, checking, and hypervigilance are common behavioural responses.

How parents and children recognise signs of anxiety for children with intellectual disability within this framework, however, is not straightforward for two key reasons. First, research has demonstrated that parents report fewer cognitive and emotional symptoms of anxiety in children with intellectual disability than those without intellectual disability (Sukhodolsky et al., 2008; Witwer & Lecavalier, 2010), despite children with intellectual disability being at greater risk of developing anxiety (Green et al., 2015). This under-reporting may be in part due to 'diagnostic overshadowing', the tendency to attribute mental health problems to pre-existing intellectual difficulties (Reiss & Szyszko, 1983), or because individuals with intellectual disability may have difficulty recognising or expressing their subjective experience of anxiety (Cooray & Bakala, 2005; Mileviciute & Hartley, 2015). Consequently, parents may have to rely on subtle and contextual cues to understand their child's behavioural and emotional reactions (Tarver et al., 2021). Therefore, parents face considerable difficulties in recognising the cognitive and emotional signs of anxiety in children and adolescents with intellectual disability.

Second, parents might also have difficulty identifying the physiological and behavioural signs of anxiety in children with intellectual disability. Individuals with intellectual disability are much more likely to be diagnosed with additional physical health conditions, such as congenital heart defects and gastrointestinal disorders, than the general population (Cooper et al., 2015). These physical health conditions may present with symptoms commonly associated with anxiety, making it difficult to disentangle the effects of each. Similarly, common co-occurring psychiatric conditions, such as ADHD and oppositional defiant disorder, may mask anxiety because they present with overlapping behavioural symptomatology. Furthermore, behavioural signs of anxiety may present differently in individuals

with intellectual disability (Helterschou & Martinsen, 2011) and be more likely to manifest as behaviour that challenges (Khreim & Mikkelsen, 1997; Puijssers et al., 2014). Parents therefore face considerable difficulties teasing apart the symptoms attributable to anxiety and other conditions. Consequently, anxiety may go unrecognised by parents—which can have serious implications for children with intellectual disability, who may miss out on accessing appropriate treatment.

Traditionally, the identification and assessment of mental health difficulties in children with intellectual disability have relied upon the report of parents and staff carers (Costello & Bouras, 2006). However, there are limitations surrounding the accuracy of parental reports of non-observable internal states, such as a child's experience of anxiety (Davison et al., 2022). A child and parent's perception on internal states, such as anxiety, can significantly diverge, especially as a child gets older (Achenbach et al., 1987). Therefore, where feasible, it is pertinent to gain the perspective of adolescents with intellectual disability to better understand the signs of anxiety and the challenges in recognising it.

Similarly, little is known about parent responses to anxiety in their children with intellectual disability. Within the general population, much is known about the parental management of child anxiety. For example, childhood anxiety has been associated with high levels of parental control, including excessive caution, overinvolvement, overprotection and a lack of autonomy granting, as well as parental modelling of anxiety and a reduced use of collaborative parenting practices (Wei & Kendall, 2014). Yet, children with intellectual disability often have high support needs and can be more vulnerable, making it unclear whether these factors are uniform across the populations with and without disabilities. Parents of individuals with intellectual disability often experience mental health concerns themselves (Scherer et al., 2019). In addition, stress levels are higher in families with an individual with intellectual disability and a co-occurring mental health diagnosis than those without (Maes et al., 2003). Therefore, it is unclear whether existing research on parental responses to anxiety in the broader population generalises to parents and their children with intellectual disability which is pertinent in considering the additional difficulties these families face.

Finally, anxiety can have a significant impact on children and their families, particularly if left unrecognised and untreated. Anxiety disorders have been shown to have a negative impact upon children without disabilities' physical health (Gurmankin Levy et al., 2007), academic achievement (Woodward & Fergusson, 2001) and social development (de Lijster et al., 2018). Despite the higher prevalence of anxiety in those with intellectual disability, less is known about the impact of anxiety in the intellectual disability population. Research has demonstrated that individuals with intellectual disability and co-occurring mental health difficulties present with higher levels of functional disability and that their families tend to experience greater family burden than parents of those with intellectual disability alone (Irazábal et al., 2012; Maes et al., 2003). Furthermore, parents of children with co-occurring intellectual disability and mental health difficulties reported feeling helpless and confused and experienced

TABLE 1 Participant demographics.

Demographic measures	Child (n = 6)	Parent (n = 6)
Child's age (M)	15 years (1.8)	48 years (7.1)
Gender		
Girl/Woman	2 (33%)	6 (100%)
Boy	4 (67%)	
Ethnic background		
White	5 (83%)	5 (83%)
Southeast Asian	1 (17%)	1 (17%)
Socioeconomic status (household income per year)		
\$1–\$25,000 per year	-	2 (33%)
\$25,001–\$50,000 per year	-	1 (17%)
\$78,001–\$104,000 per year	-	1 (17%)
\$104,001 or more per year	-	2 (33%)
Family composition		
Two parents	4 (67%)	-
Single parent	1 (17%)	-
Step/blended	1 (17%)	-
Highest level of education		
Completed primary school	6 (100%)	-
Vocational training	-	4 (67%)
Undergraduate degree	-	2 (33%)
Parent's diagnoses		
Anxiety disorder		3 (50%)
Depression		1 (17%)

Note: Standard deviations and percentages appear in parentheses.

difficulties managing behaviour that challenges (Faust & Scior, 2008). While there is some research examining the perceived impact of anxiety in children with intellectual disability from the perspective of parents, there is no research, to our knowledge, that includes those of children with intellectual disability.

1.1 | The current study

There is a dearth of research examining how parents and children recognise, and respond to, anxiety in children with intellectual disability. To address this issue, we conducted individual, semi-structured interviews with primary caregivers of children with intellectual disability and clinically significant anxiety to uncover, first, parents' experience of recognising, and responding to, the signs of anxiety in their children with intellectual disability and, second, the perceived impact of anxiety on their child and their family. We focused on adolescents with intellectual disability in particular, both because internalising symptoms increases throughout childhood, at least according to parent report (Stewart et al., 2022), and

TABLE 2 Parent-reported anxiety severity of children with intellectual disability, based on the Spence Children's Anxiety Scale (SCAS; Spence, 1999).

Measure	Mean (SD)	Clinically elevated n (%)
Total SCAS score	29 (8.4)	5 (83%)
Subscale scores		
Obsessive compulsive	4.5 (2.1)	5 (83%)
Panic agoraphobia	3.5 (1.4)	4 (67%)
Separation anxiety	3.5 (2.6)	2 (33%)
Social anxiety	4.5 (3.9)	1 (17%)
Physical injury fears	5.7 (2.5)	4 (67%)
Generalised anxiety	7.3 (2.8)	5 (83%)

Note: Clinical range represents one standard deviation above the general population mean (Nauta et al., 2004). Higher scores indicate greater levels of anxiety.

because they may be more likely to report their internalising symptoms than their younger counterparts. Critically, we also sought to understand these issues from the perspectives of the adolescents with intellectual disability themselves, who are all too often excluded from research (Thompson et al., 2020).

2 | METHOD

2.1 | Participants

The sample consisted of six parent-child dyads, who were recruited using purposive sampling (see Table 1). To be eligible, children were required to have a diagnosed intellectual disability, sufficient hearing and visual abilities and basic verbal skills, as recognised and reported by parents. They were also required to demonstrate a level of anxiety that impacted functioning or caused significant distress, according to parent report, as well as clinically significant scores on the Spence Children's Anxiety Scale for Parents (Spence, 1999; see Table 2). Four boys and two girls with an intellectual disability, aged between 12 and 17 years ($M = 15$, $SD = 1.8$), met these criteria. Two were reported to have a mild intellectual disability, two a moderate intellectual disability, one a borderline intellectual disability and one a severe intellectual disability, given previously by a general practitioner, paediatrician, clinical psychologist or other recognised professional. Most children had a primary diagnosis of 22q11.2 deletion syndrome ($n = 5$, 83%), while half had a diagnosis of autism ($n = 3$, 50%), and one had a diagnosis of WS ($n = 1$, 17%). Most also reported other co-occurring conditions (see Table 3), especially ADHD ($n = 4$, 67%).

The sample of parents consisted of six mothers aged between 42 and 60 years ($M = 48$, $SD = 7.1$). Three (50%) reported a diagnosis of anxiety and one carer (17%) reported a diagnosis of depression. Most participating parent-child dyads were in a two-parent family ($n = 4$, 67%), while one (17%) came from a step or blended family and one (17%) a single parent household. All parent-child dyads resided in

TABLE 3 Child participant characteristics ($n = 6$).

	Intellectual disability severity	Sex	Age	SCAS total score (percentile ^a)	Parent-reported co-occurring diagnoses
Child 1	Severe	Male	12 years	35 (99.7)	ADHD ASD Developmental delay Language delay Williams syndrome
Child 2	Moderate	Male	15 years	32 (99.3)	22q ADHD ASD
Child 3	Mild	Female	16 years	41 (99.9)	22q Anxiety Depression
Child 4	Moderate	Female	14 years	22 (84.9)	22q ADHD ASD Language delay Developmental delay
Child 5	Mild	Male	17 years	19 (80.7)	22q ADHD, Developmental delay
Child 6	Borderline	Male	14 years	25 (94.4)	22q
Mean (SD)		67% Male	15 years (1.8)	29 (8.4)	

Note: 22q, 22q11.2 deletion syndrome; ADHD, attention deficit hyperactivity disorder; ASD, autism spectrum disorder; SCAS, Spence Children's Anxiety Scale for Parents (Spence, 1999) higher total scores indicate greater levels of anxiety.

^aPercentile ranks were calculated based on a community sample (Nauta et al., 2004).

Australia, with most identifying as White ($n = 5$, 83%), with one identifying as Southeast Asian (17%).

2.2 | Procedure

Ethical approval for the project was granted by Macquarie University's Human Research Ethics Committee (approval number: 52021929526456). All parents provided written, informed consent for them and their children to take part prior to participation. Children also provided verbal assent.

To begin, parents completed an online survey powered by Qualtrics, which included demographic questions and questionnaires measuring anxiety symptomatology. Participants then took part in individual semi-structured interviews over Zoom during which the primary caregiver was interviewed first followed by their child with intellectual disability. Parents were present during the child interview to offer support to their child. Children and parents were asked questions on: (1) how anxiety is recognised in children with intellectual disability; (2) parents' responses to their child's demonstrations of anxiety; and (3) the impact of anxiety on children with intellectual disability and their family (see Appendix for interview schedule). The child interviews were significantly shorter (range: 15–25 min) than the parent interviews (range: 41–60 min), and utilised simplified, accessible language (e.g., focusing on 'worry' rather than 'anxiety'). Interviews were recorded with participants' prior permission and then transcribed verbatim. One child decided not to participate in the child portion of the interview, however their primary caregiver participated in the interview.

The SCAS-P (Spence, 1999) was used to measure parent-reported anxiety symptoms in children. The SCAS-P is comprised of 38 items

assessing anxiety across six domains: obsessive-compulsive disorder, panic/agoraphobia, separation anxiety, social phobia, fear of physical injuries and generalised anxiety. Parents are asked to rate the items on a 4-point scale (*never, sometimes, often, always*). The SCAS-P yields an overall measure of childhood anxiety symptoms, and six anxiety subscales that correspond to DSM-IV disorders. Any scores greater than one standard deviation from the population mean, based on Nauta et al. (2004), were considered to be clinically significant. The SCAS-P is effective in discriminating clinical and non-clinical children in samples without disabilities (Nauta et al., 2004) and, although it was not designed for use with children with intellectual disability, it has been utilised in samples of children with WS and intellectual disability (e.g., Kazzi et al., 2021).

All parents indicated that their child exhibited clinically significant anxiety, which was demonstrated by elevated total scores on the SCAS-P (83% of children) or in one or more of the subscales (see Table 2; $M = 29$, $SD = 8.4$).

2.3 | Data analysis

We used reflexive thematic analysis (Braun & Clarke, 2006) to identify themes within the dataset. Our epistemological stance fits within an essentialist framework, in which we report the experiences, meanings, and reality of the participants. Notably, our team brought a diverse range of perspectives to bear on the analysis, including training in clinical neuropsychology, clinical psychology, developmental psychology and education, as well as experiential expertise of being a parent of a child with a neurodevelopmental condition. We primarily adopted a deductive approach, based on the cognitive behavioural model for

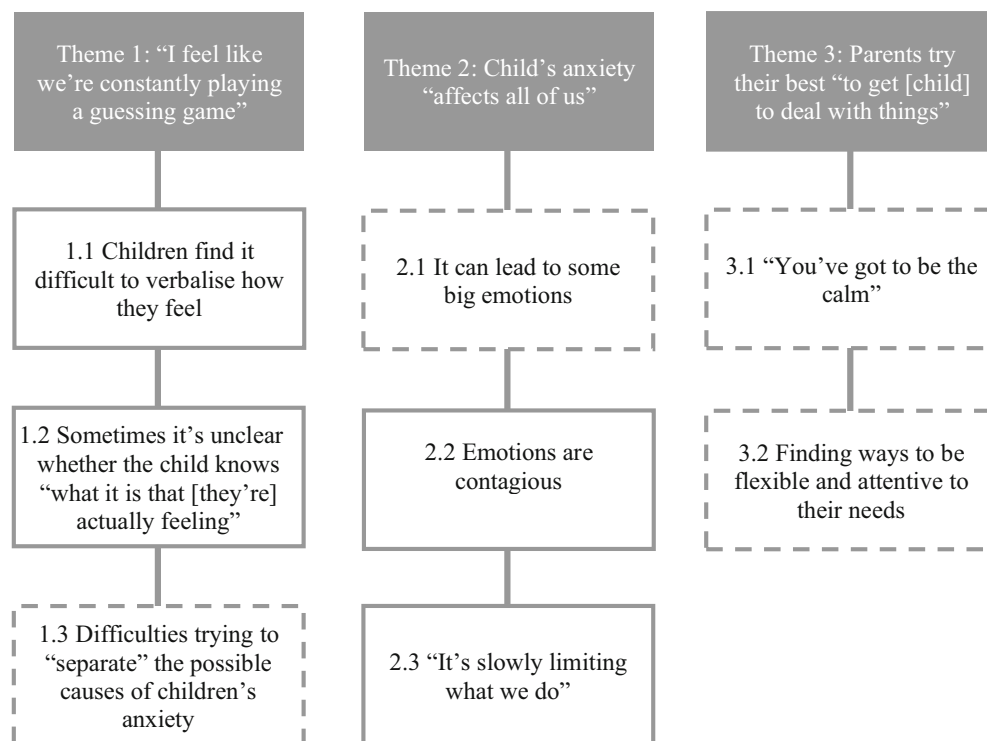


FIGURE 1 Themes and subthemes. Parent and children's experiences of anxiety: themes and sub-themes. Boxes with long-dashed line indicates subthemes predominately endorsed by parents.

anxiety in children and adolescents (Hudson & Rapee, 2004; Perini & Rapee, 2014; Rapee, 2001). Themes that did not fit within this model were captured using an inductive approach.

Once the interviews were transcribed, the lead author (G.F.) read and re-read the transcripts to ensure researcher familiarity. Reflexive notes were taken throughout this process to record any observations or reoccurring ideas. The initial phase of analysis involved coding units of text and assigning a descriptive name, managed in NVivo (version 20), in discussion with a senior colleague (E.P.). The second phase encompassed categorising the codes into preliminary themes which were based upon their similarity or meaning. G.F. generated a draft thematic map to identify overarching themes, and the relevant data were arranged under each theme and sub-theme. The draft analysis was reviewed and revised several times in discussion with EP. Themes were refined and further defined to ensure that themes were qualitatively distinct from one another and ensuring that we focused on semantic features of the data (staying close to participants' language). During the writing process, the themes were revised once again, in keeping with the iterative nature of thematic analysis. The final themes and subthemes were therefore identified through systematic engagement with the data combined with an active and deeply reflexive approach to analysis, influenced by the researchers' own aims, positionalities and interpretation of the data (Braun & Clarke, 2019).

3 | FINDINGS

Following analysis, we identified three themes that corresponded to the research questions, including how participants (1) 'feel like we're

constantly playing a guessing game'; how (2) a child's anxiety 'affects all of us'; and how (3) parents try their best 'to get [child] to deal with things'. Figure 1 demonstrates the themes and associated sub-themes which are also presented in the text below. Whilst many of the themes and sub-themes were derived from the responses of children and their parents, approximately half were predominately derived from parent responses (see Figure 1). Illustrative quotes are attributed with ID numbers (child: IDChild; parent: IDParent) to demonstrate that (sub)themes reflect a broad range of participants.

3.1 | Theme one: 'I feel like we're constantly playing a guessing game'

Parents repeatedly reported challenges with recognising anxiety in their children with intellectual disability, describing 'I feel like we're constantly playing a guessing game' [001-Parent]. There were several aspects associated with difficulties with identifying signs of anxiety in their child.

One key aspect was that *children find it difficult to verbalise how they feel* (subtheme 1.1). In the words of one child, 'it is really hard to explain' [002-Child]. When asked directly about the physical symptoms their child reports when anxious, parents described how their child 'doesn't talk about physical things, like if he's in pain' [003-Parent] and elaborated on the challenges associated with this whereby the '[child] just has no idea [...] we always feel like we're playing a guessing game' [001-Parent]. Parents described how anxiety is expressed by their child as 'just the anger outburst' [004-Parent] rather than through their words. Other parents reported their child

can be reluctant to express their worries, describing an instance where 'I'll say 'are you okay?', 'oh, mum I don't want to talk about it. Can we stop talking about this mum? Okay, I've had enough now' and it's really blunt' [003-Parent]. Despite initial difficulties communicating their worries, some children were able to elaborate on their fears. For example, one child explained their fear of heights: 'I'm worrying about like falling to my death when I see no water around there' [002-Child]. Another child explained their fear of being physically injured while riding a bike: 'I was scared of the pedals because they hurt my legs' [001-Child].

In any case, parents nevertheless felt that *sometimes it is unclear whether the child knows 'what it is [they're] actually feeling'* (subtheme 1.2). Parents described children's lack of awareness into their own worries: 'I don't think she really understands... like, what it is that she's actually feeling, why or, I don't think she can figure that out' [004-Parent]. For example, one parent recalled:

He went back to school one day a week, and then the vomiting started again. It's like reengaging back into life. It's strange. So, for a couple of months, he was vomiting. And then he said to me. 'Why do I keep vomiting on Wednesdays, mum?' [003-Parent]

This sense of 'not knowing' was also reflected in children's responses. When asked about what makes them feel worried, some children replied 'I don't know' [005-Child] and were unable to provide any detail on the physical sensations they experienced when worried. Parents also described how difficulties with understanding emotions can manifest in children's behaviour: 'you can see that she doesn't quite know what's going on, but you know that the change in behaviour is obviously how she's dealing with things internally' [004-Parent]. This was not the case for all children, however, with some being able to recognise and recall the physical sensations that they experienced when anxious. Some children described how they felt 'kind of sick, [...] most the time in my head, get headaches and stuff' [006-Child], others noticed that their 'eyes start to blur' [002-Child] and that they 'felt a bit shaky' [005-Child].

Parents highlighted the *difficulties trying to 'separate' the possible causes of children's anxiety* (subtheme 1.3): 'it's really just unjumbling the mess' [004-Parent]. Parents often reported investigating children's symptoms, but found that '[anxiety is] the only thing that the paediatrician can put it down to... he said, "you know, we've had all the tests done"' [004-Parent]. They also described trying to recognise anxiety through observing recurring patterns in anxious behaviour and by ruling out potential causes. For example, one parent recalled 'he went through this phase like every month he was vomiting. So it [anxiety] would come out that way. Like we had to take him to hospital once because he's, he started vomiting blood. There was nothing wrong with him. We thought it just has to be anxiety' [003-Parent]. Nevertheless, parents reported difficulties with identifying physiological symptoms of anxiety, due to co-occurring conditions, as one mother explained: 'well I'm presuming a fair bit of her stomach [problem] is linked to anxiety, but I think she has also severe IBS [irritable bowel syndrome] so you gotta be careful about that. I don't think it's all imagined by any means'

[006-Parent]. Others were unsure whether symptoms were attributed to health complications associated with their child's genetic condition: 'his heart just feels a bit different anyway so I'm not 100% sure if that's an anxiety thing, or just him' [001-Parent]. Parents reported slowly recognising their child's signs of anxiety over time, which included to 'run from the situation', to 'bursts into tears' [004-Parent], to 'keep asking the same question' and to 'lash out' [003-Parent]. Parents recognised 'but you sometimes aren't aware of all the little things until sometimes it's happening more and more often than not' [001-Parent].

In addition, parents found it difficult to decipher whether children's experiences were attributable to anxiety, intellectual disability or another cause: 'I don't know if it's a teenage thing, or it's a 22q thing. I think it's a combination of both. He's always anxious, always nervous' [005-Parent]. Some parents recounted how 'after the situation, he just easily, you know, he will just forget it, (he) is just gonna go to this computer and playing games then. So, he will be fine' [002-Parent]. As such, they were uncertain whether children were using distraction to manage their worries or their cognitive difficulties made it easier for them to forget.

Teasing apart the causes of anxiety was further complicated as children sometimes masked their worries. Some parents reported 'that he has this anxiety inside of him that he doesn't want to really show you that he is, you know, feeling down, so he still trying to show you know positive that 'I'm alright. I'm alright, it's OK, I can deal with this'' [002-Parent]. Others acknowledged how symptoms of anxiety can go under the radar due to the features of their diagnosis. For example, children with 22q11.2 often present as introverted: 'because she's a quiet child in class, quiet, compliant, what they didn't realise is that you have a severely distressed child, you know, high anxiety child' [006-Parent].

3.2 | Theme two: Child's anxiety 'affects all of us'

Parents spoke of going to great lengths to recognise and understand their child's anxiety—but this also had its consequences: 'I got affected with it [anxiety] every time' [002-Parent].

Parents' responses also revealed how children's anxiety *can lead to some big emotions* (subtheme 2.1). This sentiment was felt deeply by parents, who described, 'I do try and be patient but... there were times that I'd lose the plot and stick my head under a pillow because I can't handle these meltdowns and I do get frustrated with him' [003-Parent]. Another said, 'it just gets so overwhelming that that's the only way its either I cry or scream' [005-Parent]. Parents described the exhaustion associated with providing care for their child, as one mother described:

She tends to get the most upset at the end of the day [...], then I am the one that cops the brunt of it all. And usually by the end of the day I'm exhausted. So, I probably don't deal with it as best I can. [004-Parent]

Parents also spoke of how these negative emotional responses caused feelings of guilt: 'I do feel guilty when I'm like responding in

frustration to him' [003-Parent] and 'I'm just like okay just that, okay enough is enough, you know, and then I feel guilty, of course' [001-Parent].

Parents revealed children's anxiety can often lead to conflict and distress within the family: 'So, [father] doesn't know how to handle situations, in terms of anxiety. So, sometimes it does cause conflict for all of us' [005-Parent]. One parent emphasised the negative impact of a child's anxiety when they recalled, 'looking at those reports going "oh my gosh it [his anxiety] was bad". Looking back, no wonder our life fell apart' [003-Parent]. This parent also reflected how stressful it was at the height of their child's anxiety:

When (child) had a breakthrough and he got a little bit less... or he seemed to have less meltdowns. I always describe it as 'the noise stopped', I did not realise it was so noisy. Like my mum lived on a highway and when the freeway went in, the traffic noise was so loud we did not realise how loud that it was so I did not realise when I'm in it how loud it was [003-Parent].

Similar to parents' emotional responses in subtheme 2.1, participants further highlighted how *emotions can be contagious* (subtheme 2.2). Parents described how seeing their own child anxious had caused greater anxiety in the family with parents being concerned about how their child would cope with anxiety:

I worry that we're not doing enough or giving him enough coping strategies, or if he understands the coping strategies. [...] Yeah, I'm worried that it's happening more often. And that probably the same questions he asked before but now, he thought, he's finding it hard to let go of them. [001-Parent]

Parents were also worried about their ability to respond to the child's anxiety when in the community: 'dealing with my own anxieties about, you know, so it's hard when people don't understand her and how she is' [004-Parent]. Children could also recognise their parents' worries: 'Mum worries a lot more than my dad does. So yeah, they worry a lot. They don't just say 'I'm worried'; they say 'just be careful for when you're going to (somewhere)'' [006-Child].

Beyond the emotional impact of a child's anxiety on families, parents often described how it affects everyday family life: '*it's slowly limiting what we do*' (subtheme 2.3). Some recognised that children's anxiety often prevented them from taking part in new opportunities. For example, one child reported, 'I guess, like, so, with things that I haven't really done before and if it's complicated as well – that stops me from doing it' [006-Child]. Parents also recalled how their child 'doesn't feel comfortable doing a lot of things. Like she won't do dress up days and things like that at school she won't do school sports and things like that' [004-Parent]. They were aware of the negative impact of missing out on these opportunities, observing that if the child was 'able to participate in other things. Like she wouldn't feel left out or not wanting to do stuff with other kids' [004-Parent]. Often, their

attempts to manage their child's worries impacted the activities they could do: 'he was scared of butterflies so for a while we just aborted things outdoors, where we didn't want him to have a meltdown' [005-Parent]. Another parent revealed how managing their child's anxiety impacted family outings and meant they spent less time with their other children: 'because we're trying to calm [child] down or one parent has to go off and one parent has to stay with [child], so it becomes not such a family-orientated family event; it becomes separate' [001-Parent].

3.3 | Theme three: Parents try their best 'to get [child] to deal with things'

Despite the emotional toll on parents, children and families, parents emphasised how much they try their best to support their children and to encourage them to manage their worries effectively. They reported doing so in two key ways. First, parents firmly recognised '*you've got to be the calm*' (subtheme 3.1). They were aware how infectious their own emotional responses could be: 'if I'm calm, he's kind of calm. But if I'm not calm, then he's the same way' [005-Parent]. As one parent remarked, 'when emotions run high, you've got to be the lighthouse' [003-Parent].

Second, parents described in depth that, when responding to their child, it was critical to *find ways to be flexible and attentive to their needs* (subtheme 3.2). On the one hand, parents reported feeling a need to protect their child from experiencing distressing emotions. They often reported adjusting their expectations when their children were anxious: 'so, we're finding that we are changing and altering a few of the things that we do to accommodate' [001-Parent]. They also noted they often 'jump in quickly... I don't like seeing him upset' [005-Parent] and tried to prepare their children for potentially anxiety-provoking situations stating, "'this might be really loud" or "we're going to go do this or" and just pre-empting all those things that are going to happen before they happen' [001-Parent]. They also often engaged in 'just lots of reassuring' [001-Parent] when responding to anxiety in their child: 'I try to reassure him like you know "don't worry about this"' [005-Parent] and 'we reassure him that Mum and Dad will always keep him safe and then if it's not safe, we will let him know' [001-Parent]. Alongside this reassurance, parents also provided 'cuddles' [001-Parent] and physical comfort to settle their distressed child.

On the other hand, parents also reported taking a different approach, instead encouraging their children to face their fears. For example, one parent had recalled telling their child, 'I know you're scared of that, but you know what this is something that we're going to, you've got it, you've got to move past it' [005-Parent]. Another parent recounted the challenging but rewarding experience of pushing their child to go horseback riding when they were experiencing anxiety, 'it was the hardest work ever and you would've thought I was torturing her and then five minutes later she's riding around laughing and giggling on the horse cantering around biggest smile on the face' [006-Parent]. In so doing, parents attempted to instil a positive or

resilient mindset in their child: 'you're gonna be alright. It's part of your learning, part of your growing up' [002-Parent].

4 | DISCUSSION

Here, we examined how anxiety in children with intellectual disability is recognised, and responded to, by children and their parents. To our knowledge, this was the first study to elicit the views and experiences of both informants on this topic. Our findings highlighted the challenges that parents faced when trying to recognise children's signs of anxiety and the emotional impact this can have on parents, who nevertheless attempted to manage their children's worries using a variety of approaches. They also reported how anxiety may have a bidirectional effect, which can influence a parent's approach to managing their child's anxiety and have a significant impact on family life.

Parents reported that there were significant challenges associated with recognising anxiety in children with intellectual disability. Parents often reported that children had difficulties identifying and expressing their worries or their physiological symptoms of anxiety, echoing previous findings (Adams & Oliver, 2011; Mellor & Dagnan, 2005). Furthermore, some parents described how children with intellectual disability may express their anxious feelings through challenging or externalising behaviours, which also aligned with previous research (Painter et al., 2018; Rittmannsberger et al., 2020). Notwithstanding, some children were able to describe their worries and anxieties and could recall the physical sensations they experienced. This finding echoes research from adults with intellectual disability, which showed that they could reliably self-report their emotions (Lindsay et al., 1994). These findings highlight the variability present amongst children with intellectual disability to recognise and express their experience of anxiety. It might also reflect how these abilities may vary for individuals across different contexts. For example, they may be able to better express their worries with particular people in certain settings or in certain emotional states.

Parents also reported difficulties with determining whether certain physiological or behavioural symptoms were associated with anxiety or another co-occurring condition or, further still, if they were developmentally appropriate. The child participants were reported to have often several co-existing conditions, which, as a result, appeared to complicate parents' ability to recognise signs of anxiety. Indeed, they reported needing to engage in health services to investigate thoroughly the complaints to rule out other possible causes. This corresponds with literature highlighting how multimorbidity is highly prevalent in the intellectual disability population (Cooper et al., 2015) and that it can be challenging for clinicians to tease out the possible causes of a behavioural difficulty, whether the cause is organic, non-organic or a combination of the two (Borthwick-Duffy, 1994, as cited in White et al., 2005). Some parents expressed concerns around whether these experiences and symptoms of anxiety could be considered developmentally appropriate, or on par with their mental age equivalence. This highlights the challenge of misdiagnosis of developmentally appropriate phenomena in those with intellectual disability

(Hurley, 1996). Therefore, there are many factors that complicate parents' ability to identify signs and symptoms of anxiety in their child, which might affect their ability to seek out appropriate supports in a timely fashion. While there are limited resources available on identifying signs of anxiety in individuals with intellectual disability, these have not been tailored for children (e.g., Department of Developmental Disability Neuropsychiatry, n.d.). Future research should collaborate with families and people with intellectual disability to develop resources and training to assist with the recognition of anxiety in children with intellectual disability specifically.

Parents reported experiencing a range of distressing and negative emotional reactions when responding to their child's signs of anxiety. Parents themselves were worried about whether their child could cope in anxiety-provoking situations and whether they were providing sufficient support. This finding aligns with research in the population without disabilities which has pointed to the importance of parental attributions and biased interpretations of threat in the development of childhood anxiety (Abramowitz & Blakey, 2020). Similarly, studies in the population without disabilities have found that children's internalising symptoms can affect parental levels of anxiety and that there may be a reciprocal relationship between child and parent mental health (Ahmadzadeh et al., 2019; Murray et al., 2009). In this way, our research reinforces the contagious nature of anxiety in parent-child relationships, such that various child and parental factors interact to amplify or reduce the likelihood of anxiety in children. Future research should examine the impact of parental factors, such as their attributions and threat interpretation bias, on anxiety in children with intellectual disability. It also raises the question whether, in some cases, support should be targeted towards parents, at least in the first instance, and highlights the importance of including parents in the treatment of child anxiety. Treatment of anxiety in younger children without disabilities has been increasingly focused on parental involvement, including as collaborators, consultants or co-clients (Byrne et al., 2021). Yet, parental involvement in the treatment of childhood and adolescent anxiety within the intellectual disability population is hitherto unexplored.

Parents reported employing various strategies when responding to their child's displays of anxiety. Some parents reported demonstrating emotional flexibility, attempting to be a calm presence for their child when they were noticeably anxious, which has found to be less common in interactions between parents of children without disabilities with anxiety, compared to those without (Granic, 2005; van der Giessen & Bögels, 2018). Moreover, parents revealed adopting strategies to prevent their child from experiencing anxiety or distress. For example, they reported accommodating their child's needs, jumping in quickly to handle their child's worries and preparing their child for potentially anxiety-provoking situations. These strategies appeared consistent with an overprotective parenting style, which has often been found in intellectual disability population (Hemm et al., 2018; McConnell et al., 2021) and has been implicated in the maintenance of child anxiety in children without disabilities (Hudson & Rapee, 2004). Parents also reported providing substantial reassurance to soothe their anxious child. Excessive reassurance provision within

the population without disabilities has been implicated in the maintenance of anxiety (Cartwright-Hatton et al., 2004; Rapee et al., 2000; van der Sluis et al., 2015). Future research should seek to examine this factor in the intellectual disability child population.

While many parents reported adopting an accommodating approach, this was not the case for all parents, as others described encouraging their child to face their fears. Previous literature has suggested that this approach may be associated with reduced levels of anxiety in children (Hudson & Rapee, 2004). Ultimately, parents are faced with a difficult decision when responding to their anxious child, whether they protect their child from distressing and anxiety-provoking situations or rather encourage their child to face their fears so they can engage in new experiences and opportunities. Weighing up these two approaches is particularly difficult for parents with a child with additional needs and may warrant specialised support and advice from service providers around how best to approach this challenge in the context of their family. Ultimately, future research should further explore how the dynamics of the entire family unit interact with children's anxiety, as this may help shape future interventions which are tailored to the needs of children with intellectual disability and their families.

In our study, childhood anxiety was found to have a limiting effect on the lives of children and their families—impacting their ability to engage in meaningful activities, such as taking part in hobbies, joining in school activities, trying new things, or engaging with their peers, just like it does in the population without disabilities (Telman et al., 2017). Our parents also described how family activities were at times restricted, as parents accommodated their child's anxiety; this meant families would avoid going to certain settings or may have difficulties going on outings that involved all children in a family. These findings echo those of Tarver et al. (2021) who found that autistic children who spoke few or no words with co-occurring anxiety experienced a somewhat restricted world, potentially reducing their opportunities to engage in activities that they would like to do individually and as a family. Our research therefore highlights the significant impact of anxiety on children with intellectual disability and their family and brings to light the importance of investing time and resources in supporting this group.

4.1 | Limitations

There are several limitations of this study. First, the recruitment of this study was impacted by the disruptions associated with the COVID-19 pandemic. This may have resulted in a sampling bias, whereby individuals who were coping relatively well may have been more likely to take part in the study. They may have been more likely to have established support networks, be engaged in informal supports for their child and more attuned to the signs and symptoms of anxiety that their child was experiencing. Our participating parents also reported themselves to be reasonably well-educated and mostly of white racial/ethnic background. For these reasons, we cannot be sure that the results reflect the broader population of parents of children with intellectual disability and the children themselves, although it is possible that our findings

might be an *underestimate* of the difficulties associated with recognising anxiety and dealing with its impact.

Second, participating parents reported how physical conditions often precluded the recognition of their child's anxiety. We did not ask parents to report on their children's co-occurring medical conditions, but examining the impact of multi-morbidity on recognising anxiety would be a valuable avenue for future research. Third, most child participants had a diagnosis of 22q11.2 and therefore may not be representative of the broader intellectual disability population. Finally, the nature of our questions in children's interviews may have limited their responses to 'worrying' rather than other aspects of anxiety. Future research should seek to understand what anxiety means to this group of children, which should inform further research and practice in this area. Nevertheless, our inclusion of children with varying levels of intellectual disability was a strength of this study given that their 'voices' are rarely heard in research in the intellectual disability population, especially with regard to research on internalising symptoms. However, future research may benefit from examining whether children's experiences and responses to anxiety and are impacted by the severity of their intellectual disability.

4.2 | Conclusions

In sum, our study highlights both the difficulties that parents face in recognising, and responding to, anxiety in children with intellectual disability and the various—and often deleterious—ways that anxiety can impact upon their lives. Nevertheless, parents' persistence to understand and support their children's worries was encouraging. Further research is necessary to understand the most effective ways to support children and parents, in both recognising and managing anxiety.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Research data are not shared.

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APPENDIX A

INTERVIEW QUESTIONS

Core Questions for the Parent interview

1. Does [child's name] get worried or anxious quite a lot? Tell me about it.
2. What does anxiety look like in your child?
3. Could you tell me about a recent situation where your child was anxious/worried?
4. Could you tell me about how you think, feel and behave when you see your child anxious?
5. Tell me about the impact that your child's anxiety has had on your child, yourself and your family?

Core Questions from the Child interview

1. Do you sometimes worry? What sort of things make you worried?
2. Does worry stop you from doing things? Tell me about it.
3. Do you worry more or less than your friends?
4. Does your family worry?
5. Think of a recent time when you felt worried? What happened?
 - a. What did you feel in your body when ___?
 - b. When _____, what were you thinking?
 - c. What is it about ___ that upset you?
 - d. When ____, what did you do?
6. What do your parents do when you are worried?