

Autism and Parental Blame Research Project

Focus Group Report - FINAL

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Project Delivery/Supplier: WM-ADASS

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

Introduction and Context

The Autism and Parental Blame Project was commissioned by NHS England in response to complaints from a number of parents who felt their child's autism had been missed, or misdiagnosed, because professionals involved in autism assessments had wrongly ascribed their child's autistic presentation to poor parenting. The project has been facilitated by WM-ADASS with academic support provided by Dr. Jason Schaub from the University of Birmingham.

An advisory group supports each phase of the project and acts as expert guidance to inform and shape the project. Membership of the advisory group consist of parents with lived experiences of parental blame and representatives from health, education and social care. Parents in the advisory group have provided guidance and feedback on the design of the survey and questions for focus groups in their role as experts by experience. The project began in June 2022 and concluded in March 2024.

There are three discrete phases of the project:

Phase 1: Systematic Literature Review

Phase 2: Online survey of parents' experiences

Phase 3: Focus Groups to explore parents' perspectives of what good services look like

This report delivers the outcomes of the focus groups; the third phase of the Autism and Parental Blame research project.

Advisory Group

We established an advisory group to support and add additional expertise to this study, membership was made up of representatives across the East and West Midlands. The advisory group consisted of 18 members. Ten of whom are Experts by Experience, the majority are parents of autistic children with in-depth knowledge and experiences of parental blame, and included parents who are both autistic and neurotypical. Most members also have a role in a professional capacity with broad ranges of experience including SEND and EHCP expertise, as well as other relevant sector knowledge, such as research or voluntary organisations. In addition, six members work in the field: providing substantial experience from social care, health, and research in roles of influence. It is also noted that the two co-researchers/project leads have both relevant professional backgrounds and are also parents and grandparents of autistic young people.

Definitions of Key Terms Used in the Project

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.

Autistic – 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. We have used the following definition of autism from the NICE clinical guidelines as our reference.

“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.”

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. Within the context of a project about parental blame it is important to emphasise that not all behaviours/presentations occur because of a parent's actions.

Focus Group Design

The third stage of the project aimed to seek the views of parents through conversations about their experiences following on from the literature review and the survey. During the survey we asked all participants if they were willing to assist with the research further and volunteer to talk to the leads of the project about their experiences and views. From the 783 survey responses 322 participants, 41% of parents, offered to talk to the project team and share their experiences. Overwhelmed with this response and looking to find ways to maximise upon this offer we explored the use of focus groups as the best method to engage with participants. The advisory group and project commissioner were consulted on the focus group methodology and fed their ideas into the focus group design.

One of the key findings of the survey was that a third of participants identified as being autistic. We wanted to explore in more detail the impact of this when approaching services for support. For this reason, we decided to run two focus group events with the following distinction.

Focus Group One - for parents who identified as autistic.

Focus Group Two - for parents who identified as neurotypical.

The aim of the workshops was to explore in more detail parents' shared experiences and reflections of parental blame which could shape and influence a set of recommendations for change.

Each focus group was designed to include up to eight participants. The facilitators invited 25 people per session. The survey covered all regions in England, and to ensure we gathered views from across different regions, location was considered when targeting the invitations.

To support easy access to the focus groups, we held online events using Teams' meetings to host the groups. Inclusion criteria was used to determine who was invited to the focus groups to ensure a mix of genders, parental responsibilities, age range, race and ethnicity, child gender age.

Participants were sent an email with a private Eventbrite invitation, which enabled parents to book a place. Emails were sent three weeks in advance of the event, with reminders at two and one weeks, and a final email sent the day before with the Teams' invitation link.

The Eventbrite invitation contained details of the event with FAQ's and information about how the event would be recorded, guidance on participation and confidentiality, and how information would be used. <https://www.eventbrite.co.uk/e/autism-and-parental-blame-focus-group-invitation-to-participate-tickets-696504021277?aff=oddtcreator>

Graphic recoding was used to support each of the focus groups, which enabled parents to see their experiences and views captured in real time. This also empowered the group to review and reflect on the information collected in a transparent and accessible way.

Focus Group Delivery

Two focus groups took place over two consecutive weeks.

The groups ran for two hours, and the following questions were used as prompts to stimulate discussion.

When thinking about the experiences you had with professionals describe some of those experiences where you felt blamed. What words come to mind?
(Focus group 1 only) Do you think being an autistic parent made a difference in your interactions with professionals and services?
Reflecting on the experiences you have had, if we were going to redesign what the autism assessment pathway would look like, tell us what you would like to see happen when you first approached a professional for support when you considered you child may be autistic?
What would you like to see happen following the autism diagnostic assessment?
Looking at the graphics, is there anything we have missed that you feel is important and want to tell us about?
Final reflections and summary.

Key Findings from the Groups

The findings from the two focus groups delivered a similar set of powerful messages. The experiences of the autistic parents added an additional layer in terms of parents identifying good practice examples of support from professionals who were also neurodivergent, and real insight and self-awareness of how being an autistic parent could play into scenarios of parental blame.

Parents Experiences

- Parents felt judged and accused of poor parenting when using strategies that worked best for their child.
- Parents were often not listened to, felt dismissed, and not believed by professionals.
- Professionals were often quick to make assumptions based on little or no evidence or validation.
- Professionals failed to follow their own guidelines and policies.
- Professionals lacked training and understanding of autism and hidden disabilities and mistook this for trauma which in turn caused trauma.
- The multiple, devastating, and lasting impacts of parental blame, examples of child protection issues including Fabricated and Induced Illness, fractured relationships, and family breakdown.
- The need for parents to quickly become experts and skill themselves up to defend themselves.
- Parents felt that they needed to fight the system to get the basics for their child and to be heard as parents.
- Parents best experiences of services were when they were supported by a neurodivergent professional who just “gets it”.

Areas for change - parents told us they wanted to see changes that involved:

- More reasonable adjustments in place to support a productive working relationship with autistic parents.
- Recognising parents as experts and work in partnership with professionals.
- Professionals viewing parents that are asking for help as positive, not a challenge.
- Start from a position of believing the parent unless there is a real reason not to.
- More neurodivergent professionals as champions.
- More awareness through training for professionals about autism, hidden disability, and the risks of parental blame.
- More use of autism services in the third sector as the autistic community support each other well.
- More services for autistic people run by autistic people.
- Professionals need to follow best practice guidelines.
- Accountability in the system when professionals make mistakes.
- Support for parents who are or have experienced parental blame by the system.

Discussion

It was evident from discussions in the focus groups that parents had experienced multiple occurrences of parental blame across all services, health, education, and social care. The accusations that had been made about parents included such words as *obsessive*, *neglectful*, *manipulative*. Parents described the impact of being blamed for their child's behaviour/presentation as being traumatic, with several parents talking about suffering from symptoms of PTSD.

Parents in both groups had been asked why they wanted to label their child, with one parent being told "*you'll destroy him*". Some parents talked about the anxiety and the trauma they felt as their concerns were dismissed, and their knowledge of autism viewed with suspicion by professionals. Two parents described how previous family trauma (the suicide of a sibling) was used to dismiss their concerns about their child being autistic – "*It's the result of your anxiety about your loss*". Other parents described the impact of their concerns being dismissed "*I was made to feel completely stupid*". Autistic parents in the focus groups felt they had a unique perspective on how to parent an autistic child "*normative parenting doesn't work for an autistic parent and child*" but were told both that they too well informed and that being autistic meant they couldn't parent well. This contradiction about being too well informed about autism being seen negatively by professionals was described by parents in both focus groups.

All parents described a sense of fear about the power of social workers to instigate child protection procedures and remove children, especially in regard to suspicion of Fabricated and Induced Illness (FII). Several parents had been accused of FII and had their children temporarily removed from their care. Parents talked about the long-term damage these unsubstantiated accusations can have. One parent reported that their child at 25 was still suffering symptoms of PTSD from being removed without warning from her home and placed in care. Parents talked about a lack of understanding by professionals about how autism presents, some parents felt this was particularly true in relation to autistic girls.

Most parents were able to identify examples of individuals and services who provided good support. Some parents talked about the positive impact made by having professionals involved who were neurodivergent themselves. All parents described the benefit and support they had received from peer support groups. When asked what would improve service provision none of the parents talked about waiting times, which would indicate that this isn't the major concern when considering parental blame. Instead, parents talked about the need for better communication, being respected as knowledgeable and informed, and seen as experts and equal partners in the assessment and support processes, all underpinned by starting from a place of listening to and believing parents when they first seek help.

Parents identified the need for training for professionals that is evidence based, delivered by experts by experience and includes how to communicate with autistic adults. It was suggested that neurodivergent professionals could help by mentoring by neurotypical colleagues. Parents recommended greater engagement with autistic led charities and peer support organisations, referencing the support they could provide to parents and families before, during and after assessment and diagnosis.

Parents also stressed that there needs to be greater acknowledgement of the harm caused by parental blame and accountability built into services where actions taken by professionals cause harm to families. This should include aftercare for families, recognising the long term impact of parental blame, particularly when that has resulted in a child being removed from the family home, and an understanding of how this can impact on families and future relationships with professionals.

Conclusion

The two focus groups we facilitated supported the findings of the literature review and the online survey that parents of autistic children and young people experience blame by professionals when they seek help and support. This blame sometimes takes the form of not being listened to or not being believed that the child or young person is presenting with behaviours that are consistent with a diagnosis of autism. Some parents describe that when those behaviours are acknowledged by professionals, that they as parents are held accountable for the behaviour rather than considering if an autism diagnosis is appropriate. At its most extreme this blame becomes an accusation of Fabricated and Induced Illness and for some parents has resulted in their child being removed from their care.

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.

Parents are able to identify examples of good practice amongst professionals and services and can articulate what good service looks like. Parents feel strongly that their expertise and experience should be recognised by professionals and that seeking help should be viewed positively and not with suspicion.

Parents recommend that professionals should receive training created and delivered by experts by experience and that when harm occurs as a result of parental blame professionals should be held accountable and families should receive support to address the impact the harm has had.

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