directors of adass adult social services
West Midlands

Autism and Parental Blame Project

Blamed Instead of Helped

How parents of autistic children experience parental blame when they approach services for support.

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Foreword

The Autism and Parental Blame Project is a unique collaborative research initiative between NHS England (Midlands), West Midland ADASS, University of Birmingham and parents of autistic children. The project aims to shed light on the experiences of parents who have been blamed for their child's autism by health, education, and social care services. The project has involved a systematic literature review, an online survey of 685 parents, and two focus groups with parents.

The findings reveal the extent and impact of parental blame across different settings and services, and the barriers and facilitators to accessing appropriate support and diagnosis. This report presents the key findings and areas that we believe are worthy of further consideration, with quotes from parents illustrating their experiences and suggestions for improvement.

The report is intended for professionals, policymakers, researchers, and anyone who is interested in improving the lives of autistic children, young people, and their families. It also calls for more involvement of parents and autistic people in the design and delivery of services and support. By addressing the issue of parental blame, we can create a more positive and supportive environment for autistic children, young people, and their families.

The project has uncovered eight areas that we believe need to be urgently considered by professionals, policymakers, and wider society. New initiatives have been identified to establish ways that enable these concerns to be addressed. The report concludes by calling for more involvement of parents and autistic people in the design and delivery of services and support. It also highlights the need for more awareness, training, and collaboration among professionals and services to ensure that parents are treated with respect, empathy, and understanding. By addressing the issue of parental blame, we can create a more positive and supportive environment for autistic children, young people, and their families.

Professor Graeme Betts CBE,
Honorary Professor for Social Care at University of Birmingham,
WM ADASS Lead for Social Inclusion and
Director of Adult Services, Birmingham City Council (2017 - 2024)

Advisory Group Introduction

Advisory group membership was made up of parents of autistic children, including parents who themselves are autistic, in addition to professionals from a range of public and independent sectors. The advisory group provided scrutiny, advice, guidance, passion and insight at every stage of the project. Many of the advisory group members had experienced parental blame themselves and the empathy and drive for justice of all group members towards others in similar circumstances has driven a commitment to change. Below are some key messages from advisory group members sharing their motivation for being involved in this project and their hopes for its impact.

> *"Having supported parents through child protection proceedings, and EHCP Tribunals, I have seen first-hand the devastation parental blame brings. There is no accountability for those professionals who, through either a lack knowledge or other reasons, make these accusations. I have seen children left with no support, no diagnosis, and parents on their knees following unsubstantiated claims of parental negligence. This practice simply must stop. I am hopeful this research will be the start of much needed change."*
>
> Julia Carter (Parent and SEN Consultant)

> *"False accusations of FII are a gargantuan breach of Human Rights, which I have personally witnessed having been accused unlawfully of this parent carer blame in 2019 when the DfE upheld my complaint about the Head Teacher, whilst I sought support for my son. My son, then part diagnosed, is now fully diagnosed as Autistic, ADHD, Dyslexic, HMJ and Irlens Syndrome. I have been inspired to actively speak out and voluntarily advocate for other families as there is lack of training, professionals who make judgements they are not qualified to make, no robust system to ensure accountability, nor is there a robust whistle blowing system to protect the professionals who want to act lawfully and report failure to act within the law, policy and procedure. This epistemic injustice is widespread and a serious problem, which terrorises innocent families severely harming the mental health of the whole family unit, with very destructive outcomes including physical health and often financial damage too. I am now well respected for speaking out and considered to be an 'Expert by Experience'. Quite simply it is abuse and it must stop... full stop!"*
>
> Angela Favell (Parent, Advocate and Specialist Disability PA)

"For me, a parent, who as her day job, has an incredibly high level of knowledge about the SEND system, a highly trained and specialist professional does not create immunity from the professional nonsense I have experienced when discussing my child's needs over the years. Your ability as a parent of an autistic child is always under super scrutiny by all and you become used to being judged and blamed constantly by those you engage with. This, in my experience, only seeks to isolate, alienate, disempower and strengthen my resolve to change this. The highly toxic practice of parent-blaming must be eradicated from any professional way of practicing with parents of autistic children, with all parents of children who are neurodivergent. Consider the parental capital any professional could harness in flipping this particular narrative away from judgemental offers of support to parents and their children to well-informed, open hearted and minded support solutions where everyone has equal rights and a right to be treated and considered equally."

Jane Friswell (Parent and Professional)

"I was keen to be involved as I see so many parents being blamed for their children's issues. Mostly it was because the professionals involved did not have the experience or skills to understand. This puts families who are already struggling under even more pressure. I want this piece of work to show others, parental blame is not acceptable. We need to do better."

Libby Hill (Consultant Speech and Language Therapist)

"Over the past year, we've had the privilege of working with a group of parents of autistic children. Their powerful stories have shed light on the unique challenges they face. The publication of our report underscores the innovative approach we've taken to this project, and it serves as a stark reminder of the work that lies ahead. It's a testament to the lessons we can learn from those directly affected. This report is a significant step forward in our ongoing efforts to address and eliminate blame for parents of autistic children."

Pete Jackson (Improvement Director,
West Midlands ADASS and Advisory Group Chair)

"After 34 years of being a parent/carer and also a frequent parent voice representative in many settings around SEND issues, with the aim to make changes to this parent blame/FII culture which has become prevalent. It has been a journey that has inspired me to continue to be part of this much needed report, to highlight the ongoing experiences of many families which absolutely needs to be brought to the fore and acknowledged as a phenomenon, and to facilitate much needed and necessary changes."

Donna Kelso (Parent, Grandparent, Advocate
and Voice for Change representative)

"In 2015 I was accused of Fabricated and Induced Illness. My partner and I were blamed by the NHS team who were assessing my son for developmental conditions/neurodivergences. There were existing difficulties, including sensory issues, lots of movement seeking, echolalia, anxiety, a need for control, and he was very intelligent and articulate. However, they accused both of us parents of causing his anxiety, of exaggerating his challenges for our own personal gain. Having been placed on Child Protection I felt the immense injustice in this, they ripped apart every facet of my life in the CP reports. It was a manuscript of grotesques lies, misinterpretations, and invasions, we felt so alone. As it transpired by using my own voice through art and activism, we discovered that we were not a rare case at all. It was frighteningly commonplace for parents of autistic children to be accused in this way. Both of us parents have since been diagnosed autistic, particularly with a PDA profile, which is what my son was also diagnosed with, by experts, not the NHS team who dismissed the very notion of PDA. I got involved in this project in order to raise awareness and help break this pattern of institutional accusations against parents of autistic children. I also am glad to be an authentic voice of those of us who are autistic adults. I hope that the professionals we all encounter will take heed and understand the impact that their words, and accusations have on innocent families like mine. The impact is lifelong."

Bernadette Louise (Parent and Professional Advocate)

"I really wanted to bring about change having been blamed myself for my son's presentation. It is really important to get this message out to the professionals who accuse parents, in order to safeguard all the parents and children from the damage this practice causes."

Tracy Moon (Parent and SEN Consultant)

"This is an important piece of work, evidencing the impact and consequences for parents and their children when, as professionals, we don't get things right. The Advisory Group has been critical in guiding and shaping a report that captures the experiences of the hundreds of parents who contributed through the survey and focus groups. The Group's insights were powerful, informative and at times disturbing. I hope this report will help encourage reflection, discussion and ultimately change."

Catherine Nolan (ADASS West Midlands Associate
learning disability and autism regional lead)

Executive Summary

The National Autistic Society describes autism as "a lifelong developmental disability which affects how people communicate and interact with the world". Autism is a spectrum condition and therefore presents differently in each person. Autism is not caused by poor parenting, nor can it be cured by changing the way parents raise their children. However, many parents of autistic children and young people, face blame, criticism, and judgement from professionals and society when they seek help and support for their child's needs.

The Autism and Parental Blame Project is a ground-breaking research initiative that aims to shed light on the experiences of parents who have been blamed for their child's autism by health, education, and social care services. The project was commissioned by NHS England (Midlands) in response to complaints from parents who felt their child's autism had been missed or misdiagnosed due to professional bias or misunderstanding.

The project involved three research phases: a systematic literature review, an online survey of 685 parents of autistic children, and two focus groups with parents. All three phases evidence the extent and impact of parental blame across different settings and services, and the barriers and facilitators to accessing appropriate support and diagnosis.

This report presents the key findings from all three phases and areas that we believe are worthy of further consideration, with quotes from parents illustrating their experiences and suggestions for improvement. The report is intended for professionals, policymakers, researchers, and anyone who is interested in improving the lives of autistic children, young people, and their families. The report also provides a link to the full details of the project, including the methods and results of each research phase.

The Autism and Parental Blame Project is a valuable contribution to the field of autism research and practice. It highlights the need for more awareness, training, and collaboration amongst professionals and services to ensure that parents are treated with respect, empathy, and understanding. It also calls for more involvement of parents and autistic people in the design and delivery of services and support. By addressing the issue of parental blame, we can create a more positive and supportive environment for autistic children, young people, and their families.

We hope the work will provide a valuable contribution to raising the profile of the issues faced by parents of autistic children and young people and offer some guidance on how progress can be made by professionals, policymakers, and wider society to stop parental blame by listening to and working together with parents, adopting a blame-free, non-judgemental approach that enables families to obtain the help they need when they reach out for support.

Findings from the Project

The Autism and Parental Blame Project consists of three phases, a systematic literature review, an on-line survey of parents of autistic children and two focus groups, one with autistic parents of autistic children and one with parents who did not identify themselves as autistic. Further information about each phase of the project can be found on the WM-ADASS website: Autism and parental blame | WMADASS (wm-adass.org.uk).

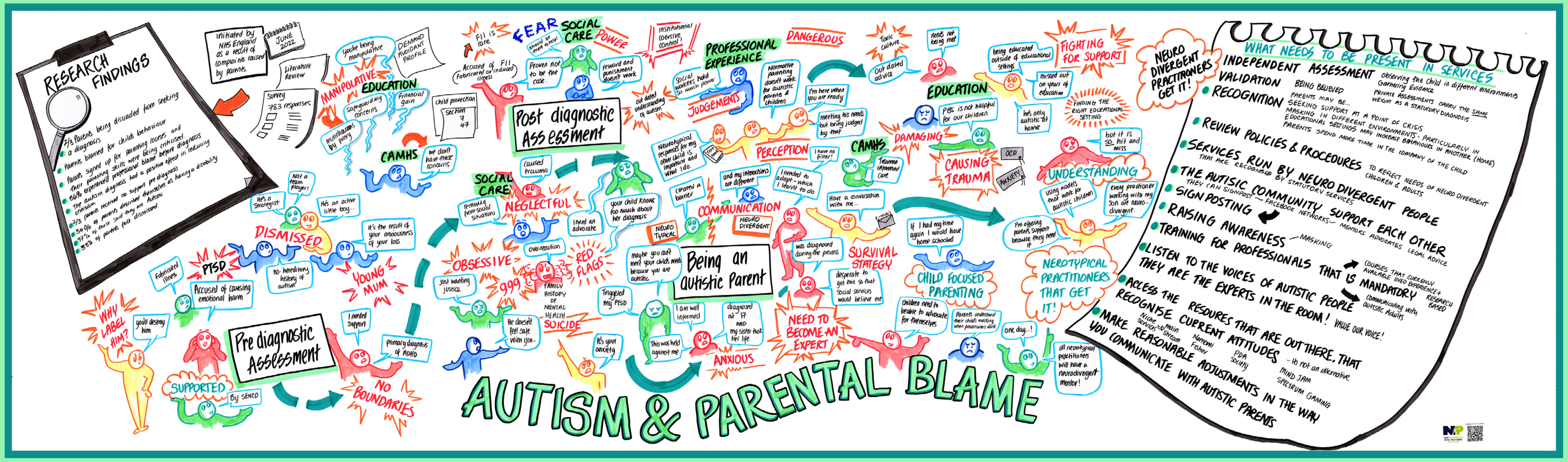
The findings across all three phases of the project reveal that:

- Parents of autistic children across England face blame from various sources, including professionals, society and communities.
- Parents feel judged rather than listened to and feel dismissed and disbelieved by professionals.
- Blame from professionals' manifests as accusations of poor parenting, disbelief in parents' accounts and accusations of neglect or Fabricated and Induced Illness (FII).
- An autism diagnosis reduces parental blame on average for most parents but not for all parents, and for some, blame gets worse after their child's diagnosis.
- There is a higher prevalence of parental blame reported by autistic parents. Our survey showed that autistic parents were three times more likely to be accused of FII than non-autistic parents.
- The current support offered to parents is often unhelpful and sometimes reported as doing more harm than good.
- Parents quickly become experts by experience and acquire the knowledge needed to defend themselves and their children, when placed in a position of fighting the system.
- Parental blame has a lasting detrimental impact including families experiencing symptoms of post-traumatic stress disorder.
- Autistic parents were positive about services where they were supported by a neurodivergent professional.
- Limited research and understanding exists regarding professionals' perspectives of parental blame.
- Training and awareness are needed for professionals around more sensitized recognition of autism and the risks of wrongly attributing autistic presentation to poor parenting.
- Professionals and services need to take action to value parents as experts by experience, working with them to support the child and family with a focus on thriving, not failing.

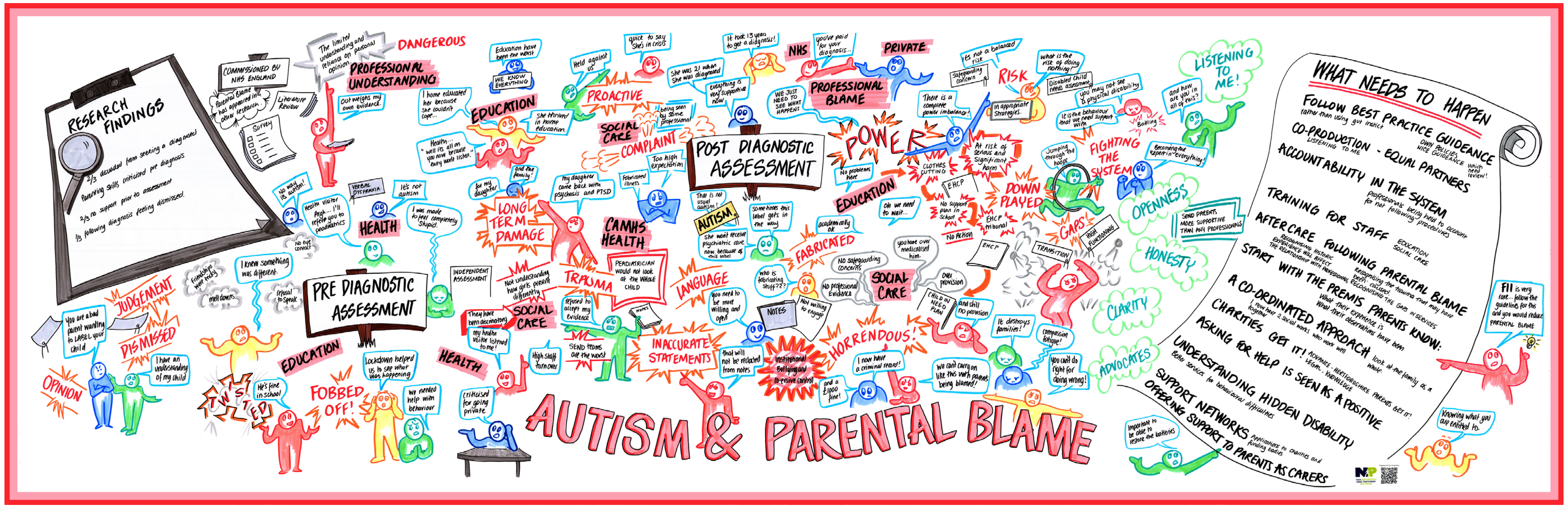
Key Areas for Consideration

Throughout the project we found compelling evidence that professional blame towards parents of autistic children and young people exists across education, health, and social care systems. From the literature review, survey and focus groups we have identified eight key concerns regarding parents' experiences of parental blame. With input from parents in the focus groups we have developed a set of recommendations which could improve the experiences of autistic children, young people, and their families when they approach services for help and support. These recommendations have been identified by parents themselves and are presented here as a set of insights and ideas for change.

Graphic Recording from Autism and Parental Blame Focus Group 8th September 2023



Graphic Recording from Autism and Parental Blame Focus Group 15th September 2023



1. Autism is widely misunderstood by professionals

"[I was] told I was imagining things and that my daughter couldn't be Autistic as she was a happy girl who never showed any misbehaviour or aggression towards others outside of the home. Common phrase used at school is 'we never see this."

– survey participant

"Not understanding how girls present differently."

– focus group participant

"Senco & head teacher say, "we're all a bit autistic". They don't have or seek training in ASD- they think they know it all. Lack of understanding re masking."

– survey respondent

"I was made to feel completely stupid."

– focus group participant

Throughout the project parents provided examples of misunderstanding by professionals. Blame for poor parenting was frequently a first response from professionals when parents voiced concerns about their child. 86% of parents surveyed experienced parental blame prior to their child's autism assessment and diagnosis. Professionals often did not consider that perplexing presentations could be autistic traits or coping mechanisms. When children presented differently at home compared to a public setting, such as school or a GP surgery, there was often an assumption that this was either due to the parent making up or exaggerating the concern (81% of parents said they weren't believed) or because the parent was unable to manage their child's behaviour at home (78% experienced judgemental or discriminatory statements and 72% experienced open criticism of their parenting abilities). Parents see this as evidence that professionals don't understand the ways in which autistic people mask or suppress their autism when they feel that is what is expected of them.

There was evidence that insufficient attention was paid to the voice of the child to understand fully why they presented in the way they did. 51% of parents said their child didn't feel believed and 46% of parents said their child developed negative associations with autism as a result of parental blame. Parents reported feeling judged and accused of poor parenting when they used strategies that worked for their autistic child, particularly when these did not fit within a normative parenting framework.

Where we found evidence of this:

- Literature Review
- Survey
- Focus Groups

Parents say this issue can be improved by:

Autism Training for Professionals – particularly in hidden disabilities, masking, differences in gender presentations and the risk and likelihood associated with making wrong judgments.

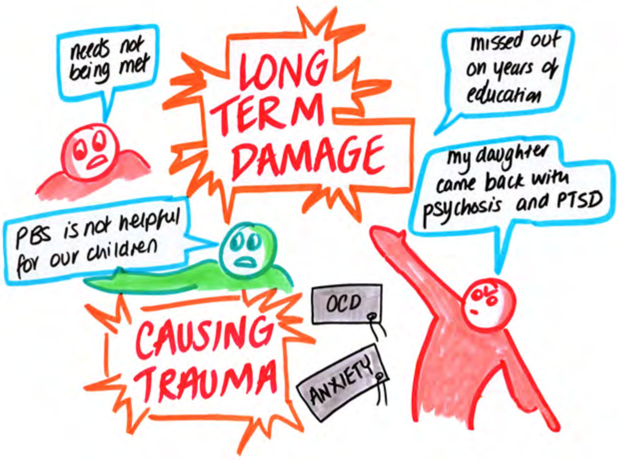
"A greater understanding of autism, particularly demand avoidance, among school staff would have made a huge difference to my child, and our parental experience."

– survey respondent

"A couple of teachers in my son's school have been amazing – they seem to really see his difficulties and understand they are part of his conditions, not down to parenting. They work with us to find effective strategies."

– survey respondent

2. Accusations of blame result in trauma, long-term damage and increased risk of suicide



"The school did not believe our evidence concerning our child's health and found us guilty of undermining the "supported placement" objectives. Our child was physically and mentally unwell which precipitated him attempting to take his own life at this time. This has been a very difficult response to articulate and write as recalling these events are particularly triggering for us as parents." – ***survey respondent***

Coping with the blame and having to defend ourselves from false accusations has led to a delay in our ability to get our daughter the right help, find the right school and generally created more work. Our daughter has missed over a year of schooling, my partner and I have struggled with our relationship and own mental health, siblings are also receiving support for their mental health. The last year and a half, since our daughter started senior school has been a living hell." – ***survey respondent***

Parents described the impact of parental blame as traumatic with some parents developing symptoms of PTSD. 90% of parents said their child did not get the right support as a result of parental blame. Over 70% of parents said their child's mental health worsened, with one in four parents reporting a high suicide risk for their child. Parents reported that parental blame resulted in a negative impact on their own health and well-being. 94% of parents experienced stress and anxiety, 68% felt more isolated and 34% were fearful of their children being removed from their care. Parents also reported that blame caused a negative impact on family relationships and caused them to change their employment to accommodate caring responsibilities.

Parents who were wrongly accused of FII, parents whose children became the subject of a child protection investigation and parents whose children were removed from the family home were particularly at risk of trauma. None of the parents in our focus groups received any support for themselves or their children to address the impact of a child being taken without warning from their family or of parents being wrongfully accused of neglect or harm towards their child. Parents are clear that all forms of parental blame are harmful and may have a long-lasting impact that can damage a family's well-being, delay diagnosis and support for their child, and create a barrier to families seeking the help they need.

Where we found evidence of this:

- Literature Review
- Survey
- Focus Groups

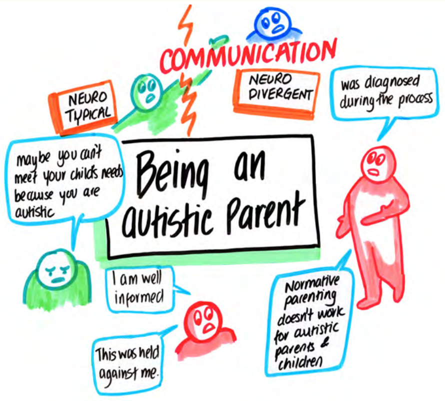
Parents say this can be improved by:

Increasing awareness about the harm of parental blame by professionals and providing support and after-care for those affected – this is not to deter professionals from acting where evidence or a strong suspicion exists that a child is at risk of harm, rather it is so that professionals understand that families will need support if these suspicions are shown to be unfounded.

"GP has been fully supportive in removing my child from educational setting due to unmet need. She has been empathetic and understanding rather than seeking to blame our personal circumstances." – ***survey respondent***

"The SENCO at secondary school has a good knowledge of autism in girls and PDA. Whilst [our daughter] was a model pupil in school, [the SENCO] acknowledged that this is common in girls and believed what we told her without judgment of our parenting. She tried to refer to services, but the support wasn't available. Once she was unable to attend school, her absence was authorised as mental health and school supported the EHCP process." – ***survey respondent***

3. Autistic parents may be at higher risk of parental blame



"I was told – 'maybe you can't meet your child's needs because you are autistic." *– focus group participant*

"I was diagnosed during the process [of seeking a diagnosis for child]. I was desperate to get this so that social services would believe me." *– focus group participant*

"Normative parenting doesn't work for autistic parents and children. I'm meeting his needs but being judged by that." *– focus group participant*

33% of parents who participated in the survey identified as autistic. 11% of participants had a formal diagnosis and 22% self-identified as autistic but didn't have a formal diagnosis. In the general population the prevalence of autism in adults is currently estimated at 1.1%. The older a person is the less likely they are to have a diagnosis of autism therefore it is likely that as well as meeting parents who recognise that they are autistic but don't have a formal diagnosis, professionals will also encounter parents who are unaware that they are autistic. In addition to the 33% of participants who said they were autistic, a further 21% said they were unsure whether or not they were autistic.

Our survey appears to show that being a parent with a formal diagnosis of autism increases the chance of facing a safeguarding or child protection investigation, having children placed on the child protection register and of having children removed from the family home. 44.6% of formally diagnosed autistic parents faced child protection proceedings, compared to 32.2% of self-identifying autistic parents and 27.1% of parents who were either not autistic or were unsure. Autistic parents were three times more likely to be accused of FII than non-autistic parents.

Autistic parents surveyed and spoken to in this project reflected that professionals often didn't work in a way which was helpful for them. They identified that parenting resources and strategies were not adapted for autistic parents and that professionals did not make reasonable adjustments in their working methods or communication.

Where we found evidence of this:

- Survey
- Focus Groups

Parents say this can be improved by:

Ensuring that practitioners are equipped to recognise and work with autistic adults – this could mean training for practitioners to adapt their practice to be accessible for autistic adults and people with hidden disabilities, enabling professionals to be proactive in making reasonable adjustments to create positive relationships. Specific training for professionals in communicating with autistic adults.

"One very senior Social Worker knew straight away I was Autistic. Recognised and understood my behaviours immediately. She helped me get my children returned to my care. One family support worker had autistic and ADHD children with complex behaviour issues. Obviously neurodivergent herself." *– survey respondent*

"The school senco is amazing. He never questions my opinions or suggestions. He has never doubted my sons diagnosis. He always asks my son for his opinion and treats us like humans." *– survey respondent*

"Listen to the voices of autistic people they are the experts in the room." – recommendation from focus group participants

"Make reasonable adjustments in the way you communicate with autistic parents." *– recommendation from focus group participants*

4. Parents of autistic children have a high level of mistrust in services and professionals

"Discriminated against because Health [service] lied to cover up their own negligence which has been utterly horrific and traumatising." – ***survey respondent***

"No support from CAMHS, even when suicidal. We had to pay for private psychiatric support." – ***survey respondent***

"It always feels like a fight to get your child's needs met." – ***survey respondent***

"I feel frustrated, yet I don't show any emotion in meetings because that's deemed to be a weakness and I might get more blame. It feels like they are all working together to push my child out of education." – ***survey respondent***

"Social Workers hold so much power." – ***focus group participant***

Parents' expectations of services have been shaped by poor experiences of approaching services for help. Many parents surveyed, spoken to in focus groups and referenced in the academic papers analysed in the literature review described seeking support for their child as a battle or a fight to be heard.

Parents told us they felt let down by services. 73% of parents surveyed said they had lost trust in services and professionals as a result of their experiences. They described professionals failing to follow their own guidelines and policies. Many said they were in fear of interaction with professionals. Over a third of parents told us that they experienced parental blame after they had made a complaint about a service. Several parents provided examples, with evidence, of professionals lying and colluding following a complaint being made. Some parents described fighting to clear their names following accusations of FII and neglect, and how even after they did this and accusations were demonstrated to be unsubstantiated, there was no accountability or consequences for the professionals concerned. Parents feel that there is a power imbalance weighted towards professionals. Research explored in the literature review described some professionals reflecting on parental blame and demonstrating they are aware that they are doing this.

Where we found evidence of this:

- Literature Review
- Survey
- Focus Groups

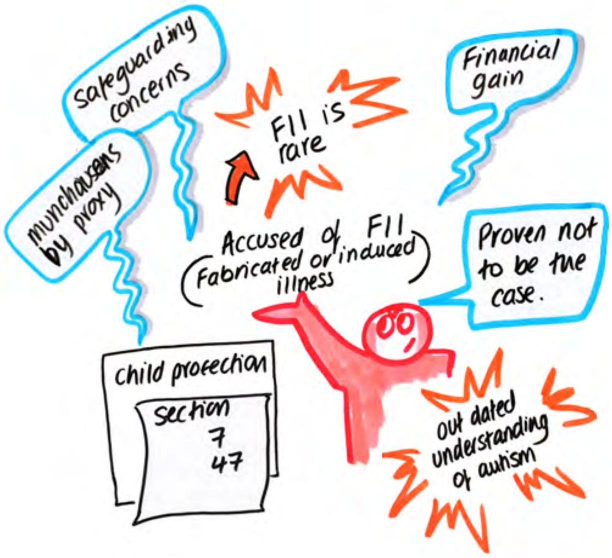
Parents say this can be improved by:

Professionals being held accountable for false or unsubstantiated accusations – organisations should have policies and processes in place that investigate false or unsubstantiated accusations against a parent so that lessons can be learnt and used to improve practice. Where evidence of deliberate falsification or malicious intent is found then there should be a process in place for holding those professionals to account.

"All parents require an independent advocate who aren't employed by schools or local authorities. There is no true accountability." – ***survey respondent***

"Accountability in the system – professionals being held to account for not following procedures." – ***recommendation from focus group participants***

5. Parents of autistic children may be at increased risk of being subject to child protection proceedings and/or suspected of Fabricated and Induced Illness



"The head of year at the mainstream school my child attended accused me of FII and made several reports to children's services. These reports were eventually considered to be vexatious because of the amount and frequency." – ***survey respondent***

"I was accused of hurting my child, which was not true. I was told my child could be removed from my care. I was told I face prosecution for child abuse, all because my nonverbal child had marks on his back which he could not explain and neither could I, photos and paperwork were submitted. I did not see the said remarks but as it turned out they were from the zipper on his onesie that he had slept in." – ***survey respondent***

"Accused of FII 3 times by a health professional but my son was also diagnosed with Dyspraxia and later diagnosed with Marfan Syndrome and Erythromelalgia. I had to make complaints to 2 separate trusts and the local authority. I had to have a stage 2 independent investigation and then a stage 3 tribunal both upheld in my favour and apologies eventually received." – ***survey respondent***

Amongst our survey participants there was a surprisingly high number of parents of autistic children who were subject to child protection proceedings. Of the 685 parents completing our survey one in four (27%) told us that they were subject to a safeguarding referral and therefore had been viewed with suspicion by services.

Of the parents who had experienced parental blame approximately one in six (16.3%) had been accused of FII which occurs only rarely in the general population.

Of further concern is the finding that parents who themselves have a formal diagnosis of autism are three times as likely to be accused of FII and three times as likely to have their children removed from their care as non- autistic parents.

These figures need further urgent investigation to ascertain why the rates of child protection investigations and accusations of FII are so high amongst parents of autistic children, and especially autistic parents.

Academic studies reviewed in our systematic literature review (Pg. 10, 23, 25) suggest that assessments of disabled children may be conducted with a primary focus on child protection rather than assessing a child in need by virtue of being disabled and identifying the support that child requires. (Autism and parental blame research | WMADASS (wm-adass.org.uk))

Where we found evidence of this:

- Literature Review
- Survey
- Focus Groups

Parents say this can be improved by:

Professionals starting from a point of believing the parent – establishing trust in every encounter, working with parents as partners (unless there is evidence or a documented suspicion that the child is at risk of harm which can be triangulated).

Specialised workers conducting assessments of need – practitioners who are sufficiently well trained or experienced in autism, and the many and different ways in which it can present, should conduct an assessment of need which places the child at the centre and recognises the expertise.

"Social care actually spent 4 hours assessing my child in the home and built a relationship and then followed up with getting a short break/enabling funding for them."

– ***survey respondent***

"Start with the premise parents know. [Ask] what their experience is. What their observations have been. FII is very rare follow the guidelines for this and you would reduce parental blame."

– ***survey respondents***

6. Parents' knowledge of their child is not recognised or valued and may be viewed with suspicion

"Accused of being too knowledgeable and utilising my professional networks to influence outcomes at the time. i.e., Ofsted - I was an inspector." ***– survey respondent***

"Despite being a professional I was shocked how my opinion no longer counted as I was now a parent. Despite having 27-year autism experience in a Professional capacity and having been involved in delivering and developing training etc to professionals. They failed to recognise my knowledge and skills." ***– survey respondent***

"I've had to do in-depth research, present print outs to explain to doctors, provide evidence in photos and videos to be believed." ***– survey respondent***

Parents told us their knowledge and experience regarding their child was frequently dismissed by professionals who regard themselves as the experts. 81% of parents who experienced parental blame said they weren't believed about their child's autistic presentation.

Parents identify a need to become as knowledgeable as possible so that they can support and advocate for their children, educating themselves to be well informed both in their child's diagnosis and strategies to support. However, parents found this knowledge and expertise could be used against them. They were accused of knowing too much or wanting to label their child and cause them harm. Parents also seek knowledge about systems and legal rights in their fight for justice and in seeking to vindicate themselves from blame. Many parents become skilled and well-informed advocates.

Where we found evidence of this:

- Literature Review
- Survey
- Focus Groups

Parents say this can be improved by:

Parents being recognised as partners – a working agreement between parents and professionals based on mutual respect and valuing parents as experts by experience would support the child and family to thrive.

"Making good relationships with practitioners helps enormously as then they take you more seriously. But I am lucky to be a white, 'educated' person." ***– survey respondent***

"Due to parental blame, I have undertaken numerous courses to better equip myself when trying to access services. It has helped as I have a better understanding of the language, and the system." ***– survey respondent***

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7. Parental blame is more likely to occur before a child is diagnosed as autistic

"I think it was more like complete lack of understanding by others so it was assumed we must be doing something wrong. He is our eldest, so we didn't know things were 'different', they were just our usual." **– survey respondent**

"It was implied that my child's anxiety was triggered by me being overprotective and that I am preventing my child from being resilient. It was implied that I am the reason my daughter was failing to thrive, and that she was fine when I am not around." **– survey respondent**

86% of parents participating in our survey felt their parenting was criticised prior to a formal autism diagnosis This is broken down as follows: Blame from Education Services 77%: Health Services 63%, Friends and Family 46%, Social Services 26%, Self and/or Partner 22%.

An autism diagnosis improves the incidence of parental blame on average for most parents across all sectors. Blame from health professionals improved the most, with 48% of parents noting it improved after their child's diagnosis.

Blame from social care professionals was more likely to stay at the same level. 54% of parents said there was no change in the amount of blame experienced after their child's diagnosis.

Although 36% of parents noticed an improvement in the amount of blame from education professionals, 25% of parents said the blame they experienced got worse after their child's diagnosis.

Parents experienced the biggest reduction in blame from their partner, friends, and family after their child was diagnosed as autistic.

Despite a national average wait of 4 years for an autism assessment, parents in the focus groups did not identify delayed access to diagnosis as the key issue of concern and were sympathetic to the pressures faced by the NHS. Nonetheless the lack of appropriate support before an assessment caused significant problems. Parents also described negative experiences of the assessment process in terms of gatekeeping by professionals and their concerns about their child being dismissed, when what they required was understanding and empathy.

Where we found evidence of this:

- Survey
- Focus Groups

Parents say this can be improved by:

All services should be a gateway to support – practitioners from all sectors should demonstrate a culture of listening and respect towards parents. Parents concerns should be taken seriously and at face value before an assessment is conducted. Practitioners should make themselves aware of the wide range of third sector and community based organisations who are well placed to provide information, advice, and resources to parents. A partnership approach, coupled with a non-judgemental acceptance of parents' concerns would help to make wait times for an assessment more manageable.

"The GP was the first person to believe my child might be autistic. He was sympathetic to my near-suicidal child, and immediately sent off letters requesting help and input to different agencies. Without his help nothing would have happened towards investigating whether my child was autistic and what was causing their poor mental health." **– survey respondent**

"The clinical psychologist was immensely supportive. It really helped when she praised us all for picking up my child's autism so young. Even when my child passed the ADOS she didn't want to let us off her books and wanted to be available as my child hit their teens (sadly she moved on and her replacement never replied to my letters, emails and phone calls requesting help as my child hit their mid-teens with a crash)."

– survey respondent

8. The current support offered to parents is often unhelpful and sometimes reported as doing more harm than good

"No support from CAHMS, even when suicidal. We had to pay for private psychiatric support." – ***survey respondent***

"Attending parenting classes – told to go before referrals could progress – used harmful strategies that broke the bond I had with my son. [He has] trauma from these approaches." – *survey respondent*

"It always feels like a fight to get your child's needs met." – ***survey respondent***

65% of parents said they were not offered any support or information whilst their child was waiting for an autism assessment. For those that were offered support there was a mixed view as to whether that support was helpful. The most helpful form of support appears to be being signposted to autism support organisations. 81.4% of people offered this support found it helpful and only 18.6% found it unhelpful.

58% of people referred to a parenting course said it was unhelpful, compared to 42% who found it helpful. Anecdotally parents told us that parenting courses were frequently aimed at neurotypical parents with neurotypical children and therefore the parenting strategies and tools shared were inappropriate, often unhelpful and in some cases damaging to the parent child relationship.

Of the 534 respondents who were not offered any support prior to an autism assessment 59% said they would have liked to be signposted to autism support organisations and 57% would have liked to have received peer support from other parents/carers. Only 20% said they would have liked a parenting course.

When asked which one word best described the support received after their child was diagnosed as autistic, the most frequently used word was "non-existent". In focus group discussions parents had clear views on what support they would like and talked of positive experiences when they were supported by neurodiverse professionals who "get it", although these encounters seemed more accidental than planned. There were also very positive experiences of third sector specialist autism organisations and peer support groups, both formal and informal.

Where we found evidence of this:

- Survey
- Focus Groups

Parents say this can be improved by:

Greater understanding of the positive role neurodivergent practitioners and autism specific services have in supporting families – services should recognise the value of third sector and peer support and this should be more visible and available to parents. Parenting courses for autistic parents or parents of autistic children should describe more specialised and targeted strategies. Courses delivered by experts by experience should be prioritised over generalised parenting courses.

Neurodivergent practitioners could be invited to mentor and/or advise colleagues working with autistic adults and/or autistic children and their parents.

"[Our local] Mencap service is really great we have had welfare calls, and my 2 autistic children attend groups which they offer." – ***survey respondents***

"Psychologist who assessed for autism was great and had good understanding of trauma too, so understood how to disentangle and diagnose." – ***survey respondents***

Opportunities for further research

There are several areas that we feel warrant further investigation to fully understand the issue of parental blame experienced by parents of autistic children and/or young people. Topics which could be investigated in more detail include the following:

1. Professionals' perspective on parental blame – this area was not the primary focus of this project, and we found only a small number of studies which addressed it in our literature review. Further investigation is needed to understand the rationale and drivers for the type of events and outcomes described in this project. We intend to explore the perspective of professionals working with autistic children and their parents in the second stage of this project, beginning in March 2024. This will provide necessary insight into the systems, practices and challenges which may underpin parental blame by professionals, whether consciously or unconsciously.
2. The survey highlights the significant detrimental impact parental blame has on autistic children, their parents and wider family. Further research could explore this in more detail, including the impact on siblings. This would enable improvements to be made in whole family support.
3. This project has found evidence that suggests a connection between parental blame of parents of autistic children and misdiagnosis of FII and/or unsubstantiated concerns which result in child protection procedures. Further research is needed to understand the impact of these actions on children, parents, and families and whether a focus on child protection results in more autistic children becoming looked after children as well as delaying recognition and autism diagnosis for children removed from their parents' care.
4. The results of our survey appear to show that parents who have a formal diagnosis of autism are more likely to experience parental blame and have a higher chance of being accused of FII, and having their children removed from their care than non-autistic parents. Further research is urgently needed to establish whether there is a correlation between being an autistic parent and being suspected of FII. There is a need to identify what factors are involved in the higher levels of autistic parents being accused of FII and facing safeguarding procedures.
5. This project has amassed a significant amount of data. Due to the breadth of data collected, there is opportunity for future researchers to interrogate and analyse further on a range of associated topics, for example, exploring whether a relationship exists between demographic factors, for example geographic location, parental age, gender or ethnicity and incidences of parental blame. We aim to secure a host for the anonymous data as a resource for future research purposes.

Definitions of Key Terms Used in the Project

Autism –

We recognise that Autism is a spectrum condition which presents differently in each person and therefore any broad definition will be inherently flawed and inadequate to describe the unique experience and perspective of every autistic person.

The National Autistic Society describes autism as:

> *""a lifelong developmental disability which affects how people communicate and interact with the world".*

NICE provides the following clinical definition, which is frequently used in clinical literature and settings.

> *"The term autism describes qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours, often with a lifelong impact. In addition to these features, children and young people with autism frequently experience a range of cognitive, learning, language, medical, emotional and behavioural problems, including: a need for routine; difficulty in understanding other people, including their intentions, feelings and perspectives; sleeping and eating disturbances; and mental health problems such as anxiety, depression, problems with attention, self-injurious behaviour and other challenging, sometimes aggressive behaviour. These features may substantially impact on the quality of life of the individual, and their family or carer, and lead to social vulnerability."*

We note that Autistic communities differ in such definitions of autism, rejecting clinical notions of disability, impairments, deficits and developmental flaws that may result in stigma and low self-esteem and putting forward more positive ideas. Replacing 'restrictive and repetitive behaviours' for example with 'a need for certainty' and 'self-regulation, whilst emphasising the difficulties and significant impacts of living as an autistic person within a chaotic and at times unforgiving world. These approaches celebrate autistic differences, strengths and identities.

Throughout the project we have not differentiated between people who have been formally diagnosed as autistic and those who are as yet undiagnosed but who feel they meet the diagnostic criteria.

Parent –

We use this term to refer to anyone fulfilling a parenting role in a child's life. This includes family carers, foster parents, guardians, and kinship carers.

Parental Blame –
This definition of parental blame was developed through in-depth consultation with experts by experience in our advisory group. We use this definition to explain to people what parental blame means in the context of this project.

Blame means to hold someone responsible for doing something bad or causing something bad to happen. The aim of this project is to find out if parents feel they have been blamed by professionals or services when they have asked for help with their child's behaviour or when they have requested an autism assessment.

The ways in which parents feel blamed can include:

- Professionals, such as social workers, teachers, health care providers questioning, criticising, or making judgemental comments about their parenting.
- Professionals questioning a parents account of their child's behavioural symptoms or the need for an autism assessment.
- Professionals accusing the parent of causing the child's behaviour.

Behaviour/presentation –
We have used the terms autistic behaviour and autistic presentation as interchangeable throughout the project. This is because our advisory board recommended that only using the term autistic behaviour could be construed negatively and correlated with bad behaviour.

Project Information

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Laura Ferguson (WM-ADASS Associate- Co Project Lead)
Debbie Hollingsworth (WM-ADASS Associate- Co Project Lead)

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Pete Jackson (Improvement Director, WM- ADASS and Advisory Group Chair)
Donna Kelso (Parent, Grandparent and Advocate)
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Commissioner:
NHS England

Co- Funded:
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Project Delivery/Supplier:
WM-ADASS

Website:
[Autism and parental blame research | WMADASS (wm-adass.org.uk)]

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We extend our thanks to the 685 participants who shared their experiences through the survey and the parents who joined us on the focus groups. All shared some very personal and painful experiences and reflections, whilst focussing on what can make things better.

Thank you also to those parents of autistic children who assisted with piloting of the survey, and for feedback in shaping and refining resources we have used throughout the project. And to all those parents, professionals and organisations who have supported the project, we hope you will continue to share the key messages and learning and take this into organisations, workforce, and practices to make a difference in the mission to reduce and stop parental blame.

Thank you too, to Anna Geyer of New Possibilities for the amazing graphic recording during the focus groups which has captured the experiences and views of the contributing parents so powerfully.

And thank you to all reading this, we hope this project shines a light on the experiences of families, parents, and autistic children and young people at the heart of this issue: families who are blamed instead of helped when they reach out for support at a time of need, parents who experience judgment, disbelief and all too often accusations that they are neglecting or harming their child, and children who do not receive the support they need because their parents are blamed for the way in which their autism presents.

We hope that the findings of this research provoke and challenge everyone engaged in providing services and support to parents and children. We appeal to those who are in a position to change policy and practice and hope they will ensure the necessary systems and environment are in place to challenge and remove wrongful parental blame and reduce the unnecessary trauma and delay to support for children that this causes.

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Autism and Parental Blame Research Project

Blamed Instead of Helped

How parents of autistic children experience parental blame when they approach services for support.

Authors Laura Ferguson and Debbie Hollingsworth
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