

- 
- Alice Running
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Parental Blame

and the PDA Profile of Autism

February 2023



"...all we want is provision which meets need, and we are treated as though everything is abuse..."

Alice Running : Danielle Jata-Hall

“They blame me having therapy, not having therapy, being on medication, not being on medication, working, not working... they used to say I'm very cooperative, but as soon as I have refused to continue to use physical force to get my [autistic] child in [to school], they [school professionals] reported me.”

“There is no help just blame. I refuse to discuss my parenting further with professionals because it is viewed as my fault when in fact it works for my 3 children. I do what I have to, to keep everyone happy and safe. The less they know the better. Ultimately, I'm afraid of losing my children because the more you ask for help, the more they pick apart parenting, piling on the blame.”

“It's hard to look for support and help and to feel you can open up and approach a professional when all you feel is judged and blamed and disbelieved...”

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Introduction

Our research into parental blame and the PDA profile of autism was born from the personal experiences of the authors, who have both been subjected to misaligned scrutiny and blame by their respective local authorities in respect of their children's autistic presentations.

This experience is not uncommon, with many families describing their experiences via social media groups on how they have been blamed for their autistic children's presentation or perceived "lack of progress".

As a parent or carer, being blamed for some aspect of your child's disability by professionals working with your child is a frightening and isolating experience. Families with autistic children fear losing their children to the care system, and the associated stigma around this fear can render sources of help as inaccessible.

Our survey – Parental Blame and the PDA Profile of Autism - sought to understand the scope of this fear amongst parent / carers and establish how prevalent an issue parental blame is within the systems of support for autistic / PDA children.

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She co-authored the children's book **I'm Not Upside Down, I'm Downside Up: Not a Boring Book About PDA** and is currently working on a fictional novel for adults called Black Rainbow.

What is the PDA (Pathological Demand Avoidance) profile of autism?

Pathological Demand Avoidance (PDA) is currently best understood as a distinct profile of autism, (O'Nions et al., 2016) with a key identifying characteristic being an anxiety-driven extreme avoidance of everyday demands, and a need for control which permeates all aspects of daily life.

Pathological Demand Avoidance (PDA) is not currently recognised within diagnostic manuals and there is some debate as to whether the label PDA is appropriate, as research hasn't yet shown it to be a discrete category within the autistic spectrum (Green et al., 2018).

Recently developed practice guidance on the assessment and identification of a PDA profile of autism (PDA Society, 2022) explains that identification is necessary because it signposts the specific strategies that help, allowing personalisation and improved outcomes.

It is expected that many children and adults receive an autism diagnosis with a secondary identification of PDA or anxiety based / extreme demand avoidance, or similar terminology.

The recognition of Pathological Demand Avoidance (PDA) varies geographically, and whilst there are many professionals who understand the profile well, there remains a significant number of autism-related clinicians and professionals who either do not recognise the PDA profile or have too little an understanding of the profile.

This impacts the support families with an autistic-PDA child receive and can lead to parent / carers finding themselves under safeguarding scrutiny.

For this study, we have collated information from families who consider their child to present as a child with the PDA profile of autism, whether they have diagnostic recognition of this or not.

What is “parental blame”?

Parental blame occurs when a relevant professional alleges or implies that a parent or carer is somehow causing their child's disability presentation.

For example, an autistic child may no longer be thriving in a school environment and subsequently be unable to attend. Blame occurs when professionals intervene by suggesting that the non-attendance at school is caused by some form of parental failure.

Common forms of blame, in relation to autism and PDA, are:

Professionals stating that they do not observe the same autistic presentations as parent / carers describe.

Professionals requesting that the parent / carer seek parental support in response to a disability need that an autistic child is presenting with.

Professionals requesting that the parent / carer seek mental health support for themselves in response to a disability need that an autistic child is presenting with.

Professionals alleging that an autistic / PDA child's failure to progress against professional expectations is caused by some aspect of the parent / carer's personality, presentation or care for their child.

Professionals alleging that the parent / carer is inventing or exaggerating the needs of their autistic / PDA child.

Professionals alleging that the parent / carer is somehow emotionally harming or neglecting their autistic child, based on observations of the child's autistic / PDA presentation.

Parental Blame and the PDA Profile - Methodology

Our survey was designed utilising a range of 32 questions, to return both quantitative and qualitative information. The survey was created in Google Forms and disseminated via relevant social media platforms (Facebook, Facebook Groups and Twitter) and was accessible worldwide. Access to the survey was not restricted thus allowing for a wide range of participants. Respondents were self-selecting and all data was collected anonymously as per Google Forms functionality. Where additional data has been collected to form part of detailed case-studies, respondents independently chose to submit contact details within their returned survey data, along with permission for researchers to contact them directly (survey participants were not asked to leave any identifying contact details).

The survey was opened for responses on the 16th of April 2022 and closed for responses on the 19th of April 2022. Due to an overwhelming number of respondents, in a short amount of time, researchers decided to close the survey at around 1000 respondents.

Statistical data was quantified as per Google Forms functionality. Qualitative data was coded thematically, and these themes used for analysis.

Our research focus necessitated gaining information directly from families with autistic / PDA children. To ascertain emerging patterns in relation to parental blame we needed to elicit information from families with experience of feeling blamed for their children's autistic / PDA presentations.

Where survey respondents have not felt blamed by professionals, they have stated so and offered explanations for why this may be.

We note that, due to the survey title and dissemination via parent / carer support groups, parent / carers who have been subjected to parental blame may have felt more motivated to participate in this research than those who have not.

What did we want to find out?

Our key research questions:

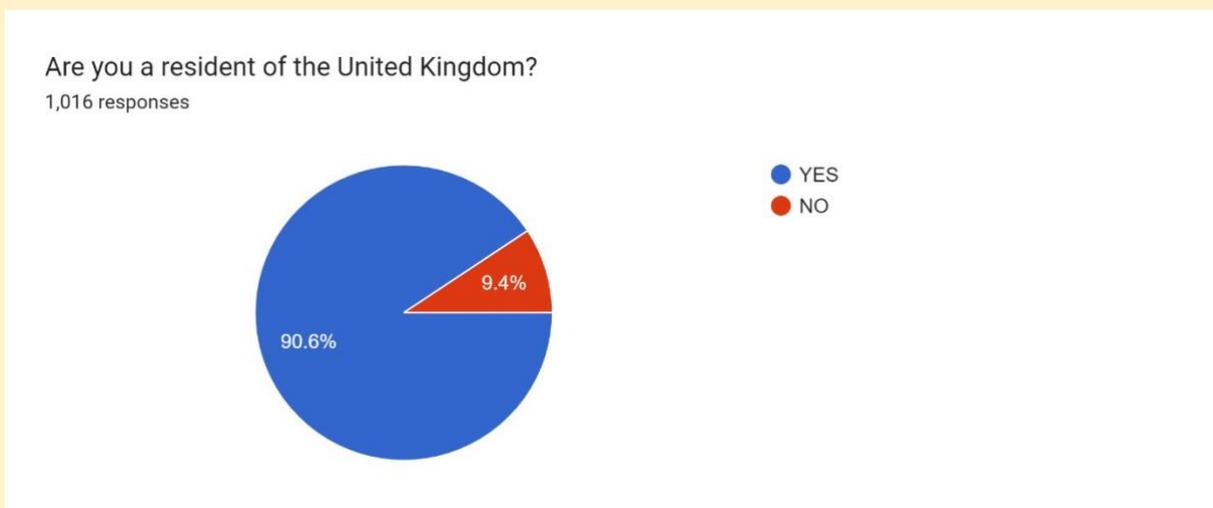
1. How prevalent is parental blame among families with PDA children?
2. Are there any emerging patterns regarding when, how or why parental blame manifested?
3. Are there any types of parents / carers who are more susceptible to being blamed by professionals for their autistic / PDA child's presentation?
4. How does being blamed for their child's disability feel for those parents / carers?
5. What is the effect of such blame upon families?
6. Can we use information from the survey to offer any advice?

Summary Statistics

We had 1016 respondents to our survey – “Parental blame and the PDA profile”.

87.8% of parent / carer respondents said they had felt blamed for some aspect of their autistic / PDA child’s presentation or “lack of progress”.

Who are our respondents:

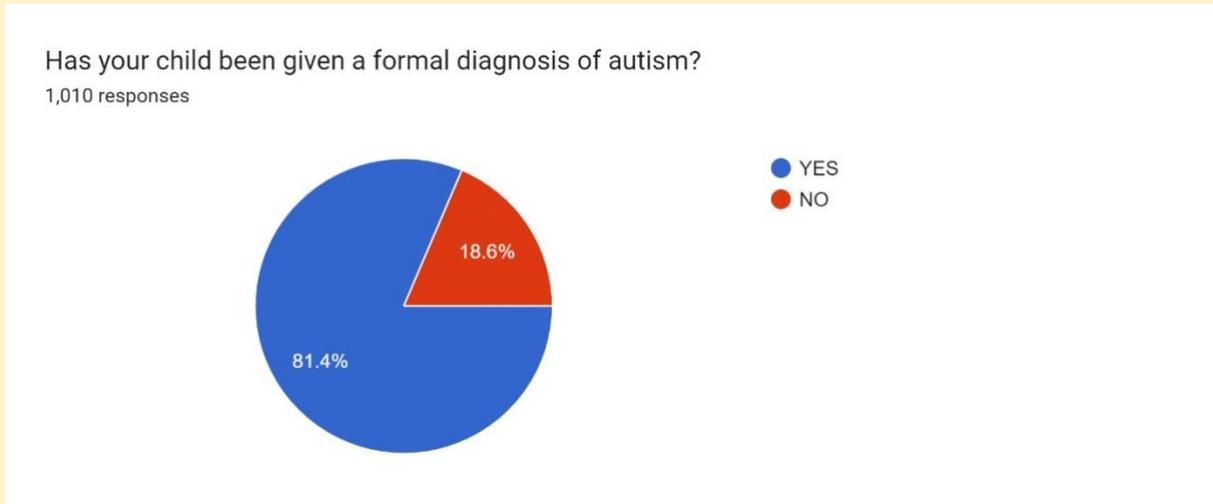


Our survey elicited responses from around the world. Parents and carers from Australia, USA and Europe provided responses, demonstrating that parental blame is not a UK exclusive issue.

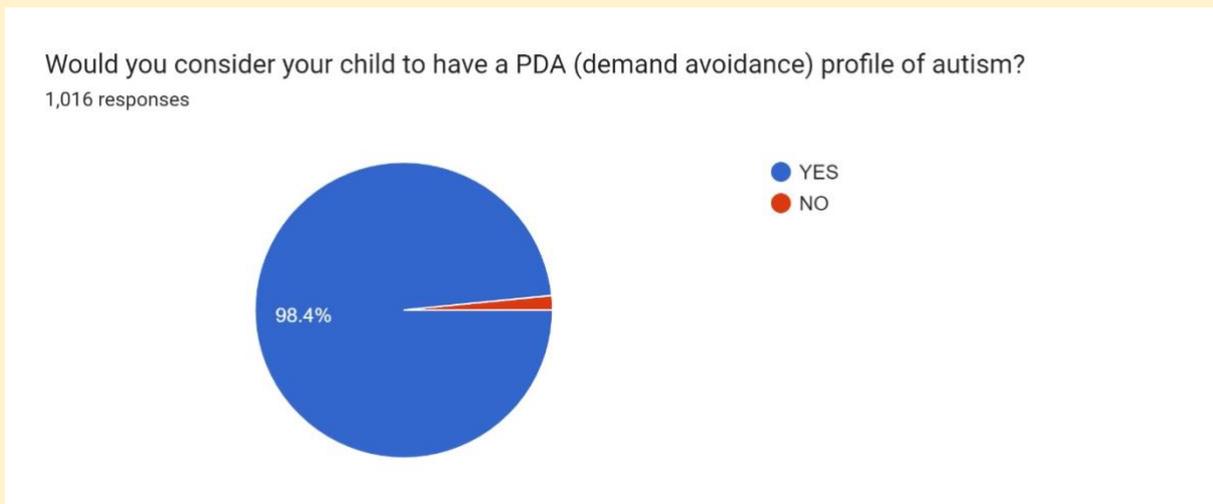
The majority of our respondents categorised themselves as residents of the United Kingdom. (90.6%)

All our respondents, bar one, categorised themselves as parents or carers to an autistic child.

81.4% of our respondents had a child, or children, with a formal diagnosis of autism.



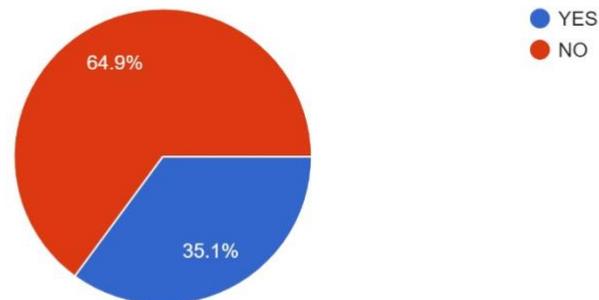
98.4% of our respondents considered their child as having the PDA (demand avoidant) profile of autism.



35.1% of respondents specified that their child had received formal recognition of a PDA profile alongside their autism diagnosis.

Does your child have a formal recognition of a PDA profile specified alongside their autism diagnosis?

1,007 responses



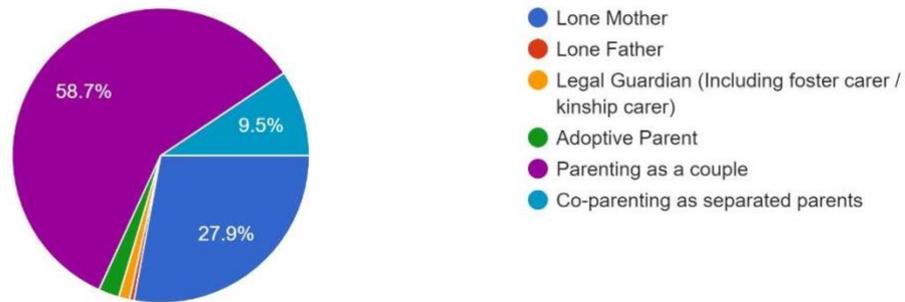
We recognise that formal recognition of the PDA profile of autism can be hard to obtain, particularly within UK NHS services.

We recognise that parents know their children best and seek to inform themselves about their autistic children's presentation regardless of diagnostic status. For this study, we include all respondents who categorised their child(ren) as autistic and / or with a PDA profile, with or without formal diagnoses.

Respondent family make-up

Which category best describes your parental / guardian status?

1,015 responses



58.7% of respondents categorised themselves as parenting as part of a couple.

27.9% of respondents categorised themselves as parenting as a lone mother.

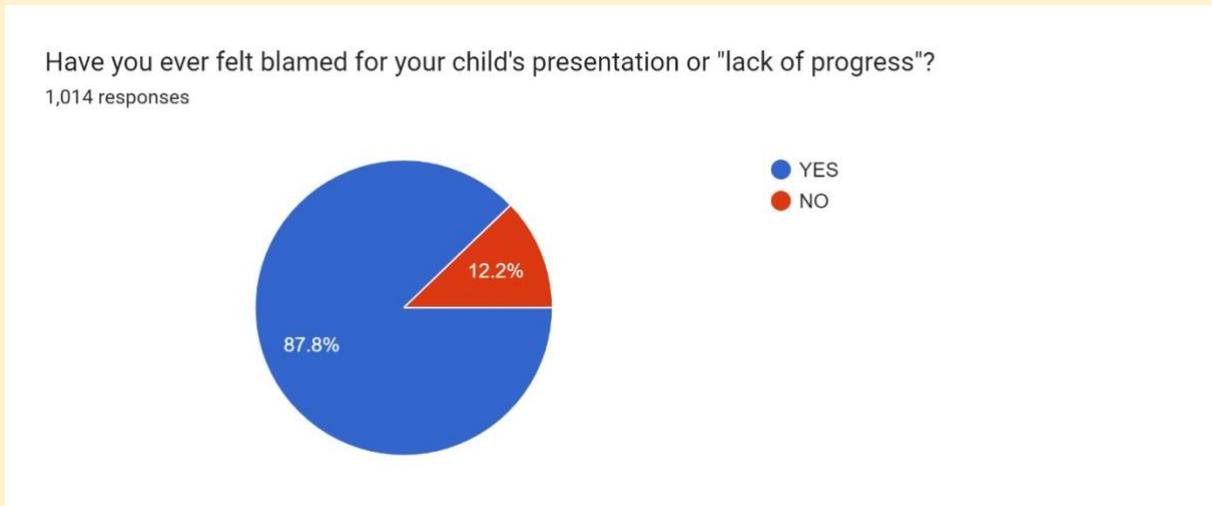
9.5% of respondents categorised themselves as separated but co-parenting. 0.5% of respondents categorised themselves as parenting as a lone father.

Collectively, 37.9% of our respondents are lone parent families.

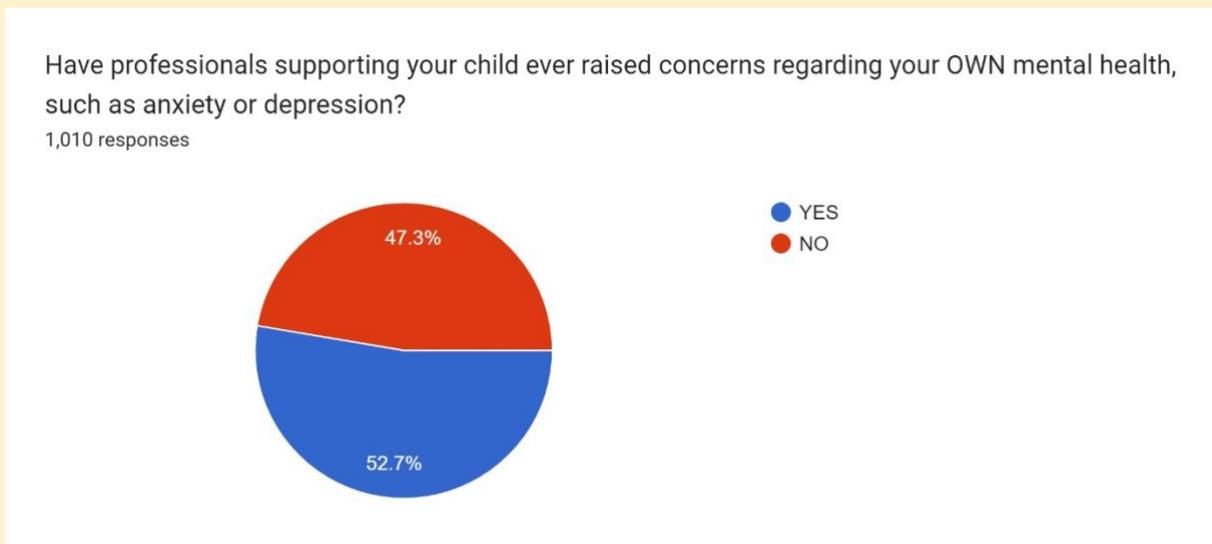
Blame. Setting the context.

Had our respondents experienced any blame for their autistic (PDA) child's presentation?

87.8% of parent / carers said they had felt blamed for some aspect of their autistic child's presentation or "lack of progress".

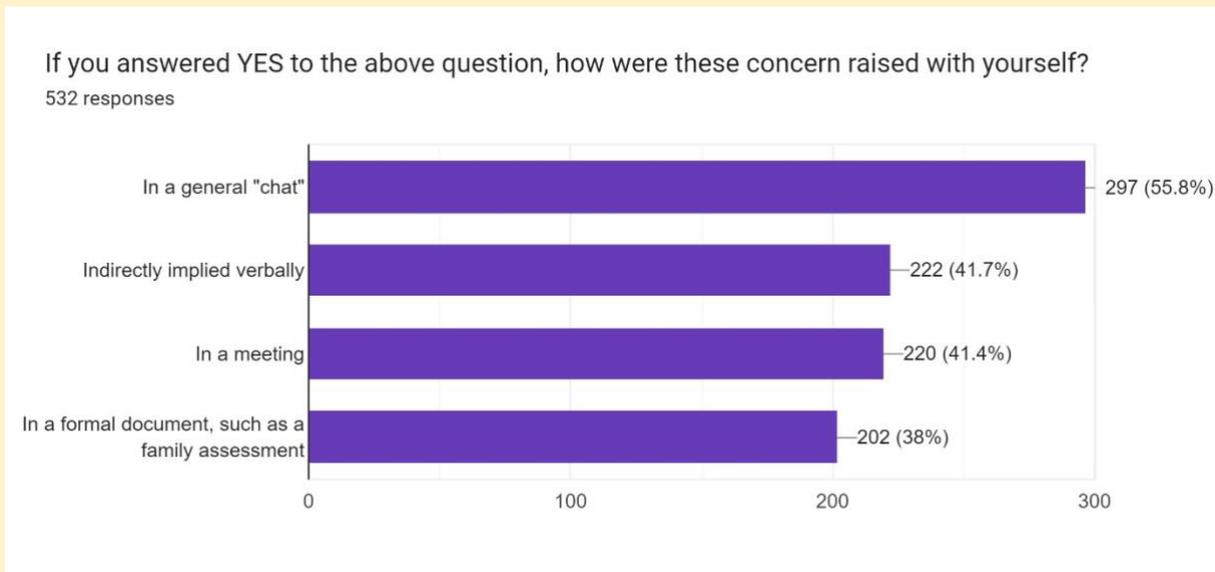


52.7% of parent / carers said that professionals had raised concerns about their own mental health.



A common feature of parental blame is for professionals working with an autistic child to raise concerns about parental mental health (either during the assessment period or when establishing support packages).

532 (52.36%) respondents identified how the concerns of professionals (regarding the mental health of parent / carer) were shared with themselves:



55.5% of respondents stated that concerns were raised about their own (parent/carer) mental health during a general chat. 38% of respondents had these concerns noted formally within documents related to their autistic child.

This is representative of the type and range of blame we were told parent / carers had experienced.

Respondents consistently reported being told by professionals that they – as parent / carers – were somehow at fault for their autistic child’s presentation. Typically, respondents complained of being told that their parenting skills were lax:

#508 *“...told we needed to be firm, do sanctions and rewards etc.”*

Or that some aspect of their own mental health / presentation was negatively impacting their child, thus causing their (autistic) presentation:

#521 *“I have been accused of being over-anxious or seeing problems that are not there.”*

Range of blame

The severity of blame appropriated to parent/carers ranged from comments made by school staff to parents on an informal basis, to formal safeguarding procedures (such as children being placed in care) being instigated.

For example:

Respondent **#60** parents as part of a couple (married or cohabiting) and does not identify as being neurodivergent. Their child has an independent diagnosis of autism. The family is supported via school services. No safeguarding procedures have been brought about. They have received blame for their child’s autistic presentation.

#60 *“Headmaster has said, “I don’t care what label you’ve got for your daughter...” and blamed her violent behaviour at home on inadequate and inconsistent parenting, “because we never see anything like this at school”. Head, deputy and Senco have each separately said the problem is that my children don’t know what the boundaries are at home and have argued back to an extremely insulting degree when I have said this is not true. They constantly tell me both my children (one diagnosed and one not) are fine in school and it’s not possible for children their ages to mask as well as they do. I gave examples of concerning behaviour by my undiagnosed 7-year-old which they and I had witnessed, and they said the common factor was that I had been there, and he’s completely different when I’m not there. They refuse any support in getting him assessed and say if they receive any questionnaires about him, “we’ll just say no to everything””.*

Respondent **#25** is a lone mother, autistic herself and has children with diagnoses of autism from Camhs (NHS). She has been subjected to significant blame, with formal allegations being made against her of emotional harm and neglect of her children by way of Fabricated and Induced Illness (FII) and pseudo-compliance.

#25 *“Apparently, I medicalise my children. [Local authority] have separated me from eldest and put my youngest in care and [are] currently trying to nab my middle one and I’m being criminally prosecuted for alleged wilful neglect of eldest.”* **Qualitative Data in Detail**

How do we identify parental blame? What does parental blame sound like? What are professionals saying to parents?

#12 “Every time I raise an issue my child is having [or] request further support, the school directly reply with a safeguarding concern.”

#28 “School never saw anything (apparently but had to pull him off me each morning for him to attend school) and told us it was a negative attachment causing him not wanting to go to school.”

#317 “[Professionals] claimed I had researched this illness to excuse my son’s poor behaviour... Until I pulled out the paperwork and emails originally given to me by the professional who first suggested PDA! If it hadn’t been for that it would be on my notes / his notes that I was a neurotic mother!”

#304 “I was told that I was causing the problem and seeing things that aren't there because I was so far into a 'rabbit hole”

#502 “A teacher told the school my child was not autistic and that probably her mother was harming her.”

#508 “...told we needed to be firm, do sanctions and rewards etc.”

#521 “I have been accused of being over-anxious or seeing problems that are not there.”

#525 “Because she regulates at school, they said at home it’s my parenting to blame so wasn’t given any funding.”

#531 “They used my personal childhood trauma against me – often saying I was refusing to do things as a result. That I let him have too much control.”

#554 “Senco told me my child couldn’t be autistic as he [had] told a lie, and that all his problems were from home.”

#569 “They [Local Authority] refused to assess us for an EHCP. They said our parenting style of no demands was to blame for school refusal.”

#571 “[The] Local Authority frequently state that my anxiety is causing my child’s anxiety.”

#576 Parent told “child has too much control”, “you cater too much to your child.”

#583 “During [a] school meeting we offered information about autism...we were categorically told no, and it was laughed off by all professionals in attendance.”

#587 Parent told “stop looking for a reason to blame his behaviour and concentrate on strict, firm boundaries as these are clearly lacking.”

#596 “They say my mental health is the cause, yet I don’t have mental health.”

#598 “Pre-diagnosis [they said] anxious mother. Then over-anxious mother. Then depressed mother. Then bi-polar mother. Then rubbish mother.”

#604 “Senco shouted at me [that] there was no way my child had autism, let alone PDA. Told me I put too much pressure on my children due to my own illness. My illness was repeatedly used against me.”

#616 “School said he was happy in school, not autistic, and it was me that needed help.”

#622 “I sent information to my child’s social worker who then turned it round saying I’m looking to label my child and cover up my abuse.”

#626 “School played me and my partner against each other...school criticised that I was advocating for our child.”

#632 “Camhs blamed our parenting and said they could not help as she would not engage.”

#683 Professionals suggested that a “tricky mother /daughter relationship” was the cause.

#707 “[The] teacher said it’s a home problem. Senco accused my child of attention seeking.”

#723 “Social services say getting my son assessed has caused the problems and refuse to involve anyone with autism expertise in our Child Protection plan. They say I must be mentally ill to explain why he behaves differently in my care to his father’s care.”

#773 “School made false allegations that I was going to drive off a cliff with my children in the car to enable them to send the police to my home.”

#778 A professional said, “knowing too much suggests I am making my child autistic.”

#785 “[I was] told I’m enabling him, told that I’m putting words into his mouth.”

#794 “I was told by school that working full-time was impacting my child’s behaviour.”

#825 “Camhs told us his behaviour was controlled and he knew exactly what he was doing.”

#822 “I have been accused of imagining her behaviour to be worse than it actually is due to my physical health condition.”

#892 “I told them I have a younger child with down syndrome and a lot of blame was then transferred to them – it’s because mum is busy looking after younger child.”

#899 “You’ve built your own adjusted world around you son.”

#932 “I was told that my conflict with Camhs had caused my child’s trauma.”

#968 A parent was asked “how are they [the child] supposed to fit into society when they’re older.”

#970 “The school said I’ve made him sick with multiple diagnoses, [that] I am diagnosis driven.”

#977 “The social worker laughed and said she’s not disabled, it’s you. The social worker then went on to place me in a cell and interview me [under] caution.”

Section Summary

It is notable that similar phrases, with the same function, are being said to parents across the UK and beyond.

Parents are being told by professionals that they do not observe the same presentation of the child, as reported by parents.

Parents are being told directly by professionals that some aspect of their parenting is causing their autistic child’s presentation.

Parents are being told by professionals that they have mental health issues.

Many of the professionals stating such as the above, are first tier school staff and not clinicians in the field of autism or mental health.

The ramifications of such are that no support, or the wrong support, is being put in place to enable autistic / PDA children to thrive. Parents are instead categorised as presenting a safeguarding risk to their children.

Patterns of Vulnerability

Do parent / carers recognise any patterns or reasons as to why professionals blame parents, or why some parents are more / less targeted?

#42 “I think my marital status, material wealth and professional credentials have provided me with a level of cushioning and validation amongst agencies. I noticed a shift in treatment when moving from a 2-bed ex council house to a larger detached property in a relatively affluent area.”

#85 “I feel incredibly lucky that I have not encountered the same prejudice as many friends with similar profile children, I think my married status helps although it shouldn't!”

#90 “I wonder if it's because I am a Dr and [my] partner [a] headteacher but we have not been accused of being responsible for our children's difficulties and behaviour.”

#120 “As adoptive parents, I think we're less likely to be blamed by professionals.”

#176 “I volunteered my profession and aspects of my job which directly related to being autism aware and identifying behaviours. I was then accused of "teaching" my child to be autistic.”

#218 “I think that we are fortunate. I work for the NHS and am well respected in our trust. I know our child's guidance teacher and head of school personally. I'm not sure that I would be answering the same if I wasn't known within the bodies who make the decisions as our other daughter who is dyslexic the experience has been slightly different with the school but still not negative.”

#245 “Professional status spares me from a lot of judgement.”

#279 “I'm married now and professionals treat me and my husband far differently than they did me when I was on my own.”

#347 “I have a degree in SEN [special educational needs] and inclusive practice, that’s why school didn’t blame me face to face...I’m a practitioner [and] I have never met anyone who understands PDA or even genuinely wants to accept these children.”

#383 “As a single mum I face stigma and blame for my son’s behaviour.”

#400 “I’m a social worker and work in the area of mental health with lots of ND [neurodiversity] overlap. I feel as though my professional role has been an advantage.”

#508 “We had the means to pay for an independent assessment and the means to pay for a school that can meet his needs. This means we are not having to fight underfunded and overworked schools for accommodations and understanding they are actively disincentivised from providing.”

#616 “[The] paediatrician said no to autism at stage one until my mother, who is a retired doctor, wrote to them, then they said yes in assessment two...my child is mixed race...I believe my history of domestic violence and child’s mixed race led to years of zero support or diagnosis and parent blaming.”

#633 “I am certain that because we’re married, heterosexual, well-educated, white, and comfortably off that we get full respect from professionals that work with us. They have nothing to pin on us and we never cause a fuss.”

#722 “As musicians it was suggested that as creatives, we probably don’t have much structure to our parenting.”

#772 “Parental blame is the first strategy they use to avoid having to pay money.”

#829 “If we didn’t have the means to pay for support, I dread to think where we would be.”

#885 “I am shocked about the lack of understanding amongst education and social care professionals of demand avoidance in autistic children.”

#901 “It was explained to me that had I not been a primary teacher, I would have been sent on a parenting course...I have had it implied that being a single parent is part of the problem.”

#1010 “I told them [professionals] I was training to be a person-centred psychotherapist; I believe this is why [school] said I was medicalising his anxiety.”

Profession of Parent / Carer

Parent / carer respondents cited their professional status as a protective factor against being blamed for their autistic / PDA child’s presentation:

#42 “I think my marital status, material wealth and professional credentials have provided me with a level of cushioning and validation amongst agencies. I noticed a shift in treatment when moving from a 2-bed ex council house to a larger detached property in a relatively affluent area.”

#90 “I wonder if it's because I am a Dr and [my] partner [a] headteacher but we have not been accused of being responsible for our children's difficulties and behaviour.”

#218 “I think that we are fortunate. I work for the NHS and am well respected in our trust. I know our child's guidance teacher and head of school personally. I'm not sure that I would be answering the same if I wasn't known within the bodies who make the decisions as our other daughter who is dyslexic the experience has been slightly different with the school but still not negative.”

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CASE STUDY #546

We identified a parental respondent whose professional status as an NHS Psychologist did not protect her from being accused of emotionally harming her child.

Respondent #546 was accused of fabricating and inducing illness (FII) in respect to her child's autistic / PDA presentation, leading to two initial child protection conferences (ICPC) being undertaken.

#546 *“My daughter was an inpatient twice at 10, to observe for FII (I didn't realise at the time) then sectioned age 14. A Camhs psychiatrist first mentioned PDA but from then on, his colleagues scoff if I mention it saying it is not recognised here. They have made no progress in helping and have subjected us to 2 child protection conferences, social care just used their safeguarding social workers with no expertise in complex autistic presentations and the disability social care refused to take us on as no learning disability. Referral for PDA assessment turned down. 5 years on we are broken as a family and blamed for this too. I try to stay positive but living in hell scared of what they will do next.”*

We undertook a further detailed interview with respondent #546 and compared the qualitative data from this with other parental respondents who had cited that their professional status had protected them from blame, to further understand what additional factors may have resulted in blame being apportioned in this instance.

Parent respondent #546 is a lone mother. She is an NHS Psychologist and is autistic. She has made formal complaints against services involved with the care of

her child. Her child has a formal diagnosis of autism via Camhs – NHS, which was given at age 13. Her child has an Educational and Health Care Plan in place (EHCP).

Respondent #546 encountered difficulties with having her child formally assessed for autism.

“[At] age 10 she was struggling massively - severe OCD, unable to attend school. Psychiatrist asked two questions, does she have friends and can she make eye contact. As both were yes, he dismissed autism altogether. He was the Camhs local lead for the neurodevelopmental assessment service! A few months later when an inpatient at the Priory their psychiatrist said she thought she was autistic, but they were unable to get my daughter to do the ADOS and didn't seem able to assess via observation instead. The following year a different local Camhs team agreed to assess but were unable to find a way to observe my daughter and eventually discharged her. She was finally diagnosed after being sectioned in an NHS adolescent mental health unit.”

Further difficulties were encountered when respondent #546 applied for an EHCP for her child.

“No help from professionals, I had to apply myself when my daughter was 10. This was after spending months as an inpatient. The Camhs keyworker refused to help saying “other children with autism go to school”. The Sendco claimed she was fine at school despite being hardly there, unable to join her class, eat, wear school uniform. The LA agreed to an EHCP. Rather than support the emphasis was on trying to force my daughter back to school even though she was so unwell with OCD that she would spend up to 12 hours trying to get ready to go.”

Respondent #546 implemented formal complaints regarding CAMHS service provision.

“For a long time, I didn't complain as [I] wanted to focus all my energy on helping my daughter. Eventually I went to my MP and later used the CAMHS complaint procedure. This was because my daughter asked me to complain when Camhs instigated her being dragged naked and handcuffed by 4 police officers to A and E in an ambulance and then Camhs left her there wearing just a blanket and a taxi ordered to take her home. Age 13. I detailed my complaints against the service that had led to this point. All I got from that and from the MP intervention was a defensive reply. When she was an inpatient, I used PALS [NHS healthcare complaints procedure] and wrote to the chief executive as they insisted on opening the toilet door regularly to see her when she was naked, further traumatising her. Again, all I got was defensive responses.”

The professional status of respondent #546 was cited in formal safeguarding procedures.

“In the report for the child protection conference when my daughter was 10 it stated that they were concerned that I was using my professional knowledge of OCD to make up my daughters’ problems.

The first social worker who was overseeing the FII investigation knew me from when she was a volunteer where I used to work, and I was her supervisor. This was wrong on so many levels. The psychiatrist who was part of the accusation also knew of me professionally and referred to this with me as did the social worker.”

Respondent #546 considers her status as a lone mother to be a potential factor as to why she has been blamed, rather than supported, for her child’s autistic presentation.

“My friend who has 2 autistic children and had a very different experience told me she thought I had been treated badly because I am a lone parent.”

Respondent #546 self-identifies as an autistic person but does not have a formal diagnosis. Professionals working with her, and her child are not aware of her own neurodivergent presentation. Respondent #546 describes this as being problematic.

“All communication with them [professionals] is difficult, I think this is because it triggers PTSD from everything that has happened and my expectations of being judged. All meetings are now video consultations, I would rather do phone or face to face.”

Respondent #546’s autistic communication style has been cited within safeguarding reports.

“In a report they judged me for talking in an animated way about my daughter. I asked an advocate for feedback after a difficult meeting, and she said that other parents tend to keep quiet when psychiatrists are recommending things that are unhelpful whereas I will respond. This instance was when the psychiatrist was trying to take my daughter off her antidepressant which is the only thing keeping her fairly stable. Eventually their psychologist persuaded her not to.”

“I provided diaries and lists and videos [to professionals]. These were used in child protection attempts and evidence of FII.”

We identified further instances where parent respondents cited their professional status had been raised within safeguarding concerns:

#803 *“I’m an ex-teacher with a psychology degree. Still gaslighted. Educational Psychologist at school said my son’s behaviour was [an] attachment disorder with me.”*

Respondent **#803** is a lone mother who identifies as neurodivergent (ADHD). She is a teacher. She has used legal redress to appeal an unsuccessful application for an EHCP assessment. Her child has an independent diagnosis of autism. Education

attendance and welfare protocol have been instigated with regards to her child, but not child protection procedures.

#971 *"[The] fact that I was a mental health professional myself was written as a safeguarding risk."*

"Following PDA parenting advice and about sons' meltdowns and self-harm attempts - it was implied it was my fault rather than his PDA or reaction to citalopram and I was put under section 47 investigation - horrific time."

Respondent **#971** is a lone mother who identifies as neurodivergent (autism). She is a mental health professional. She has used formal complaints procedures to address issues regarding service provision for her child. She has been investigated to ascertain whether she was inflicting emotional harm to her child (FII) under safeguarding measures (Section 47).

We identified further instances where parent respondents cited their professional status as being protective against blame / safeguarding concerns being raised:

#90 *"I wonder if it's because I am a Dr and [my] partner [a] headteacher but we have not been accused of being responsible for our children's difficulties and behaviour."*

Respondent **#90** parents as part of a couple. One parent is a doctor, and the other parent is a headteacher. They have used legal routes to appeal a decision in relation to their child's EHCP. Their child has an independent diagnosis of autism. At least one parent identifies as neurodivergent (autism / other learning difference). No safeguarding concerns have been raised. They have never felt blamed for their child's presentation or 'lack of progress'.

#611 *"We haven't been accused of [the] worse things and have been generally listened to, which we attribute in part to our white, middle-class background. Dad is a clinical psychologist – we can afford to pay for professionals who are experts in PDA."*

Respondent **#611** parents as part of a couple. The father is a clinical psychologist. They have not used any legal or complaints procedures to secure decisions or services for their child. Their child has an independent diagnosis of autism with PDA. They identify as neurodivergent (ADHD / autism). No safeguarding concerns have been raised.

#859 *"I'm knowledgeable and have studied psychology and I'm a family therapist...this is what has saved me from professionals penalising me. But it's also hindered me as they tell me I know what I'm doing and I'm too much of a good mum to receive help."*

"Everyone hates me because I'm a know it all and I fight for my children's rights."

Respondent **#859** parents as part of a couple. The mother is a family therapist. They have used formal complaints procedures in relation to services provided for their

child. The mother identifies as neurodivergent (ADHD / dyslexia). Their child has a diagnosis of autism via Camhs, NHS, with Camhs also recognising the PDA profile. No safeguarding concerns have been raised.

#907 *“My husband and I are lawyers. [This] has particularly helped to get school to provide adequate support.”*

Respondent **#907** parents as part of a married couple. Both parents are lawyers. They have used legal routes to appeal a local authority EHCP decision and have used both disability discrimination law and formal complaints procedures in relation to decisions and/or services made/provided for their child’s care. They do not identify as neurodivergent. Their child has a diagnosis of autism via Camhs, NHS. No safeguarding concerns have been raised.

Section Summary

It is notable that in the examples given above (within this section):

Where parents are stating that their profession(s) has (ve) afforded them protection against safeguarding allegations, the parents are parenting together – as part of a couple (married or cohabiting). No safeguarding concerns, allegations or procedures have been raised or instigated in these examples.

Where professional status has been directly raised during safeguarding procedures, the parent is both a lone mother and neurodivergent (predominantly autistic).

If we directly compare respondent #546 with respondent #611, both families have parents who are psychologists. Both respondents identify as neurodivergent (autism). Yet it is the lone mother who has her profession and autistic presentation noted in formal reports as safeguarding concerns.

We recognise that we were unable to directly compare the ‘complexities’ (or not) of the children’s autistic presentation and how much external service support was requested / required for the care/support of respondent children. Therefore, we are not able to rule these factors irrelevant within these case study comparisons.

Safeguarding Procedures

Out of 1016 respondents, 111 families (10.93% of respondents) had been subjected to some element of formal safeguarding procedures which cited the parents / carers at fault for the child’s autistic presentation.

By ‘formal safeguarding procedures’ we are specifically referring to:

* Child protection enquiries and investigations

- * Initial child protection conferences
- * Children placed on a Child in Need Plan where parents have been identified as being at fault
- * Children made subject to a Child Protection Plan
- * Children made subject to Public Law Orders such as Supervision or Care order
- * Children removed from the family home and placed in care by the local authority
- * Criminal investigation and / or prosecution of parents

Where safeguarding procedures have been undertaken but for a reason other than concerns parents are causing harm resulting in child's autistic presentation (such as domestic violence), these responses are not included here.

Where children are being supported under safeguarding plans reflecting their disability needs without apportioning blame to the parents, these responses are not included here.

Of the 10.93% of respondents subjected to safeguarding procedures, the following characteristics have been identified:

Family make-up

Lone mother: 64/111 (57.66%)

Parenting as a couple: 40/111 (36.04%)

Adoptive parent / other legal guardian: 4/111 (3.6%)

Lone father: 3/111 (2.7%)

Childs Diagnostic Status

Children with a diagnosis of autism and / or PDA via CAMHS (or other NHS body): 76/111 (68.46%)

Children with a diagnosis of autism and / or PDA via an independent professional: 33/111 (29.73%)

(This includes children who may have a PDA diagnosis in addition to an autism diagnosis given elsewhere.)

Children with NO diagnosis of autism and / or PDA: 17/111 (15.32%)

Use of Legal Redress

For clarification, by 'legal redress' we are referring to parents who sought to challenge local authority decision making (relating to their children's needs) via any of the following: formal complaints procedures / judicial review / Sendist tribunal / discrimination law.

Parents or guardians that undertook legal action in relation to their child: 85/111 (76.57%)

Neurodiversity of Parent(s)

Parents that identified as neurodivergent: 85/111 (76.57%)

Section Summary

It is notable that, from the 111 families that have been subjected to safeguarding procedures in relation to their child's presentation, neurodivergent parents (76.57%) and lone mothers (57.66%) make up most of this cohort.

By comparison, 52.5% of the general survey population identified themselves as being neurodivergent, indicating a statistical significance. This leads us to suggest that lone mothers and neurodivergent parents are the most susceptible to formal safeguarding measures being implemented.

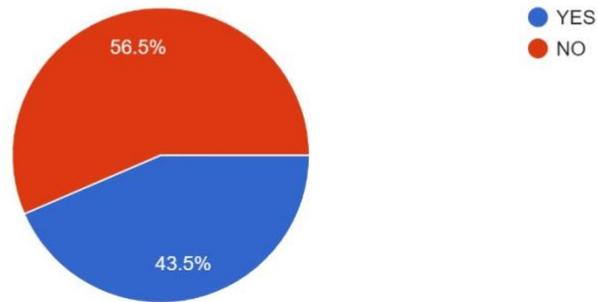
It is also notable that 68.46% of families subjected to formal safeguarding procedures have children with formal NHS / CAMHS diagnoses of autism. This leads us to suggest that having a child with a formal diagnosis of autism via NHS / Camhs, does not protect against those parents having safeguarding allegations made against them regarding their child's autistic / PDA presentation. Why is this? We would suggest that once a child receives an accepted diagnosis via NHS / Camhs, it is expected that an autistic child make "progress" following post-diagnostic support and intervention. With less information around PDA presentations of autism and / or autistic anxiety available to professionals, generic autism support may exacerbate a child's "difficulties" leaving professionals with nowhere to go other than to blame parents for lack of expected "progress". In the extremity, this can lead to accusations of emotional harm or neglect.

Use of legal redress by the families subjected to formal safeguarding procedures is high (76.15%), but instances of parent / carer's using legal redress in the general respondent population is also high meaning that we cannot say with any certainty if using legal redress offers a protective factor against safeguarding procedures being instigated, or not.

Parent / carer's from the general respondent population told us the following:

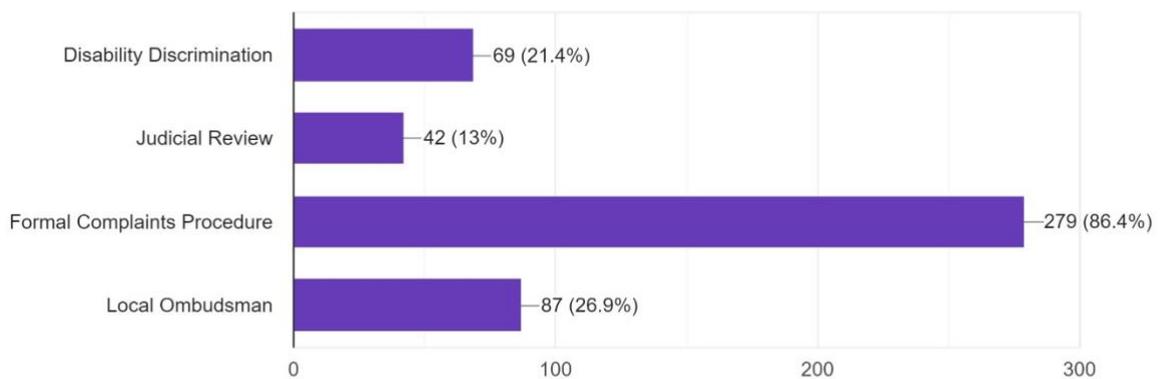
Have you ever had to appeal a decision relating to an EHCP? Including, refusal to assess and appealing contents / placement.

945 responses



Have you ever had to take any of the following legal actions in relation to your child's education, health and social care? (Tick all that apply.)

323 responses

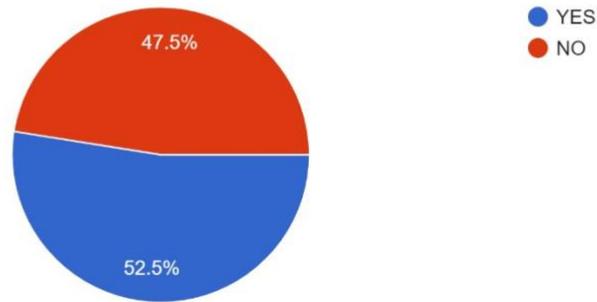


Autistic / Neurodivergent Parents

52.5% of parent / carer respondents identified as neurodivergent.

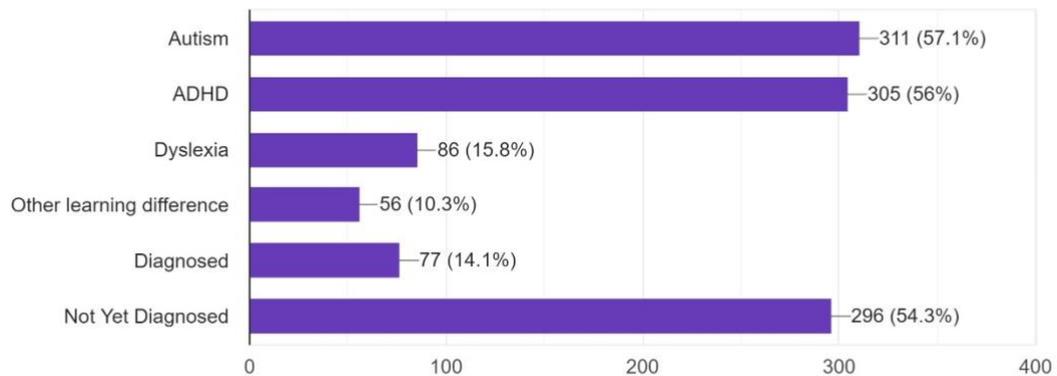
As a parent / guardian, do you identify as neurodivergent? (Neurodiversity refers to all neurodiverse conditions such as dyslexia, autism, adhd...)

1,011 responses



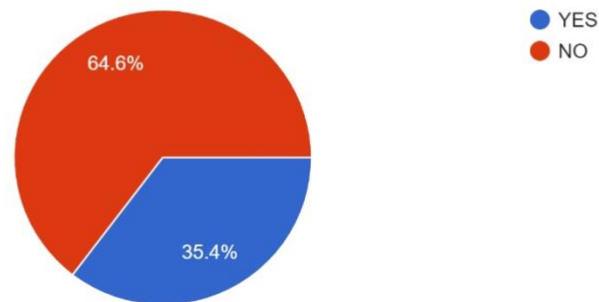
If you answered YES to the above question, which of the following apply to YOURSELF? (Tick all that apply.)

545 responses



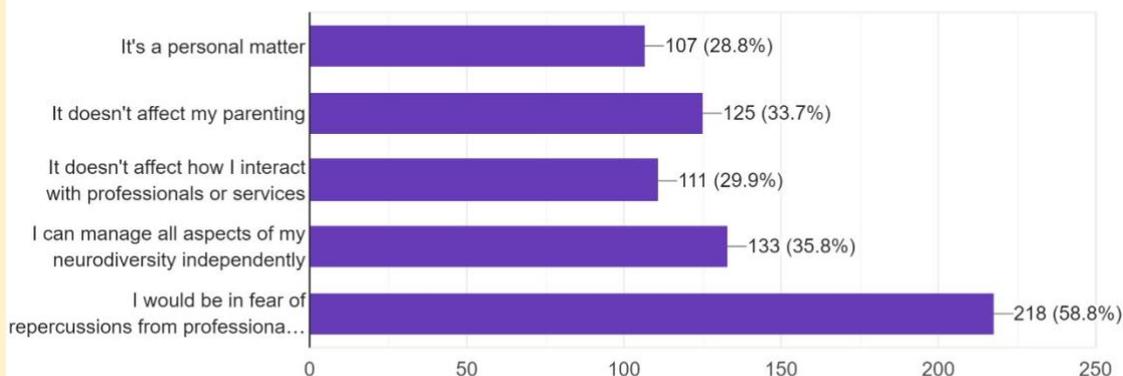
Are professionals working with your child aware of your neurodiverse status?

622 responses



If you have chosen NOT to reveal your neurodiverse status to involved professionals, why do you think this is? (Tick all that apply.)

371 responses



Parent / carer respondents commented upon how their own neurodivergence had been perceived by professionals working with their children:

(Note, all the following respondents have identified themselves as neurodivergent within the survey.)

#12 "My mental health is raised despite me telling them I have no mental health concerns." (Respondent is autistic with ADHD.)

#64 "The HSLW [health support worker] even gave written examples to justify "her professional opinion" about how my anxiety presented - e.g. I wrote long emails." (Respondent is autistic with ADHD.)

#161 “They suggested ... I am manipulative.” (Respondent is autistic.)

#438 “Apparently {according to professionals} my black and white view of things gets in the way.” (Respondent is autistic with ADHD.)

#766 “They [professionals] all judge [me]. [They] think it’s something to do with my mental health (prior to my diagnosis especially), many mainstream professionals presume I’m just crazy not autistic. My communication during an appointment can be very disorganised, we can all mask etc - I need to prep and bring notes.”
(Respondent is autistic with ADHD.)

#774 “I was told that the school SendCo wouldn’t consider looking into support for my son until me and my husband had sorted our mental health concerns out.”
(Respondent is autistic with ADHD.)

#846 “When my son was 4, I asked for an ASD assessment [for him], report came back [stating] it was an attachment problem, and the Dr refused any further support or assessments. Report said I was hindering his development due to mental health issues I had as a teenager. I was sectioned as a teenager and this was used against me multiple times when my son was younger, including refusal for assessments.”
(Respondent is autistic.)

#928 “I was accused by the Senco of having an unfortunate manner.” (Respondent is autistic.)

Section Summary

The majority of parent / carer respondents identified themselves as being neurodivergent (52.5%), with the majority of these neurodivergent parent / carer’s further identifying themselves as autistic / ADHD / or both.

The majority of neurodivergent parent / carer respondents reported choosing not to disclose their neurotype to professionals working with their child (family). (64.6%)

The majority of neurodivergent parent / carer respondents reported being in fear of repercussions from professionals should they disclose their ND status. (58.8%)

The qualitative data presented above demonstrates how some professionals have viewed neurodivergent parent / carers in a negative way, misidentifying neurodivergent presentations as mental health issues or parental obstruction – both of which are often further categorised as safeguarding concerns. This highlights a nationwide professional ignorance to how both neurodivergence presents, and how occurring neurodivergence is within family units.

For those parent / carers who are in fear of disclosing their neurotype to involved professionals, they miss being eligible for reasonable adjustments around working with professionals (which should make communication and interaction with professionals more accessible).

Qualitative Data in Detail

How does being blamed for your child's autistic / PDA presentation make you feel?

What are the effects of being blamed for your child's autistic / PDA presentation?

#33 "I am a teacher and having social work involvement with my family caused me great stress. Especially when I know the education professionals are acting illegally, yet they have the audacity to blame our home. It has made us less willing to take him places in case someone reports us."

#42 "Both myself and partner have had increased anxiety and Autistic burnout running ourselves to exhaustion trying to get our child's needs met. I began to become suicidal a few years ago."

#52 "The forceful nature of what social care services did to my child left her distrustful, having physical symptoms of anxiety and more social communication problems when engaging with services. My daughter has been at a point of complete refusal to engage with anyone outside of the family home for the last 2 years."

#170 "Lack of early intervention and no action to support left my child to have three complete breakdowns over a two-year period. Our child has PTSD specifically from the school experience. I was also assessed for PTSD symptoms and scored highly but I didn't want that written anywhere for fear of repercussions. My symptoms relate specifically to my treatment by professionals whilst trying to support my child."

#175 "...son has deteriorated since services put in place."

#176 "My personal career has been impacted by attempts to imply my parenting is unacceptable. Even when no formal charges are brought, much damage can be done. We have been left isolated and there has been a great deal of hostility."

#193 "...too scared to ask for support for my second child."

#199 "I am completely exhausted having to explain PDA to everyone."

#213 "I cry when I have alone time, which isn't very often."

#367 "There is no help. People give words. But words don't help. It feels like a prison with an impending sense of doom and despair."

#370 "Dealing with the SEN team has broken us. All we want is provision which meets her needs, and we are treated as though everything is abuse...and not a basic right."

#409 “I’m being slandered, gaslighted and bullied all over again...[I] suffer panic attacks.”

#418 “[Blame] made it difficult for me to feel that we were being seen or taken seriously. I think I had a breakdown.”

#440 “It’s crushing us, the constant watching.”

#470 “I was threatened with being reported to social care for not protecting her. This was said in front of her, and she stopped telling anyone (including me) when things were wrong because she was frightened of being taken away. I felt like I couldn’t ask for help -I work with children and my daughter’s school told me it would affect my DBS and future employment opportunities I was -and still am - broken.”

#505 “Involvement with professionals made parenting harder. I get no help, just blame. I have PTSD about this period.”

#511 “I began to believe that the issues are my fault and so I stopped asking for help.”

#512 “I ended up having a breakdown and ended up in a secure unit for two months. This was when the Local Authority refused to look at alternative provision for my daughter, despite the fact she wasn’t going to school.”

#515 “...made me question my ability in my job which is twenty years of SEND education.”

#517 “...made me feel isolated from mainstream society.”

#520 “It’s destroyed my marriage as no time for anything other than advocating for two kids.”

#529 “Involvement of professionals has led directly to violence from daughter. Every professional involved has led to worsening situation, so I don’t ask for help anymore.”

#536 “At one point I was suicidal and had to go on anti-depressants...the whole system is a joke...too many meetings and pen pushing but no action.”

#559 “It can be humiliating because you have to prove that you are good parents.”

#560 “I won’t allow anyone from outside our family circle to be involved with my son as I now don’t trust anyone.”

#562 “For years I have not sought help as I was always made to feel it was my parenting that was the problem. He’s now eleven and has years to wait until a formal assessment.”

#569 “They refused to assess for an EHCP. They said our parenting style of no demands was to blame for school refusal...[we] now home educate, which is amazing.”

#571 “Alleged safeguarding issues stopped my child accessing an appropriate EOTAS package...we live in fear that if we speak up or ask for help, we will be blamed.”

#575 “The lack of support and understanding has forced us to withdraw, and home educate...I’ve tried not to let it, but it has made me anxious.”

#581 “It has almost ripped my family apart. 4 out of 5 of us are on antidepressants and struggle with our mental health.”

#582 “I have ended up on anti-depressants due to school threatening fines and giving us ultimatums to home educate him or to be prosecuted.”

#596 “I feel as if they’ve pushed me to the brink...I started off being honest and transparent about all the difficulties...I wouldn’t tell them if my head was hanging off now.”

#601 “I can’t work properly...I had four years of counselling and psychotherapy.”

#602 “Children’s mental health was terrible after a year of seven different social workers.”

#609 “My own mental health has suffered greatly with not being believed and [being] blamed. I was an accountant for thirty years, with a team of eight but had to give it up.”

#614 “I have zero trust in any services and I’m unwilling to request help again as the services aren’t set up to help families like mine.”

#627 “Even though he’s received a genetic diagnosis, I still question due to many years of non-believers and parental blame.”

#731 “After three years of professionals blaming me, I really believed I was the issue...I had a mental breakdown which made me even more to blame. We had to sign a Section 20...they were threatening to remove him full-time.”

#738 “The horrible letters from school make you and the child feel blame.”

#747 “I wish I could explain my son’s needs without it having to feel like I’m on the defensive.”

#785 “We’ve stopped looking for help.”

#787 “It led to me doubting myself...trying completely inappropriate parenting methods on [professional] guidance and subsequently damaging my relationship with my daughter.”

#826 “My son is scared someone will take him away...he has tried suicide at seven.”

#868 “Parent blame is destabilising...it makes you a worse parent...the harm it does is long-term...it has ruined my relationship with my child.”

#889 “Now I have found my own strategies, things are better, and I will never ask for help again.”

#894 “Social services brought in an intensive family support worker to implement routine charts...if I don't comply, I get blamed for being obstructive...child has had to endure further demands...we've had extensive damage done to our property because of this.”

#913 “Six Sendist tribunals; two years in family court and a judicial review.”

#969 “We have been passed between social services, Camhs...no-one is accountable...Camhs is not fit for purpose, they are 100% failing PDA children...I would like to convey how broken we are as a family and how utterly abandoned we feel despite being in plain sight of agencies.”

#970 “I think about all those professionals who have put me down and said bad things and I do sometimes believe myself.”

#977 “I wake up with nightmares where I relive what happened to me.”

Section Summary

Parent / carer respondents report significant deterioration in mental health following professionals placing blame for their autistic / PDA child's presentation on some aspect of their parenting.

Parent / carer respondents report interventions (implemented by professionals to address issues attributed to parenting) as causing harm to the functioning of the family unit.

Parent / carer respondents report professional interventions as causing stress, anxiety, and trauma, impacting on their work life and personal relationships.

Parent / carer respondents report professional interventions as being unsuccessful in bringing about positive change for their child, and in some cases, have reported professional intervention as causing regression in their child.

Parent / carer respondents report feeling distrustful of services and a reluctance to seek support for their child or themselves.

SURVEY ANALYSIS

1. The function of blame:

Respondent #269 noted how blame was appropriated to them, regarding their child's difficulties, as part of the local authority defence strategy during a Send tribunal.

"The social worker passed on information to the SEN officer of Local authorities that she had believed that it was all in my head & it is something she hadn't observed in the family home. It was used as evidence against me in tribunal [to secure provision]."

Respondent #690 – a grieving parent – believes that by blaming parents, authorities avoid having to provide appropriate support, which has the longer-term effect of funnelling autistic children into inappropriate mental health facilities where they suffer harm.

"It's not done out of innocence. Loads of our children end up in adult mental health services where they are killed so efficiently and rapidly your head would spin."

Respondents #923 and **#1014** highlight how blaming parents diverts away from service access, and as such preserves funding.

#923 *"I feel that [blame] is part of the process...I feel [blaming us as parents] was a deliberate attempt to get us to stop asking for help...I felt that anything I said wasn't taken seriously."*

#1014 *"Every single service has been heavily guarded by gatekeepers, wanting to tell me I am wrong and being combative."*

UK NHS services and Local Authorities are often without adequate monies to fund assessments and correct support packages, within this context the widespread use of parental blame could be seen as a strategy to limit access to services. This is certainly how it feels for many families desperately trying to secure basic support for their children.

Our survey data shows that parental blame is present at all tiers of (specialist) support. From early years education to secondary school education, school staff are telling parents of autistic / PDA children that it is their fault that their child is experiencing difficulties within a school or home environment. Some parents have explained how they have been threatened with children's services (safeguarding) interventions when requesting support for their child. Other parents have been told that they are imagining their child's autistic presentation, and that the child is "fine" when away from the parent(s). This is not happening in a small selection of instances, this is a widespread phenomenon, with professionals using similar phrases that blame, and parents reporting similar experiences of blame across the UK (and beyond). This cannot, therefore, be a problem located within the individual parent – "parental blame" appears to be a systematic way of dealing with parents seeking support.

The effects of such are that parents find difficulty in accessing assessment routes and sourcing useful support. “Parental blame” is a barrier to autistic / PDA children accessing support for their disability – “parental blame” places a barrier between a disabled child and their right to accessible education and support services.

Parents have reported ‘opting out’ of the “system” to avoid being blamed for their child’s presentation.

#126 *“We look to change the environment around the child in order to maximise their capacity to learn. Many home educators are in a similar position, and many children with a PDA-profile are home educated. We use self-directed education as an approach and think it is ideally suited to those with a PDA profile, however few professionals understand this approach.”*

#304 *“We now home ed and avoid all professionals as best we can as they can’t be trusted.”*

When parents choose to home educate their child, or move from the area, or cease asking for support because they fear being blamed, the service providers save money.

We would suggest that any savings to authorities and services made by parent withdrawal are short term in effect. Our survey data demonstrates that by exposing families to blame, longer term mental health decline is created, leaving families in further need for support in the future.

#581 *“It has almost ripped my family apart and 4 out of 5 of us all are all on antidepressants and struggle with our mental health.”*

Many respondents to our survey reported not having any historical mental health issues, but after experiencing blame, have subsequently struggled with a range of mental health conditions – trauma, depression, anxiety – that they attribute specifically to how they have been treated by professionals working with their autistic children.

2. A climate of fear:

Respondent comments show how blame culture and associated working practices have alienated parents from professionals. There is a lack of trust between parents and professionals, with parents adopting extreme measures (such as moving their family out of the country or removing their child from school) to make their autistic / PDA children’s lives more bearable.

The propensity for professionals to blame parents for their autistic children’s presentation, as identified throughout this survey, creates a climate of real fear among parent carers. This fear is present within families irrespective of safeguarding allegations being made or safeguarding procedures being followed. This climate of fear only serves to alienate parents from professionals, as parents seemingly

develop a lack of trust towards professionals and respond by withdrawing themselves and their children from avenues of support.

#82 *“There is no help just blame. I refuse to discuss my parenting further with professionals because it is viewed as my fault when in fact it works for my 3 children. I do what I have to, to keep everyone happy and safe. The less they know the better.”*

#467 *“Many parents I know of will not seek support due to the horror stories we have all heard and the very real risk of our children being removed by people who have no idea what PDA is.”*

3. Neurodivergent Parent / Carer’s:

Neurodivergent parent / carer’s make up the majority of survey respondents. In addition, from the families who have been made subject to safeguarding procedures, the majority of these parent / carers are also neurodivergent. But there is a very real fear amongst neurodivergent respondents to disclose their own neurotype to supporting professionals. There is evidence to suggest that these fears are justified, as several parents have shared how supporting professionals have misidentified neurodivergent traits and have made disparaging comments instead. This demonstrates a potential professional ignorance of autism and how it presents.

#928 *“I was accused by the Senco of having an unfortunate manner.”* (Respondent is autistic.)

It is concerning that, by not feeling able to share their own neurodivergence, parent / carer respondents are subsequently not able to access the reasonable adjustments that they would otherwise be legally entitled to. This further perpetuates the cycle of professional lack of understanding which can lead to parental blame.

4. Profession of Parent / Carer:

Survey responses show us that where parent / carer’s have higher status or autismrelevant professions, and if these parent / carers are parenting as part of a couple, parent / carer professional status is seemingly respected, with a clear lack of blame / safeguarding concerns raised. Where a parent with a high status / autism-relevant profession is a lone mother, and neurodivergent, the profession of the mother is seemingly used against her and identified as a safeguarding concern.

This raises concerns around impartiality and fairness of professionals working with families. It would appear, from our survey responses, that perceived wealth and professional status is a protective factor (in terms of parent / carer susceptibility to blame via safeguarding procedures) unless the parent / carer is both a lone mother and neurodivergent. Are professionals involved with autistic families relying on

outdated stereotypes of both autism / neurodivergence and competency of lone mothers to inform their practice and decision making?

Additionally, there have been parent / carer respondents who have stated that their financial wealth has enabled them to source professional opinion and assessment from the independent sector, therefore taking them (largely) out of the realm of local authority scrutiny. Accessing support via the independent route offers many benefits for families – assessments are often quicker to access, more thorough in analysis and are not constrained by local politics (such as financial decision making and funding). Independent professionals can also offer specific areas of expertise, such as knowledge around the PDA profile of autism, which in turn, offers more useful strategies of support.

#42 *“I think my marital status, material wealth and professional credentials have provided me with a level of cushioning and validation amongst agencies. I noticed a shift in treatment when moving from a 2-bed ex council house to a larger detached property in a relatively affluent area.”*

5. Parent / Carer use of legal redress:

Respondent information shows us that the use of complaints procedures and legal interventions against service providers, by parent / carers, is high, both within the general respondent population and those families subjected to formal safeguarding procedures. It is too complex an issue to draw any firm conclusions as to whether making complaints (or undertaking legal action) against service providers makes parent / carer’s more susceptible to being blamed for their children’s autistic / PDA presentation.

Some parent / carer respondents have shared how safeguarding allegations have ceased when they have threatened to seek legal redress.

#632 *“We were threatened with a child protection order to move my child and section her...only when I threatened judicial review did they alter their opinion and find a suitable place.”*

6. Diagnostic status of child:

Within respondent families subjected to safeguarding procedures, 68.46% of these families have received Camhs, or other NHS provider, diagnoses for their children. The assumption that parent / carers with a child in receipt of an NHS diagnosis of autism are less susceptible to safeguarding allegations – such as emotional harm or neglect – is untrue. Even with an accepted diagnosis of autism for their child, a parent / carer can find themselves being blamed for their child’s presentation or lack of “progress”.

We would suggest that when autistic children fail to “progress” or “adhere to” professional (Camhs) expectations, and Camhs have provided a level of support / intervention / assessment, professionals seek to understand this by finding fault elsewhere, outside of the “system”. Camhs professionals are often part of the multiagency safeguarding panels and are often involved in multi-agency meetings.

Camhs primarily deliver Cognitive Behavioural Therapy (CBT) interventions which may be considered inaccessible for the autistic neurotype, and this could be a reason why “progress” for autistic / PDA children is not achieved via Camhs intervention.

“When a person has CBT they must be able to interact with their therapist, think flexibly and talk about their emotions. These are all things which autistic people may struggle with.” (<https://www.autistica.org.uk/our-research/researchprojects/anxiety-treatment-autistic-adults>)

This is also true of children with the PDA profile of autism, who additionally require less demand-based support strategies to engage successfully with sources of support.

What can be done?

Advice from parent / carer respondents on how to protect yourself from blame:

#6 "I always played the game with health care professionals and as a result of that I've had help and respect...I know people who have gone in more hot tempered and been declared problem parents."

#31 "I now record every appointment and only give the minimal of information."

#82 "There is no help just blame. I refuse to discuss my parenting further with professionals because it is viewed as my fault when in fact it works for my 3 children. I do what I have to, to keep everyone happy and safe. The less they [professionals] know the better."

#126 "We home educate and have done since the start, due to recognising that my son's needs would not be met at school. We therefore have not needed a diagnosis or EHCP and have minimal contact with professionals. This has been extremely effective for us, and our son is thriving."

#146 "My mum has been the person challenging everyone to get him the support to protect me [from blame]."

#176 "It was implied that I was too knowledgeable, and I was privately informed of a soft case being built about me."

#203 "I remain forceful and low emotion, professional approach and keep every communication tracked."

#226 "We moved abroad and are now home educating with an online school."

#304 "We now home ed and avoid all professionals as best we can as they can't be trusted."

#334 "By making a SAR [Subject Access Request] to then be able to deal with matters so you can build your case although we shouldn't have to."

#343 "I am very clear, precise, and strong in my advocacy. I cite evidence / sources. I prepare for meetings with answers and evidence."

#405 "I have been careful to come across as calm, rational, open minded, well informed, and well-presented when dealing with authorities as I am wise to the way LA professionals (and others) make judgments. I try and work with them and save my no's for things that count e.g. no thanks for early help or any social care assessments."

#552 "[I] took own initiative and undertook courses to avoid parent blame."

#602 "I have learnt to only briefly answer questions as social workers would twist our words."

#612 “I’ve been careful about what I’ve shared and with whom.”

#614 “Our Children’s Services report misinterpreted everything that was said and missed out lots which I considered relevant.”

#632 “We were threatened with a child protection order to move my child and section her...only when I threatened judicial review did they alter their opinion and find a suitable place.”

#667 “I was full and frank with all professionals, much to the detriment of our situation.”

#751 “The [professionals] who work closely with your children are the important ones. The teaching assistants.”

#762 “We pulled him out of school and away from all services and our lives have improved beyond belief.”

#765 “Concerns were not listened to or taken seriously [so] I then prepared an 8 page document with a birth to 8 history of my child...only then [did] school put is in the very first rung of help.”

#870 “Be assertive, concise, present in a methodical way. Treat all meetings as if it’s work.”

#879 “I’ve always been extremely honest, too much so...maybe my general openness allowed us to be victimised by school.”

#880 “I was told to desist from using medical terminology.”

#888 “I’ve always been open about everything at home...they tried to blame home life for issues.”

#899 “Become aware of what you say to professionals...become aware of the language you use...become very cautious about discussing the full truth.”

#914 “I only offer what is strictly necessary as they can twist anything.”

#923 “You have to stay strong and present...any sign of weakness is held against you.”

#976 “It doesn’t matter how nice someone is if they cannot help or support in a meaningful and productive way.”

What changes would parents like to see?

#317 “The social care system is broken. Children (and adults) with autism and other mental health conditions are being failed. Police and ambulance services are often forced to pick up the pieces and act like interim social workers and this puts additional pressure on them and they in turn are failing those they are sent to help as well as others without mental health issues who are waiting for emergency services. The police system and court system and probation services have a little training and don’t understand how to work with someone with autism...particularly PDA which is STILL NOT RECOGNISED in so many areas. The system is overwhelmed and broken.”

#386 “There needs to be more help to educate parents on legal rights. Help should be available at CAMHS.”

#570 “Camhs is not fit for purpose...there needs to be a huge review in how support for families with ND is delivered.”

#585 “There is a big lack of support for ND children when they are not in the standard education system...if we need help, everything has to be paid for privately.”

#593 “Teachers need specific training in understanding this profile and its impact on family life.”

#653 “They say they are working with parents but they are not. They are following protocol, and part of that is judging the parents and trying to find fault.”

#708 “The Working Together guidance is not written for us in mind.”

#865 “[There should be] changes in law to show [when] social workers are not trained in autism enough to work with families.”

#990 “The current system isn’t suitable for ND families...[the] system [is] based on parental failings...assuming parents need the support.”

Concluding Remarks

In situations where parent / carers are blamed for their autistic / PDA child’s presentation, it is the child that ultimately suffers. Families under scrutiny, due to allegations that they are responsible for their child’s disability presentation, live with intense pressure, which can cause longer term difficulties within a family unit, such as trauma. When blame occurs, families struggle to access the correct support for their child, either due to a fear of engaging with professionals, or because the type of support offered by professionals is not in line with an autistic / PDA child’s needs (and the advocating parent / carer is blamed, rather than seen as a source of expertise).

Systems of support for autistic / PDA children can create mental health issues for the navigating parent / carer. Several respondents have talked about the creation of a self-fulfilling prophecy in relation to mental health – professionals have initially alleged that parent / carers have mental health needs, where there have been none, in explanation for a child's autistic / PDA needs. This in turn has created distress, anxiety, and trauma for involved parents to an extent where support for these emerging mental health needs has subsequently been required.

Certain types of parent / carers are more susceptible to the most extreme form of parental blame – safeguarding. Our findings show that safeguarding procedures are most prevalent amongst families headed by either a lone mother and / or neurodivergent parent (s). Are professionals conflating adult neurodivergent presentations with mental health concerns and / or parental obstruction? Are outdated stereotypes and assumptions surrounding autistic people and lone mothers impacting decision making amongst professionals?

Neurodivergent parents are understandably fearful of disclosing their neurotype to supporting professionals. However, without disclosure parent / carers are unable to access reasonable adjustments for themselves, which could improve communication with professionals and offer a certain level of legal protection against discriminative treatment.

There is a need for more autism / PDA informed professionals. Increasing professional education around neurodivergent parents could help minimise the misidentification of neurodivergent presentations as safeguarding concerns. Increasing professional education around the PDA profile of autism could help minimise the misidentification of PDA parenting as permissive parenting.

A note about our research design:

Our research focus necessitated gaining information directly from families with autistic / PDA children. In order to ascertain emerging patterns in relation to parental blame we needed to elicit information from families with experience of feeling blamed for their children's autistic / PDA presentations.

Where survey respondents have not felt blamed by professionals, they have stated so and offered explanations for why this may be.

We note that, due to the survey title and dissemination via parent / carer support groups, parent / carers who have been subjected to parental blame may have felt more motivated to participate in this research than those who have not. We recognise that this may have contributed to our findings regarding the prevalence of parental blame.

We have identified a large cohort of parent / carers who have been subjected to parental blame, enabling us to draw valid findings regarding the geographical

widespread use of blame by professionals and the types of parent / carers most susceptible to receiving blame.

We would like to thank all respondents who participated in this survey. Every individual response has been read and every individual response has counted towards our final analysis. We hope that our collective voice will be recognised and that this may affect positive change.

Glossary of acronyms

A&E	Accident and Emergency Department
ADHD	Attention Deficit Hyperactivity Disorder
ADOS	Autism Diagnostic Observation Schedule
CAMHS	Child and Adolescent Mental Health Services
CBT	Cognitive Behavioural Therapy
DBS	Disclosure and Barring Service
EHCP	Education and Health Care Plan
FII	Fabricated or Induced Illness
ICPC	Initial Child Protection Conference
LA	Local Authority
MP	Member of Parliament
ND	Neurodivergent / Neurodiverse
NHS	National Health Service
OCD	Obsessive Compulsive Disorder
PALS	Patient Advice and Liaison Service
PDA	Pathological Demand Avoidance
PTSD	Post Traumatic Stress Disorder
SAR	Subject Access Request
SEN	Special Educational Needs
SENCO / SENDCO	Special Educational Needs Co-ordinator
SEND	Special Educational Needs and Disabilities
SENDIST	Special Educational Needs and Disability Tribunal

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