



Recognising Autism Parents' and Practitioners' Perspectives

Introductions



Debbie Hollingsworth
(WM-ADASS Associate)



Laura Ferguson
(WM-ADASS Associate)



Jason Schaub (Academic
Advisor) Birmingham University

Outline of the session

A question for you to start

Overview of the project

Gathering Parents' Perspectives – What we've learned about families' experiences

What parents say would improve experiences for them and their children

The next phase – Gathering Practitioners' Perspectives

A couple more questions for you

Any questions for us?

Close



Poll Question 1:

**What prompted you to attend the
webinar today?**

Context for the project

- Social context
 - Autism diagnoses up 787% between 1998 and 2018
 - Changes in diagnostic criteria and increased awareness
 - Increased number of referrals, long waits for assessments
- Parents
 - High stakes, sometimes desperate
 - Seeking explanations and help
- Practitioners
 - Balancing limited resources with increasing demand
- Sometimes (Often?)...
 - Child's presentation/behaviour blamed on parenting approach
 - Parents long term intimate observations less valid than other people's limited observations

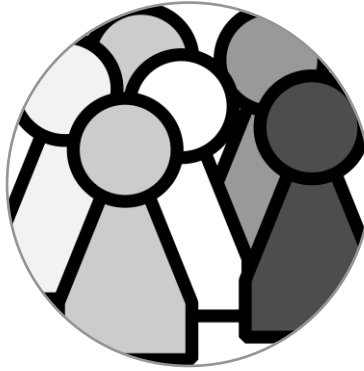
The story so far...



Commissioned
in 2022 by
NHSE Midlands
in response to
concerns raised
by parents



Managed by
West Midlands,
ADASS. Phase 2
funded by ADASS
(Facilitated by
Debbie and
Laura)



Parental and
Practitioners
contribution
through Expert
by Experience
Advisory Group



Academic
oversight from
University of
Birmingham.
Phase 1
findings and
considerations
published Nov
2024



Phase 2 -
gathering
practitioners'
perspectives
through survey
and focus
groups - 2025



Analysis of
results,
conclusions,
and final report
- Early 2026

Collaborative research with parents and practitioners



Autism and Parental Blame Project

Blamed Instead of Helped

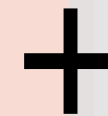
How parents of autistic children experience parental blame when they approach services for support.

Authors Laura Ferguson and Debbie Hollingsworth
(WM-ADASS Associates and Project Leads)



November 2024

Parents'
Perspectives



Practitioners'
Perspectives

Survey

Focus Groups

Report
Findings

Future Survey

Future Focus
Groups

Systematic Literature Review

Project Contributors

Advisory Group:

Julia Carter (Parent and SEN consultant)

Angela Favell (Parent, Advocate and Specialist Disability PA)

Jane Friswell (Parent and SEND Consultancy)

Libby Hill (Consultant Speech and Language Therapist)

Pete Jackson (Improvement Director, WM- ADASS and Advisory Group Chair)

Donna Kelso (Parent, Grandparent and Advocate)

Berni Louise (Parent and NHS Professional Advocate)

Dyllan Mathieson Dodd (Autistic Champion and Expert by Experience)

Tracey Moon (Parent and SEN Consultant)

Shona Murphy (Parent and Director Autistic Parents UK)

Trevor Wright (Parent, FRSA member and OMG Trainer)



Project Team



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



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



Catherine Nolan (WM-ADASS Project Manager)



Jason Schaub (Academic Advisor)
University of Birmingham /Bristol

Phase 1- Gathering Parents' Perspectives

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

Project Phases

1. Systematic Literature Review
2. Survey of 685 parents of autistic children mapping their experience of contact with health, education and care services
3. Two focus groups, one with autistic parents and one with neurotypical parents providing further detailed description of parental experiences
4. A series of reports and 8 key considerations that identify opportunities to improve parents' experiences

Systematic Literature Review: Method

Search terms:

- Children & Young People
- Autism
- Parents & Carers
- Parental Blame
- Fabricated and Induced Illness

- 5 databases searched for peer reviewed articles
- Grey literature search
- Consulted with experts for relevant literature to include
- Initial search returned 231 papers after duplicates removed
- 59 papers assessed against quality criteria, 23 papers removed which did not meet the threshold.
- 32 papers were assessed using the Critical Skills Appraisal Programme (CASP).
- 14 identified for full critical analysis

Literature Review Findings

- Parents experience blame from **multiple sources**
 - community,
 - family,
 - friends
 - and professionals.
- **Blame from professionals'** manifests as:
 - blaming parenting as a cause of child's autistic presentation,
 - not listening to or believing parents,
 - accusations of neglect or FII.
- **Parents/families impacted** by blame from professionals
 - describe battling the system,
 - experience guilt, symptoms of trauma,
 - become informed and knowledgeable to advocate for themselves and their children
- Limited evidence of **professional perspectives** of parental blame
- **Majority of studies examine mothers** – little research about fathers, other family

Online Survey of Parents' Perspectives –

685 responses from parents of autistic children. What we wanted to find out...

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?

Online Survey of Parents' Perspectives – 685 responses

Some key findings:

- 86% of respondents experienced parental blame prior to their child's autism assessment and diagnosis.
- Blame described as judgemental or discriminatory statements about parents, disbelief about child's presentation, criticism for being under or overprotective.

Blame comes from everywhere and everyone:

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

Key findings cont.

- Blame results in a lack of support for families – 90% of respondents
- Worsening mental health for children (and parents) – 70% (94%)
- Children at increased suicide risk - 25%
- Children feel negatively about autism - 46%

- An autism diagnosis improves the incidence of parental blame on average for most (but not all) parents across all sectors.
- Biggest reduction in blame is from partner, friends, and family

- 37% experienced parental blame after they had made a complaint about a service.
- Autistic parents 3 times more likely to be accused of FII than non-autistic parents.
- And twice as likely to face safeguarding or child protection investigation

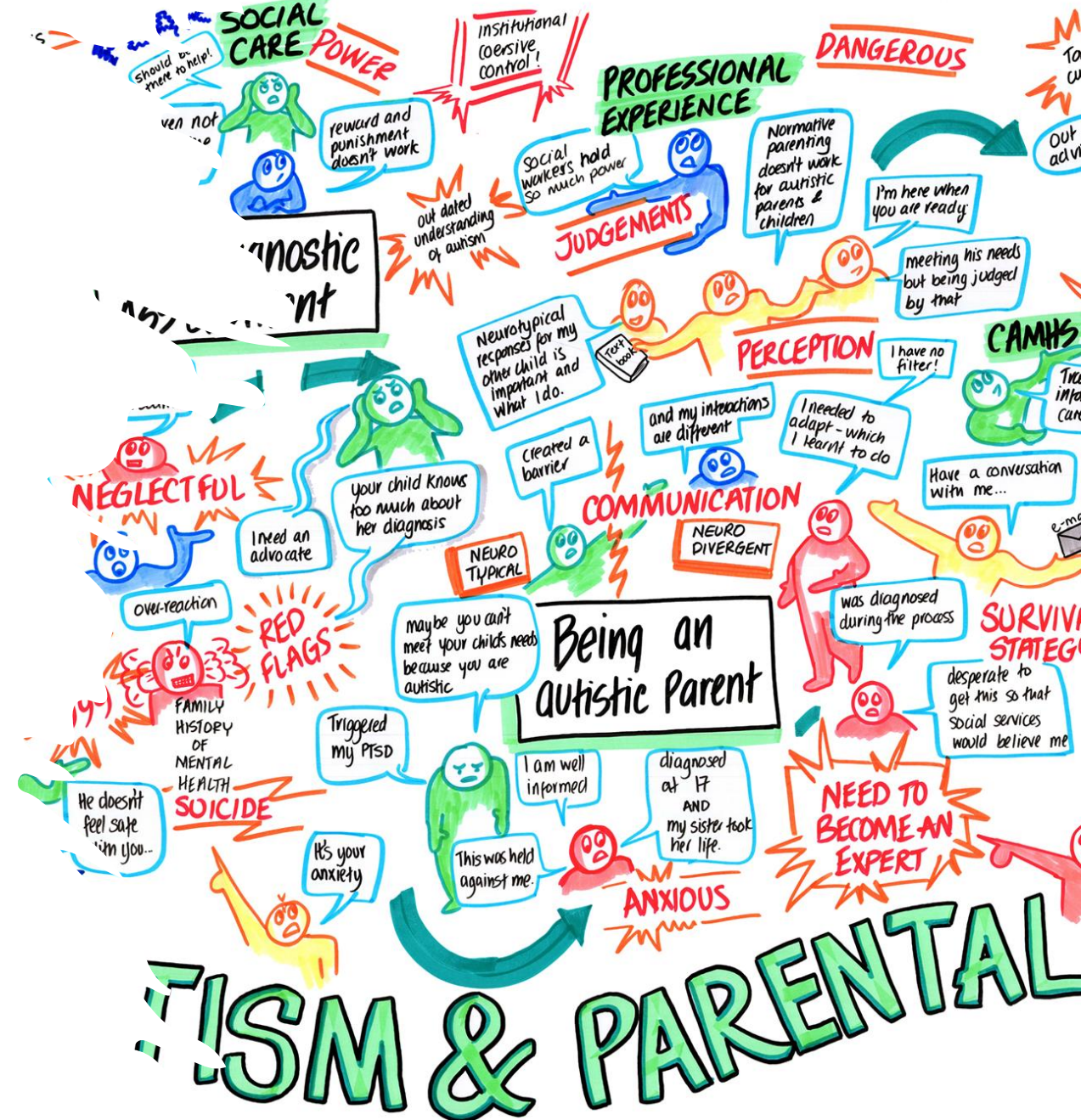
Focus Groups

“In designing support for parents before and after autism diagnosis, what would good look like?”

2 focus groups: 9 participants

Group 1: Autistic parents

Group 2: Parents not identified as autistic





Focus Groups – Finding and Recommendations

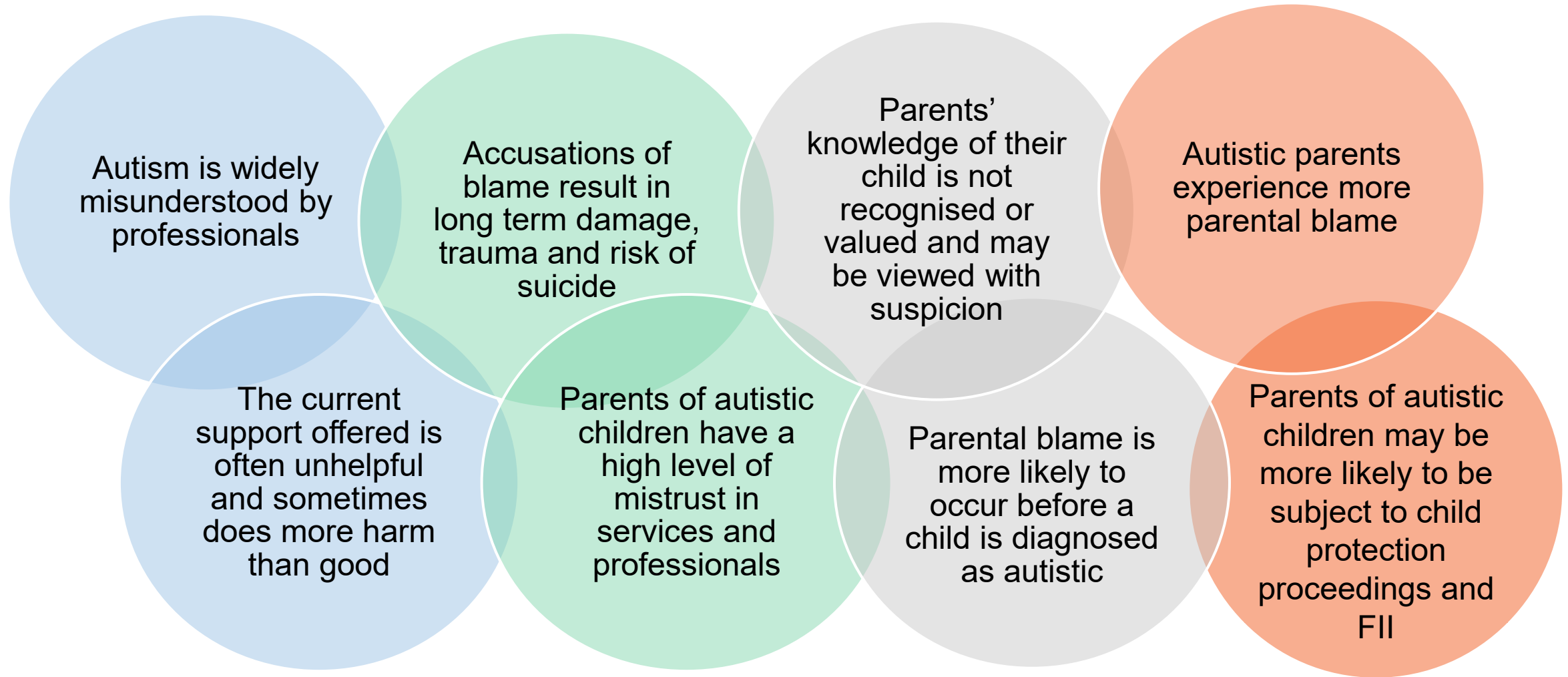
Improving recognition and awareness of autism to reduce harm caused by delayed or mis-diagnosis

Reducing blame and **improving support** for families


Recognising and **valuing parents' knowledge and expertise**

Ensuring safeguarding and FII concerns are based on **accurate assessments**

8 Areas for Consideration



Misunderstanding can cause harm



Autism is widely
misunderstood by
professionals

The current
support offered is
often unhelpful
and sometimes
does more harm
than good

Vast majority of parents said they:

Experienced parental **blame prior to their child's autism assessment and diagnosis**.

Weren't believed about their child's autistic presentation.


Experienced **open criticism of their parenting** abilities.

Less than 2% of all participants said they **get the help they need** from services.

Most parents were **not offered any support or information** whilst their child was waiting for an autism assessment.

The most frequently used word to describe post-diagnosis **support was "non-existent"**.

Blame from professionals leads to trauma and mistrust



Accusations of blame result in long term damage, trauma and risk of suicide

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

1 in 4 parents reported their child at a **high risk of suicide** following parental blame.

1/3 of parents were **fearful their children might be removed** from their care.

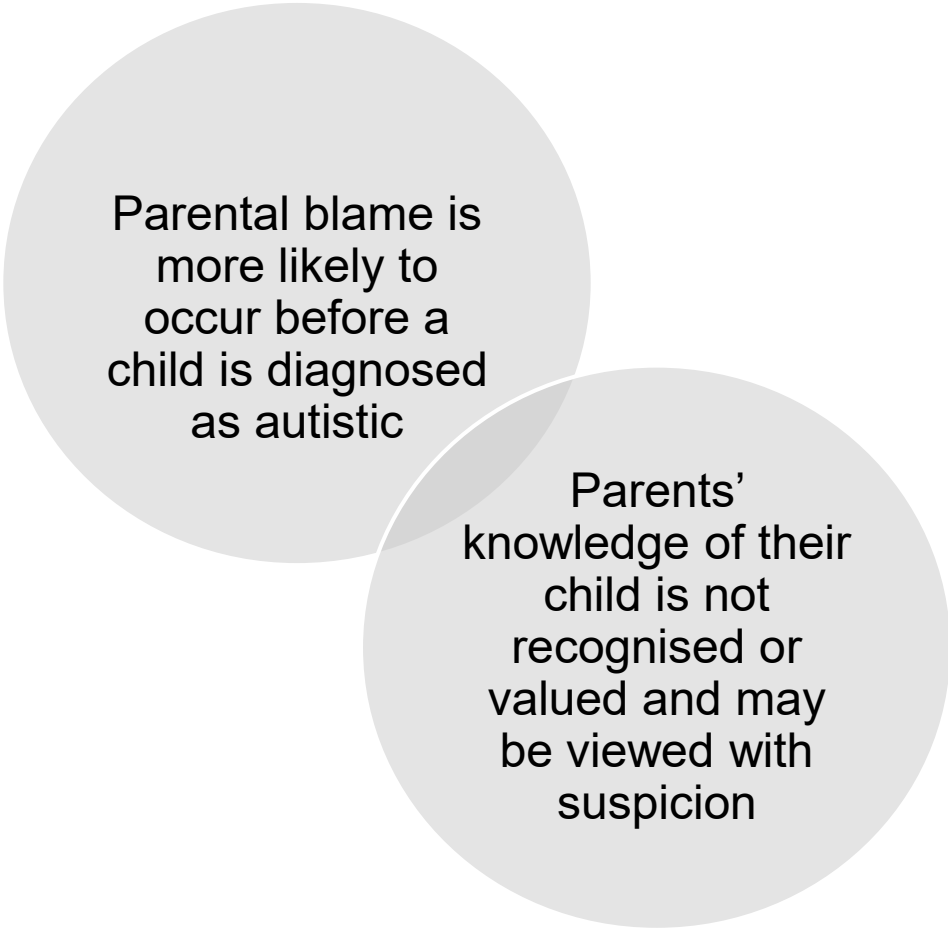
Almost half reported **loss of income** due to increased caring responsibilities.

Nearly 3/4 participants **lost trust in services** and professionals because of their experiences.

Over 1/3 experienced parental blame **after they had made a complaint** about a service.

Parents felt a **power imbalance** weighted towards professionals. They felt there was no accountability or consequences for professionals who get it wrong.

Parents' knowledge and expertise is disregarded



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

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

81% of parents who experienced parental blame said they **weren't believed** about their child's autistic presentation.

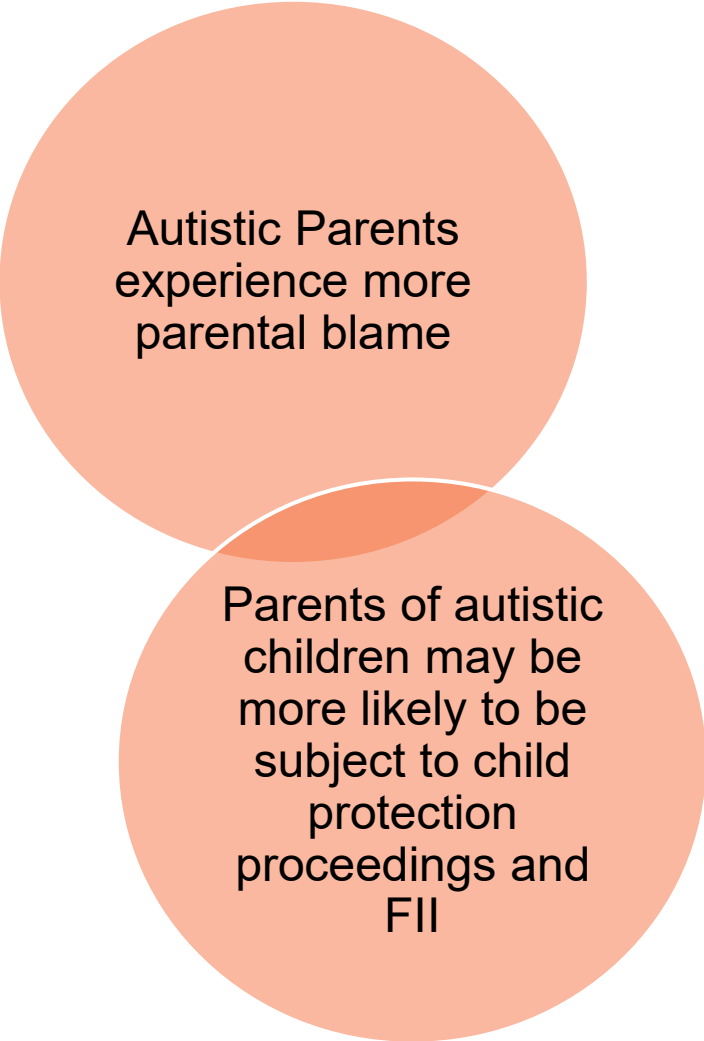
86% of parents said their **parenting was criticised** prior to a formal autism diagnosis

- Education 77%
- Health 63%
- Friends and Family 46%
- Social Care 26%
- Self and/or Partner 22%

An **autism diagnosis improves the incidence of parental blame** for parents across all sectors.

But it doesn't eliminate it. **For some parents blame got worse after the diagnosis**

Safeguarding, FII and Autism



Autistic Parents
experience more
parental blame

Parents of autistic
children may be
more likely to be
subject to child
protection
proceedings and
FII

One in four parents were subject to a **safeguarding referral**

Approximately **one in six accused of FII**.

Parents with a formal diagnosis of autism were **3x more likely to:**

- be accused of FII
- have their children removed from their care.

1/3 of survey participants identified as autistic. (majority self-identified)

A further 1 in 5 said they were unsure whether they were autistic.

What good support looks like:

Autism training for professionals

Parenting courses delivered by experts

Neurodivergent practitioners mentoring and/or advising colleagues

Increasing awareness about the harm of parental blame by professionals

Providing support and aftercare for those affected

False and unsubstantiated accusations investigated, and lessons learned, where evidence of deliberate falsification is found, people to be held to account.

What good support looks like cont.

Recognising **parents as partners**

Working agreements based on mutual respect and value

Professionals **starting from a point of believing the parent.**

Practitioners adopting a **culture of listening and respect** towards parents coupled with a **non-judgemental** acceptance of parents' concerns.

Specialised workers conducting assessments of need.

Ensuring practitioners are **equipped to recognise** and work with autistic adults



Phase 2 – Gathering Practitioners' Perspectives

Research Question: How well equipped are practitioners to recognise autism in children and provide the support families need?

Inclusion Criteria: Practitioners in England, working in health, education and social care services, whose work brings them into direct contact with children and families.

Coming soon...

Identifying Autism in
Children and Young People -
Exploring Practitioners'
Perspectives



TBC 2026

Project Outline

On-line Survey (Aug & Sept 2025)

Focus Groups (Oct 2025)

Evaluate and report findings

Develop recommendations

Final Report & Dissemination (early 2026)

How you can be involved

- Take part in our survey and encourage others to participate
- Be a focus group participant
- Read our report on parents' perspectives
<https://bit.ly/parentalblame>
- Join our mailing list Email us at
APB@wm-adass.org.uk



The background of the slide is an abstract painting. It features a large, faint silhouette of a human face in profile, facing left. The colors are soft and blended, with shades of light blue, pale yellow, and muted pink. The texture appears to be that of a pastel or soft paint application.

Just before we finish, a few questions for you

Q.2. How relevant do you feel the research findings are to your professional practice?

Q.3. How relevant do you feel the research findings are to you as a parent?

Q.4. How motivated do you feel to seek out further information or training on this topic?

A painting of a man's face in profile, looking left. The face is rendered in shades of blue and orange, with a soft, painterly texture. The background is a mix of light blue and yellow. The text is overlaid on the right side of the image.

And finally
Any questions for us?

Thank you for listening.

Share your perspectives on autism with us.

