

# Autism and Parental Blame Project

## Survey Report

### Project Information and Background

The Autism and Parental Blame Project aims to shed light on how parental blame is experienced by parents of autistic children when seeking support from professionals for their child. 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 National Autistic Society describes autism as “*a lifelong developmental disability which affects how people communicate and interact with the world*”. 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 project involved three research phases: a systematic literature review, an online survey of parents of autistic children, and two focus groups with parents with the aim of answering the question:

*How do parents of autistic children experience parental blame when they approach health, education and social care services for support?*

This report delivers the findings of the online survey of 685 parents of autistic children and young people.

### Project Team (and roles):

- Catherine Nolan (Project Manager) WM-ADASS
- Jason Schaub (Academic Advisor) University of Birmingham
- Laura Ferguson (Co-Project Lead) WM-ADASS Associate
- Debbie Hollingsworth (Co-Project Lead) WM-ADASS Associate

### Commissioner:

- NHS England (Midlands)

### Co- Funded:

- WM- ADASS

## Project Delivery/Supplier:

- WM-ADASS

## Project Advisory Group

An Advisory Group was established to add additional expertise to the study, with membership drawn from across the East and West Midlands. The group consisted of eighteen members, ten of whom are Experts by Experience, the majority of these being parents of autistic children with in-depth knowledge and experience of parental blame. Some parents in the group are themselves autistic. Advisory Group members also have a broad range of professional experience including SEND and EHCP expertise, as well as other relevant sector knowledge from social care, education, health, and academic research.

## Positionality

Both project leads have relevant professional backgrounds, having worked within social care or advocacy supporting autistic people. Both are parents of adult autistic children and one of the project leads is the grandparent of an autistic young person. A person centred co-productive approach has been used throughout the project to ensure that people affected by the topic being studied have had an opportunity to influence the direction and design of the project.

## Aims of the Survey

The systematic literature review identified several themes and questions about parental blame that the project team wanted to explore further through the survey. The survey questions were developed to provide more detail about these themes, which included:

- Where and when in the autism diagnostic process does blame occur?
- How is blame expressed and which services and professionals does the blame come from?
- What is the impact of blame on parents, children and young people and their families?
- Is there a connection between obtaining an autism diagnosis and parental blame?
- Is there a connection between challenging or complaining about professionals and parental blame?
- Is there a connection between being an autistic parent and parental blame?

## Method

A definition of parental blame was developed through in-depth consultation and co-production with parent members of the project advisory group. This definition of parental blame reflects their lived experience as parents of autistic children and young people, and the experiences of parents as revealed through the findings of the literature review. The explanation of parental blame provided in the context of this project states that:

*Blame means to hold someone responsible for doing something bad or causing something bad to happen.*

*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.*

*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 survey was created in Microsoft Forms and comprised eighty-six questions. When assessed for accessibility via the Flesch–Kincaid readability calculator the survey returned a reading age of 10 years old, which was determined to be accessible to a majority of participants. The survey took an average of 22 minutes and 53 seconds to complete.

The survey was designed to return both quantitative and qualitative information about parents' experiences and the impact of parental blame on themselves as parents as well as on their children and wider family. A draft of the survey questions was refined following guidance from the Advisory Group. A pilot survey with a small representative group of the target survey population provided further feedback and increased the comprehension, clarity and validity of the questions and responses being sought.

The survey was open for 6 weeks and distributed via specialist networks, social media platforms, autism organisations, parent/carer support groups across England, as well as the project team and advisory group members personal and professional networks.

The survey was open to parents, carers and/or guardians living in England who had approached health, education, and care services for an assessment and/or support for their autistic child, whether formally diagnosed as autistic or not.

Respondents were self-selecting and participation was voluntary. No incentives were offered for participation. All data was collected anonymously. Respondents are not identifiable in the presentation of the findings. Only the project team have access to the raw data which will be stored for five years beyond this study, with oversight from Shropshire Council's Caldicott Guardian.

## Characteristics of participants

685 respondents met the inclusion criteria for participation in the survey out of 783 initial responses.

Of the survey respondents:

- Responses were returned from nine Local Authority regions in England, with the host region, the West Midlands, receiving the highest share of returns (24%). The remaining eight regions returned between 6 and 10% of responses each.

- 99% were parents of autistic children, the remaining 1% were grandparents or a formal guardian. 92% of participants were birth mothers, 5% were birth fathers and 2% were adoptive parents.
- 64% of participants were aged 40 -54, 24% were aged 25 – 39, 11% were over 55 and 1% were under 25
- 95% of participants were white, 2% were Asian or Asian British, 2% were from mixed or multiple ethnic groups, 1% were Black, Black British, Caribbean or African, 1% were from other ethnic groups.

Of the children represented by survey participants:

- 36% were girls, 60% were boys, 3% were described as other and 1% declined to answer. 4% of respondents said their child identified as transgender.
- 90% of children represented were white, 7% were from mixed or multiple ethnic groups, 1% were Asian or Asian British, 1% were Black, Black British, Caribbean or African, 1% were from other ethnic groups.
- At the time of completing the survey 46% of respondents' children were aged 11 – 16, 30% were aged 5 – 10, 12% were over 18, 8% were 17 – 18 and 4% were under 5.

## Survey Results

In this report we present the most notable findings from the survey. A complete breakdown of results from all survey questions along with the anonymised raw data will be available on the WM-ADASS website from December 2024.

### ***Where and when in the autism diagnostic process does blame occur?***

- 86% of parents who experienced parental blame reported that it occurred prior to their child's autism assessment and diagnosis.

### ***How is blame expressed?***

- 78% of parents said they experienced judgemental or discriminatory statements about their parenting.
- 72% experienced open criticism of their parenting abilities.
- 73% were criticised for being under or overprotective of their child
- 81% of parents said they weren't believed about their child's autistic presentation.
- One in four parents (27%) were subject to a safeguarding referral.
- One in six (16%) were accused of Fabricated and Induced Illness (FII)

### ***Where does blame come from?***

- Professionals working in Education Services - 77%
- Professionals working in Health Services - 63%
- Friends and Family - 46%
- Professionals working in Social Services - 26%
- Self - 22%
- Partner- 22%

### ***What is the impact of parental blame from professionals on children and young people?***

- 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.
- One in four parents (25%) reported a high suicide risk for their child.
- 51% of parents said their child didn't feel believed.
- 46% of parents said their child developed negative associations with autism as a result of parental blame.

### ***What is the impact of parental blame from professionals on parents?***

- 94% of parents experienced stress and anxiety
- 68% felt more isolated
- 34% were fearful of their children being removed from their care
- 73% of parents said they had lost trust in services and professionals as a result of their experiences
- 51% changed their employment to accommodate caring responsibilities

### ***What is the impact of parental blame from professionals on the wider family?***

- 73% of parents reported increased tension within the family
- 45% reported a loss of income
- 52% identified that other siblings felt isolated or sidelined
- 81% said family members mental health was poor as a result of parental blame

### ***Is there a connection between obtaining an autism diagnosis and parental blame?***

- An autism diagnosis improves the incidence of parental blame on average for most parents across all sectors.
- 86% of parents who experienced parental blame reported that it occurred prior to their child's autism assessment and diagnosis.
- 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.
- 36% of parents noticed an improvement in the amount of blame from education professionals.
- Across all three sectors blame increased for some parents following a diagnosis, most notably from education professionals. 25% of parents said the blame they experienced from education professionals 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

***Is there a connection between making a complaint about professionals and parental blame?***

- Over a third (37%) of parents surveyed experienced parental blame after they had made a complaint about a service.

***Is there a connection between being an autistic parent and parental blame?***

- Autistic parents were three times more likely to be accused of FII than non-autistic parents and twice as likely to face a safeguarding referral or child protection investigation
- 33% of parents who participated in the survey said they were autistic. 11% had a formal diagnosis of autism, 22% self-identified as autistic but didn't have a formal diagnosis. A further 21% of participants said they were unsure whether or not they were autistic.
- 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.
- 31% of formally diagnosed autistic parents were accused of FII compared to 21% of self-identifying autistic parents and 11% of neurotypical parents.

***Other notable findings***

- 65% of parents said they were not offered any support or information whilst their child was waiting for an autism assessment.
- Of the 35% of respondents who were offered support prior to an assessment 81.4% found autism support organisations the most helpful
- When asked which one word summed up parents' experience of support offered to their child after being diagnosed as autistic, the most frequent response was that support was "*non-existent*".
- Less than 2% of all participants said they get the help they need from services.

## Limitations of the Study

The survey was specifically aimed at parents and carers of autistic children who had experienced parental blame and survey participants were self-selecting; therefore, caution should be exercised in interpreting these results as representative of the wider UK population.

The majority of respondents were mothers. Very few responses were received from fathers or from ethnic groups other than White British. Further research is needed to establish whether there is any correlation between parental blame and parent ethnicity, gender or geographical location.

While this survey focused on the experience of parental blame from the perspective of parents, the systematic literature review revealed a gap in academic knowledge regarding the experiences of professionals and their understanding of parental blame towards parents of autistic children and young people. Further research is needed to develop a full understanding of how parental blame appears to professionals as well as parents.

The survey returned a vast amount of data making an in-depth formal thematic analysis unfeasible within the time constraints of the project. The project team are intending to undertake further analysis and to make the anonymised data available for use by other researchers.

## Summary and Conclusions

Parental blame exists in all areas of society. Parents in this survey report that friends, family and their own partner level blame and criticism against them because of their child's autistic presentation. However, when parents seek help and support for their child and instead face criticism, judgement and safeguarding accusations from professionals, then the impact on autistic children and their families can be devastating. Parental blame by professionals means that autistic children do not get the support they are entitled to and need to live happy and fulfilled lives, they face worsening mental health, and many are at an increased risk of suicide. For parents, this form of parental blame impacts their own mental health and de-stabilises families emotional and economic well-being.

The survey provides evidence of parents' experience of parental blame as they navigate autism assessments and support services. Parents describe how parental blame ranges from criticism and judgement of their parenting skills through to accusations of harm and neglect, including accusations of fabricating their child's autism. A significant number of children are removed from the care of their parents by the state because of these accusations.

Of concern, is the disproportionate number of autistic parents who face accusations of fabricating and inducing illness (FII), and having their children removed from their care. The survey found that parents with a formal diagnosis of autism were three times as likely to be accused of FII and have their children removed from their care as non-autistic parents and parents who do not have a formal diagnosis of autism.

The survey demonstrates a gap in understanding between many professionals working with autistic children and those children's parents. Further research is urgently need to explore parental blame from a professional's perspective, so that actions can be identified which will close the gap and ensure that parents of autistic children are not blamed for their child's autistic presentation and that autistic children get the support they need.

## Acknowledgments

The project team would like to thank everyone who has contributed to this study, in particular the 685 respondents who have shared their stories including some very personal and painful experiences for the benefit of raising awareness of the issue of parental blame from professionals, to gain more transparency and wider recognition.

We would also like to thank the Advisory Group members for their guidance, challenge, and direction, and the parents of autistic children who assisted with piloting of the survey and provided feedback to shape the final version.

## Definitions of Key Terms used in this 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.

**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.