

Exploring Perspectives on Autism

Findings from Survey of Education, Health & Social Care Practitioners

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



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Practitioner Perspectives

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Project Background

The Exploring Perspectives on Autism Project aims to shed light on the experiences of parents and professionals when parents of autistic children and young people (CYP) seek support for their child. The first phase of 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 findings from Phase 1 of the project revealed that parents of autistic children frequently experienced blame in their dealings with practitioners from whom they have sought support for their child. Parents expressed the view that practitioners often have an outdated understanding of how autism presents in children and lack a full understanding of how and when autistic children mask. A survey of parents demonstrated that autistic parents may be at substantially increased risk of being subject to a safeguarding review or being suspected of misleading professionals (sometimes intentionally) about their child's autistic presentation, a phenomenon which falls into the category of Fabricated and Induced Illness (FII), a very rare but potentially very dangerous form of child abuse.

A systematic literature review returned two studies exploring the concept of parental blame from the perspective of practitioners. Both were small scale studies, providing limited evidence.

To develop a fuller understanding of the interactions between parents and professionals a second project phase, exploring professionals' perspectives was commissioned by WM-ADASS to answer the question: *"How well equipped are professionals to recognise autism in children and provide the support families need?"*

This report delivers the most notable findings of an online survey of 96 practitioners working within health, education and social care services. A report detailing the findings from 3 focus groups and a final project report along with all reports on the findings from Phase 1 of the project are available on the WM-ADASS website from July 2026.

Aims of the Survey

This survey was designed to investigate whether practitioners have the knowledge, understanding and resources to recognise autism in children and provide the support families need. Specifically, the study aims to:

- **Quantify baseline knowledge:** Evaluate self-assessed understanding of autism and masking across health, education, and social care.
- **Measure confidence in practice:** Assess professional confidence in distinguishing autistic traits from parenting styles or Fabricated and Induced Illness (FI).
- **Analyse practitioner experience:** Explore what factors, if any, might impact a practitioner's professional insights.
- **Identify barriers and challenges to supporting families:** Uncover the structural pressures, gaps, and shortages that frustrate practitioners' efforts to support families and which may contribute to parental blame.

Method and Limitations

Method

The survey was created in Microsoft Forms. It comprised 44 questions and took participants an average of 39 minutes and 21 seconds to complete. 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 to Health, Education or Social Care practitioners in England whose role brought them into direct contact with autistic children and young people and their families. It was open for 22 weeks and distributed via specialist professional networks, social media platforms, the project team and advisory group members' personal and professional networks.

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.

The survey produced both quantitative and qualitative data. Qualitative responses were analysed using inductive thematic coding. A detailed set of provisional codes was developed by the researchers which were then iteratively refined into broader themes. Frequencies were then calculated based on the number of respondents mentioning each theme. To ensure analytical rigor and maximize coding objectivity within operational timelines, a dual-stage verification process was deployed using two independent Large Language Models (LLMs) to verify coding consistency, accuracy, and ensure no marginal themes were overlooked.

Limitations

Survey participants were self-selecting and the survey population was small. The survey relied on respondents' subjective self-assessment of their knowledge, understanding and confidence and was not designed to objectively test competency in any of these areas.

There was significant underrepresentation of certain groups in the survey, particularly practitioners from minoritised ethnic groups and male practitioners. Additionally, there was a disproportionately high number of autistic respondents (10% vs ~1% of general population), and respondents with a close familial relationship to an autistic person, compared to the general population.

Caution should therefore be exercised in interpreting these results as representative of the wider population of practitioners working within Health, Education and Social Care.

Further in-depth research is needed to fully understand the experiences of more diverse practitioner populations, in particular how cultural intersections might impact practitioners' knowledge and confidence, and additionally the differences that might exist between service areas and roles within those services. This would enable more nuanced recommendations to be made.

Definitions of Key Terms

Autism – Autism is a spectrum condition which presents differently in each person and therefore any broad definition will be 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”. 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. Our advisory board recommended that only using the term autistic behaviour could be construed negatively and correlated with bad behaviour.

Parental Blame – This definition was developed in consultation with parents. 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. 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 parent's account of their child's behavioural symptoms or the need for an autism assessment.
- Professionals accusing the parent of causing the child's behaviour.

Key Findings

Characteristics of participants

- **96 responses** from 8 Local Authority regions in England
- **51% worked in Social Care, 25% in Health and 24% in Education.**
- **93% of respondents were female**, 5% male and 2% preferred not to say.
- **90% of participants were White**, 4% were from mixed or multiple ethnic groups, 3% were Black, Black British, Caribbean or African, 2% were Asian or Asian British, and 1% were from other ethnic groups.
- **18% of respondents said they were disabled**, 5% preferred not to say.
- **10% of respondents said they were autistic** – 3% had a formal diagnosis, 7% were self-diagnosed. 17% of respondents said they were unsure whether they were autistic. 68% of respondents said they were not autistic and 5% preferred not to say.
- **33% of respondents were the parent or carer of an autistic child**, 10% had a partner who is autistic and 9% had an autistic parent or sibling. 61% of respondents said they had wider family, friends or colleagues who were autistic

Practitioners feel knowledgeable in theory but less confident in practice

82.3% feel knowledgeable about how autism presents in children and young people **but only 40% feel confident** when identifying autism vs parenting.

86.5 % understand masking and how it might affect a child's presentation, **but only 51% can tell** if a child is masking their autism.

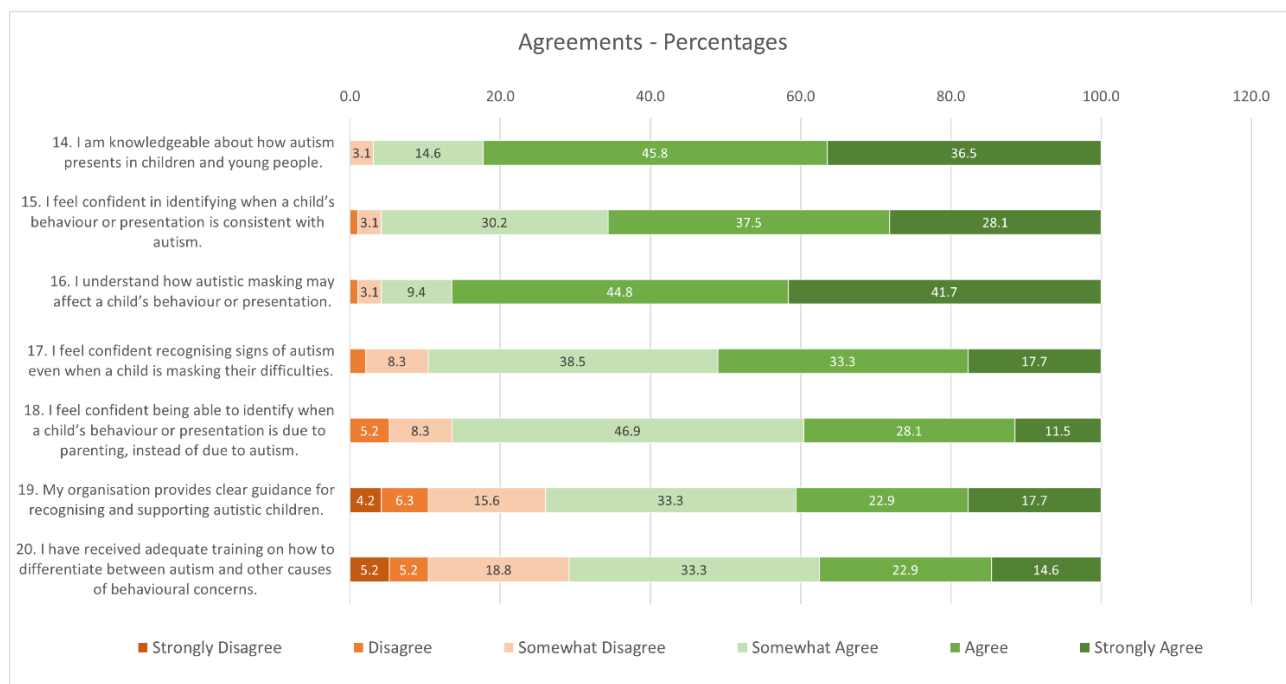


Figure 1: Graph to show how highly respondents rated their knowledge, understanding and confidence

There is a gap in FII knowledge and training

64.5% of practitioners **have zero training in FII**, however, **29% of practitioners** have been **involved in cases** where FII is a concern.

Of the **13** practitioners who had **investigated concerns** about FII, **only 3** had had **formal training**.

56% of all practitioners were unsure if their workplace had a **FII policy** and **over 75% were not aware of FII guidelines** produced by British Association of Social Workers or Royal College of Paediatrics & Child Health.

Lived experience of autism increases practitioner confidence

Practitioners with personal, familial or lived experience of autism are more confident about identifying autism in practice and more critical of workplace guidance

82% of respondents with a close familial relationship were confident about identifying autism **compared to 55% of those without** a close familial relationship and 71% were confident about identifying masking compared to 38% of respondents without a close familial relationship (*Figure 2*).

Only 20% of autistic respondents agreed or strongly agreed that **they had clear guidance** on both autism and FII compared to 48% of non-autistic respondents who agreed or strongly agreed that they had clear guidance about autism and 34% who agreed or strongly agreed that they had clear guidance about

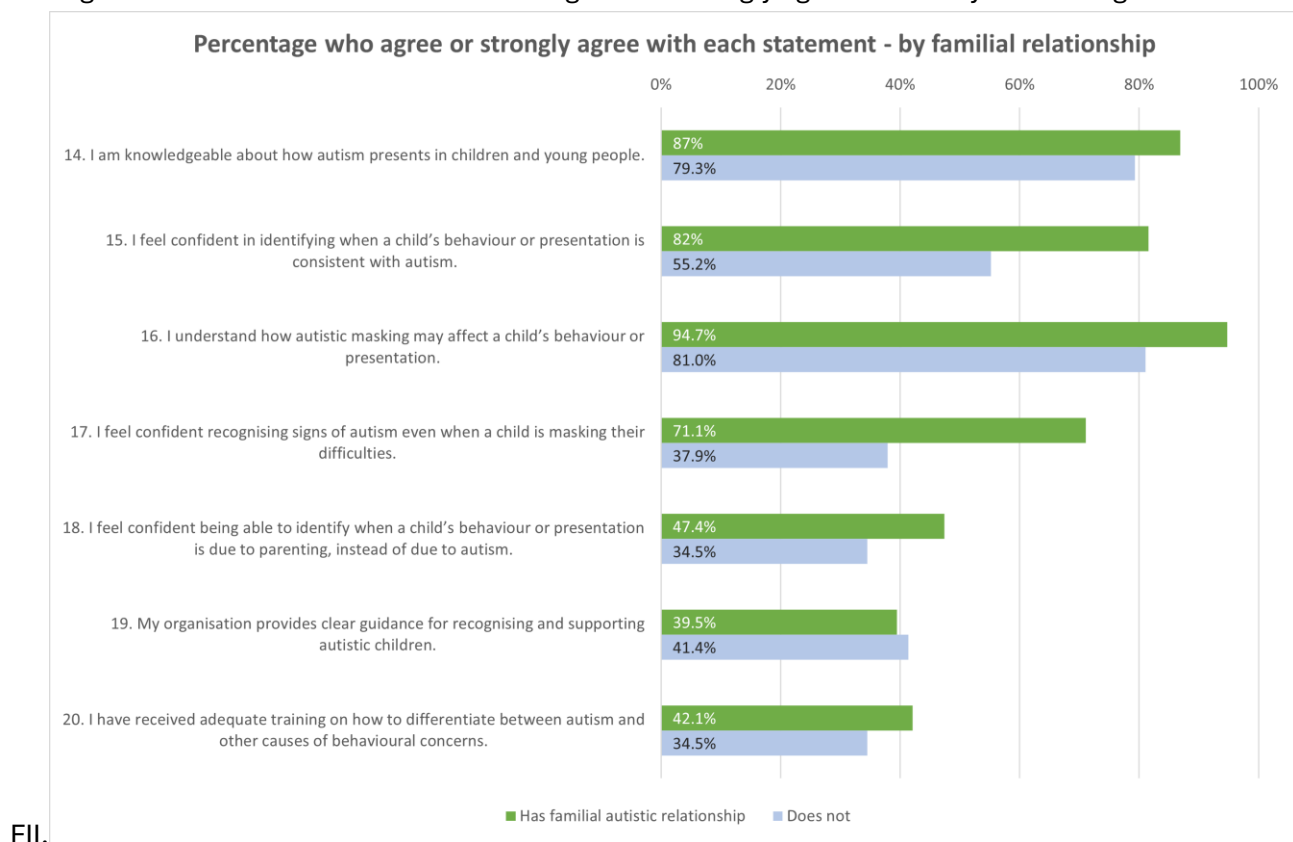


Figure 2: Graph to show knowledge, understanding & confidence of practitioners with close familial relationship

Barriers and challenges to supporting families

An open text question asked respondents: “What do you consider to be the most pressing challenge when working with parents and children seeking a diagnosis of autism?” Responses were analysed using inductive thematic coding. A detailed set of provisional codes were iteratively refined into broader themes and finally grouped into 3 main categories.

1. Service Capacity and System Constraints - what practitioners think about systems, policies and processes

Families have to wait a long time for an autism assessment – Over 60% of respondents referred to the length of time children have to wait for an autism assessment as the most pressing concern when working with families. Respondents identified that children can be waiting many years for an assessment and receiving an autism diagnosis does not automatically lead to support being offered.

"The length of time it takes from point of referral to the initial appointment with the Community Paediatrician – around 4 years at present." (#58 Education Respondent)

"TIME!!! What support is out there for both children and parent?" (#5 Social Care Respondent)

"the pathway is long and there is little support during this, and also a lack of support post-diagnosis" (#65 Health Respondent)

Diagnosis as the gateway to support is problematic – Practitioners noted that support is frequently dependent on a diagnosis and therefore the impact of long waiting lists increases pressure on families and practitioners. This is compounded further by inadequate services, resources and staffing.

"Lack of resources within the neuro development pathways, long waiting times for parents and families and not enough staff to help them." (#17 Social Care Respondent)

"Accessing appropriate support/services specific to the needs of the child/young person who displays autistic behaviour and challenges but [has] no formal diagnosis" (#48 Social Care Respondent).

Delayed diagnosis may lead to poorer outcomes - Respondents noted that early intervention supports better outcomes while delayed diagnosis and support can have serious negative outcomes for families.

I worked with one young person where he got a diagnosis at age 16, after concerns were raised...at 11 years old...Consequently, his secondary education was significantly impacted (negatively) by not having the correct diagnoses (which would have meant appropriate support measures would have been put in place...a lack of understanding around needs can, and does, lead some young people into the criminal justice system” (#75 Social Care Respondent).

2. Professional Knowledge and Collaborative Working - what practitioners think about their own and others' practice

Outdated diagnostic criteria risks missed or mis-diagnosis - Several respondents commented that diagnostic criteria used in some settings or by some practitioners has not been updated to enable timely identification of children who mask or autistic girls.

“...the diagnostic criteria does not match how autism presents for those that do mask and don't display the stereotypical idea of autism, particularly in girls.... The whole diagnostic criteria is outdated.” (#8 Education Respondent)

Practitioners have inadequate knowledge about autism - Practitioners identified gaps in their own and other practitioners' knowledge of autism and how it presents in different children. Specifically, they identified poor understanding of masking, sensory needs and autistic presentation in girls.

"Lack of understanding about autistic and neurodivergent presentations in schools... THIS is the biggest factor in outcomes”, (#7 Health Respondent).

Diagnostic overshadowing can cause uncertainty - A frequently occurring theme was concerns that trauma, attachment, or other neurodivergent traits (like ADHD) are either confused with or ignored because of autism. Several respondents noted concerns that a child's environment and life experiences may complicate a diagnosis.

“There are many myths around autism, and these may well impact on whether an individual has a diagnosis or whether it may well be other, or a mixture of difficulties, such as ADHD. In other words, we have to be careful not to assume that autism is the actual outcome when it may not be.” (#44 Education Respondent).

“widespread lack of understanding around the impact of autism vs the impact of the child's environment, e.g. the impact of neglect in childhood being labelled as a symptom of autism” (#25 Social Care Respondent).

Fragmented services and school-centric assessment disrupt and delay support - Respondents identified that fragmented and siloed services, along with a lack of collaboration between services could disrupt the assessment pathway and delay support for children

Several respondents highlighted the central and critical role that schools have in the assessment process and noted how challenges occur when the evidence from a school is weighted more heavily than evidence from parents or other practitioners.

“CAHMS and CAHS crisis refusing to work with children who are presenting in crisis because they believe their needs to be arising from autism as opposed to mental health...” (#41 Health Respondent).

“Community paediatric services in my area not providing guidance on what to do when healthcare professionals & families believe the child is autistic but education setting disagrees/refuses to fill out paperwork.” (#73 Health Respondent).

3. Trust, Communication, and Professional Perspectives - what practitioners think about the parents/carers they work with

Parental expectations, understanding, and beliefs can be challenging – Practitioners noted the difficulties in communicating with parents when raising potentially controversial views. They identified the challenge of managing parents’ expectations and suggested that the fixation on obtaining a diagnosis could be addressed by moving to needs-led support.

“...as a professional feeling able to talk about behaviour vs autism and that everyone still needs to adhere to what is “right and wrong”” (#49 Health Respondent)

“lack of support to manage behaviours...parents thinking the diagnosis will change the child behaviours” (#55 Health Respondent)

“If we had a much more need led approach to autism then the system, and indeed some parents may not be as fixated on receiving a diagnosis. It all feels too deficit driven” (#10 Education Respondent)

Parents resist competing narratives for autistic presentation - Respondents suggested that some parents were overly focused on obtaining a diagnosis and were reluctant to accept that factors such as parenting, environment, trauma or attachment might explain their child’s presentation rather than autism. Respondents also noted some parents’ resistance to try parenting strategies until a diagnosis had been obtained.

"... how much is a need for a diagnosis... and how much of it is an excuse to allow behaviours to continue." (#6 Social Care Respondent).

"Some parents are only focused on getting a diagnosis and don't want to try different strategies" (#76 Health Respondent)

Autistic parents may face and present unique challenges – Practitioners noted the lack of specialised support for autistic parents and the possibility of professionals making judgments about their parenting or communication.

"Neurodivergent parents may present as though they are disabling or speaking for their own child" (#98 Education Respondent)

"Parents with autism finding it challenging to support children with additional needs" (#83 Social Care Respondent)

Parent-practitioner relationships and blame - Some respondents noted that parents encounter disbelief about their child's autistic presentation from professionals and may face obstacles when advocating for their child.

"If the child is coping while at school they perceive the issue as being around parenting, or parental anxiety... some settings are quite quick to 'blame' parents rather than looking in more detail." (#81 Health Respondent).

"Their reality is not always received by professionals in the way that they intend and they are worn down by the assumptions made by professional unconscious bias, within the decision making process." (#16 Social Care Respondent)

While a number of statements coded positively as examples of attitudes and beliefs consistent with the definition of parental blame by practitioners developed in Phase 1 of the project (see Definitions section), one practitioner identified the steps required to provide effective compassionate support to families.

"I don't see this as a challenge, [parents] need support, empathy, clear guidance and relevant information. Extended time to listen to their views and their child's views and collaborative working and liaison with schools and external pathway services. Ideally a multi-disciplinary/agency/peer support." (#66 Health Respondent)

Discussion

Overall, the health, education and social care practitioners surveyed reported feeling very knowledgeable about how autism presents in children and young people and stated a high understanding of how masking may affect a child's presentation. All practitioners reported slightly less confidence about using that knowledge and understanding to identify autism and masking behaviour in practice, and their confidence further reduced when asked about distinguishing between an autistic presentation and a presentation caused by other factors, such as parenting.

Respondents who are themselves autistic, or who have a close familial relationship to an autistic person expressed a higher confidence in identifying autism and masking behaviour in practice, and in being able to distinguish between presentations caused by autism and other factors. They were also more likely to express dissatisfaction with the guidance provided by their employer, suggesting that their lived experience may mean they are better placed to critique autism related policies and guidance.

Neither 'sector worked for' or 'level of qualification', appeared to make a significant difference as to how highly respondents rated their knowledge, understanding and confidence about autism.

30% of survey respondents said they had been involved as a practitioner in a case where FII had been a concern and just over 13% had been involved as a practitioner in investigating concerns about FII. Given that a third of respondents had some role in case where FII is being considered, it is perhaps concerning that only 6% of respondents had received formal training about FII, and 65% had not received any training at all.

There was consensus among respondents that long waiting times for children to have an autism assessment, coupled with diagnostic-led support provision is problematic for everyone. Whilst practitioners would like to signpost families to support or provide support themselves, a lack of available resources creates challenges and leads to frustrations amongst families and practitioners.

Practitioners point to a fragmented system where professionals and services operate in silos, despite their dependency on each other to cooperate in assessing children's needs. A number of respondents in the survey highlighted the drawback of school-centric assessments where more weight is given to the views of schools than either parents or health care practitioners, particularly when a child's presentation in school is different to that outside of school, perhaps because the child is effectively masking when at school.

There is also concern amongst practitioners that autism is not fully understood. Some practitioners identify that there is a gap in other practitioners' professional knowledge where differing autistic presentation in girls and/or masking are not accounted for during diagnostic assessments. Others suggest that it is the parents who lack a complete understanding of autism, where trauma, neglect and attachment issues may be confused with an autistic presentation. Some practitioners describe interaction with parents as characterised by a reluctance to accept differing narratives as an explanation for the child's presentation and a resistance to try different parenting approaches until an assessment has been completed.

While practitioners were not questioned specifically about whether they felt parents were to blame for their child's autistic presentation, or whether they held parents accountable for their child's behaviour, the analysis of respondents' answers reveal many that are consistent with the definition of parental

blame developed in Phase 1 of this project (see Definitions of Key Terms). The findings of this report, however, do not reveal to what extent this is due to a conscious or unconscious bias.

Conclusions

The challenges identified by practioners do not exist in isolation. Poor system design, disjointed services and a lack of resources place an undue burden onto families. Long wait times for diagnostic assessments create a vacuum where children's need go unmet. When support is often only accessed through a diagnostic gateway and families have to wait for years to even approach the gate, children's needs are likely to escalate, and reach crisis point. A lack of collaboration between services, outdated diagnostic criteria and gaps in knowledge about autism are further obstacles for practitioners to overcome in attempting to provide support to families.

The vast majority of practioners feel knowledgeable about autism and understand what masking is. However, they are less confident about identifying autism in practice or being able to identify if an autistic child is masking their autism, and less confident still in being able to determine whether a child's presentation is due to autism, or perhaps, a result of the way in which they have been parented. Despite this reduced confidence, many practitioners identify that the most pressing challenge in working with parents and children seeking an autism diagnosis is parents' reluctance and resistance to accept the practitioner's perspective on their child's presentation before a diagnosis is made.

Parents who approach services to ask for help deserve to be listened to, respected as experts by experience, and to be regarded as equal partners in understanding and meeting their child's needs. Practitioners have a duty to be alert to potential safeguarding concerns, and must sometimes exercise sceptical evaluation, but this should occur within reflective, collaborative non-adversarial practice. If it doesn't, then trust between families and practioners will inevitably break down. While practioners may have little to no control over the system they are working in, or the availability of resources, they *are* able to affect each and every individual interaction with families.

Acknowledgments

The project team would like to thank everyone who has contributed to this study, in particular the 96 respondents who have shared their experiences through the survey.

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

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:

- 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.