directors of adass adult social services
West Midlands

Exploring Perspectives on Autism

"Who's to Blame for Parental Blame?"

A study on the prevalence, causes, and impact of parental blame from parent and practitioner perspectives.

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Contents

Foreword

As Chair of West Midlands ADASS, and the West Midlands Care and Health Improvement Advisor we are pleased to introduce Exploring Perspectives on Autism, a report that brings together the experiences and insights of parents and practitioners working across health, education and social care.

At its heart, this work is about listening. It brings together the voices of many parents who have felt unheard and practitioners working within increasingly complex and pressured systems. In doing so, it approaches a difficult and sensitive subject with compassion, integrity and a genuine desire to deepen our understanding.

The findings remind us that parental blame cannot be explained through a single lens. Instead, it is impacted upon by the interaction between professional knowledge, organisational cultures, service pressures and wider societal attitudes towards autism. The report challenges all of us to think carefully about how systems, policies and importantly, relationships shape the experiences of children and families seeking help.

This project also demonstrates the value of practice-led inquiry. By bringing together lived experience, practitioner perspectives and wider evidence, it makes an important contribution to our understanding of an issue that deserves greater attention.

We would like to thank Debbie Hollingsworth, Laura Ferguson and Catherine Nolan for their leadership and commitment over the past four years. We would also like to acknowledge the parents, practitioners and Advisory Group members who have shared their experiences so openly and generously. Their contribution has made this work possible.

Our hope is that this report stimulates discussion, informs and advances practice and encourages all of us to approach families with respect, curiosity, compassion and humility. Above all, we hope it helps ensure that children, young people and their families encounter understanding, collaboration and support when they seek help.

Pete Fahy
WM-ADASS Regional Chair
Director of Care, Health and Housing - Coventry City Council

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WM-ADASS Care and Health Improvement Advisor
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Executive Summary

Introduction - Purpose of the Research

The Autism and Parental Blame Project was commissioned to investigate concerns that parents seeking support for autistic children and young people were being blamed for their child’s presentation, behaviour or difficulties, rather than receiving appropriate assessment and support.

Conducted between 2022 and 2026, the project explored the issue from both parent and practitioner perspectives. Phase 1 examined the experiences of 685 parents of autistic children and young people through a systematic literature review, survey and focus groups. Phase 2 explored the perspectives of 96 practitioners working across health, education and social care.

The research sought to understand the prevalence, causes and impacts of parental blame, identify the factors that contribute to it, and inform improvements in policy, practice and service design.

Key Findings

The findings demonstrate that parental blame is not an isolated issue resulting from individual practitioner behaviour. Rather, it is a systemic phenomenon that emerges at the intersection of workforce capability, service design, organisational culture, safeguarding practice and wider social and political narratives about autism.

Parents reported widespread experiences of being disbelieved, judged, criticised or viewed with suspicion when seeking support for their child. These experiences frequently occurred before diagnosis and were associated with significant emotional harm, trauma, loss of trust in services and, in some cases, safeguarding interventions and allegations of Fabricated or Induced Illness (FII).

Practitioners recognised many of these concerns and acknowledged that parental mistrust often reflects previous negative experiences with services. However, the research also found significant gaps between practitioners’ theoretical understanding of autism and their confidence in applying this knowledge in complex real-world situations.

The findings suggest that parental blame should be understood as both a systems issue and a workforce issue. It reflects broader challenges within autism pathways, SEND systems, safeguarding processes and public services operating under increasing pressure and demand.

What Drives Parental Blame?

System Pressures

The strongest drivers of parental blame were found within the wider systems in which practitioners operate.

Long waiting times for autism assessments, fragmented service pathways, workforce shortages, increasing demand and limited access to early support create conditions in which families must repeatedly justify their concerns. In many areas, diagnosis has become the gateway to support, placing significant pressure on both families and professionals.

Practitioners described systems characterised by risk aversion, high caseloads and performance pressures, reducing opportunities for relationship-based practice and increasing reliance on procedural responses. Under these conditions, professional curiosity and reflective decision-making can be displaced by a desire for certainty and reputational risk management.

The research suggests that system design can inadvertently create environments where parental concerns are questioned before children’s needs are explored.

Professional Knowledge and Practice

Although most practitioners self-reported good knowledge of autism, confidence declined substantially when applying that knowledge in complex cases involving masking, differing presentations across settings, communication differences and co-occurring needs.

Significant gaps were identified in autism-specific training, particularly in relation to safeguarding, FII, autistic parenting and contextual presentations of autism. The findings also highlight the importance of lived experience in developing professional understanding, with practitioners who had personal or family experience of autism reporting higher levels of confidence.

Current workforce development approaches do not consistently equip practitioners to manage uncertainty, recognise bias or balance safeguarding responsibilities with collaborative, strengths-based practice.

Parent-Practitioner Interactions

Interactions between families and professionals represent the point at which wider system pressures are experienced by children and parents. Families typically approach services because they are worried about their child, struggling to understand complex needs, or seeking support at a point of significant stress. For some, repeated difficulties at school, deteriorating mental health, or escalating family pressures mean they are already approaching crisis when they ask for help. The findings suggest that when these requests are met with disbelief, judgement or criticism of parenting, the impact can be profound.

While system pressures undoubtedly shape professional practice, parents also described encounters with practitioners whose language, attitudes and assumptions were experienced as openly judgemental and blaming. Parents consistently described not feeling heard, believed or valued as experts in their child's life. Practitioners recognised that language, assumptions and professional attitudes can either strengthen or undermine trust.

Repeated disbelief, dismissive language or assumptions about parenting have a cumulative effect, contributing to significant long-term harm and disengagement from services. Improving relationships between families and professionals therefore requires both individual practice change and organisational commitment to relational working.

Social, Cultural, and Political Factors

Parental blame is influenced by wider societal narratives about autism, disability, parenting and public spending.

Historical assumptions that linked autism to parenting continue to shape perceptions, despite overwhelming evidence regarding the neurodevelopmental basis of autism. More recent debates regarding SEND expenditure, welfare reform and rising diagnosis rates have contributed to increasingly polarised public discourse.

These wider narratives can reinforce stigma, influence professional attitudes and shape how parental advocacy is interpreted by services. Addressing parental blame therefore requires attention not only to practice and systems, but also to organisational culture and public messaging.

Key Recommendations

The findings support a programme of system-wide reform centred on early support, relational practice and autism-informed services.

Strategic and Policy Recommendations

- Develop needs-led support pathways that enable children and families to access help before diagnosis.
- Reduce reliance on diagnosis as the primary gateway to support across health, education and social care.
- Review autism, SEND and safeguarding pathways to ensure they promote collaboration, curiosity and proportionate risk assessment.
- Strengthen safeguards, oversight and accountability where families are subject to FII allegations or safeguarding interventions that are subsequently unsubstantiated.
- Commission independent advocacy services for families navigating complex diagnostic, SEND and safeguarding systems.
- Embed lived experience within service design, workforce development, governance structures and policy development.

Workforce and Practice Recommendations

- Introduce mandatory autism-informed training for practitioners involved in neurodevelopmental pathways, SEND decision-making, and safeguarding processes.
- Strengthen training on masking, contextual presentation, communication differences, autistic parenting and co-occurring conditions.
- Review FII guidance and promote autism informed training and good practice frameworks to reduce the risk of autism-related presentations being misinterpreted.
- Promote reflective supervision, curiosity-led practice and approaches that support practitioners to manage uncertainty safely.
- Recognise and utilise the expertise of autistic professionals and parents within workforce development and service improvement initiatives.

Service Improvement Recommendations

- Prioritise relationship-based models of support that improve continuity, trust and family engagement.
- Improve multi-agency collaboration and information sharing across health, education and social care.
- Ensure the voices of children, young people and families remain central to assessment, planning and decision-making processes.
- Develop mechanisms to identify, monitor and address experiences of parental blame within services.

Conclusion

This research demonstrates that parental blame is a significant and preventable systems issue with serious consequences for children, families and public services.

The findings indicate that parental blame arises when system pressures, workforce capability gaps, organisational cultures and wider societal attitudes combine to create environments in which parents’ concerns are questioned rather than understood.

Addressing parental blame requires more than awareness raising. It requires coordinated action across policy, commissioning, workforce development, safeguarding practice and service design. A shift towards autism-informed, needs-led and relationship-based approaches has the potential to improve trust, reduce harm and achieve better outcomes for autistic children, young people and their families.

The central message from both parents and practitioners is clear: families seeking help should encounter support, curiosity and partnership - not blame.

Context

The National Autistic Society (2023) describes autism as “a lifelong developmental disability which affects how people communicate and interact with the world”. Autism is a spectrum condition (Havdahl et al., 2021), and each autistic person has a unique autistic profile. Some autistic people require full time care and others, whose disability may be hidden, appear more able to live independent lives (National Autistic Society, 2023). Autism is a neurodevelopmental condition (Chen, Cheng and Lv, 2026; Baker et al., 2019), now broadly accepted as genetic in origin, with a high probability of multiple genes being involved, rather than one single autism gene (Havdahl, et al., 2021; Smalley, Asarnow and Spence, 1988).

In the UK, diagnoses of autism have increased exponentially over the last 25 years; a rise of 787% between 1998 and 2018 was reported by Russell et al. (2022). Alongside this there has been an accompanying increase in waiting times for an autism assessment. As of March 2026, only 3.7% of people had been seen within the recommended 13 weeks from initial referral to first care contact (NHS England, 2026). The average wait for an autism assessment in the UK is now 16 months (National Autistic Society, 2025).

Rising diagnoses and the associated demand for services have sparked frequently heated debate within mainstream and social media. Political parties, Autism charities, professional bodies and parents often express very different views. Debate has focused not only on the cost and reform of SEND and welfare provision (Department of Health and Social Care, 2026) but in some cases concerns about overdiagnosis and the motivation behind seeking an autism diagnosis (Centre for Social Justice, 2026) alongside querying the necessity or validity of a diagnosis (National Autistic Society, 2026; Reform UK, 2025; Badenoch, 2024). In the UK, debates about autism have become increasingly politicised and contested.

When autism was first identified in the 1940’s, Leo Kanner’s description of “refrigerator mothers” (Bettelheim, 1967) created a narrative that autism is an undesirable condition and that parents, particularly mothers, are responsible for both causing autism and their child’s autistic presentation (Kenny et al., 2016; Waltz, 2015). This perspective persists as can be seen by recent claims that autism may be caused by taking paracetamol during pregnancy. Bauer et al. (2021), a group of scientists, medical and public health professionals, voice their concern at rising diagnoses of neurological conditions, including autism, along with “*disturbing increases in the number of children with cognitive, learning and/or behavioural problems*” (p.757). They recommend that paracetamol should be avoided in pregnancy unless medically indicated.

Whilst these claims are strongly contested by other scientists and medical professionals (Sheikh et al., 2025; Ahlqvist et al., 2024), they nevertheless support the narrative that parents are responsible for autism and that if they can prevent autism from occurring in their child then they should do so.

Within this environment of contested views about autism, families seeking help and support frequently encounter blame, challenge, and suspicion. Experiences of blame have a negative impact on the health and well-being of children, their parents and the whole family. Courcy and des Rivières (2017) describe a known increased risk of depression, anxiety and social isolation amongst mothers of children with autism. Baker et al. (2021) have documented symptoms of complex post-traumatic stress disorder amongst families who have repeated negative experiences of services. Boshoff et al. (2018), and Jackson, Keville and Ludlow (2020) describe how this can lead to distress and loss of trust.

The challenge for health, education and social care practitioners working within this context of polarised opinions about who needs or deserves an autism diagnosis, is how to reduce parental blame and establish trust in every encounter with families.

Project Background

The Autism and Parental Blame Project was initially commissioned by NHS England (Midlands) 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 first phase of the project explored the concept of parental blame through the experiences of parents of autistic children and young people who had approached services for support and had instead encountered judgement and blame for their child’s behaviour/presentation.

The second phase of the project, funded by WM-ADASS, explored the perspectives of professionals working with families seeking an autism diagnosis. The aim of the second phase was to discover how well-equipped practitioners feel to support parents and to explore reactions to the findings of Phase 1. Academic support throughout the project was provided by Dr. Jason Schaub from the University of Birmingham. The project began in June 2022 and concluded in June 2026.

> *“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, Advisory Group Member

> *“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 of 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, Advisory Group Member

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.

“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, Advisory Group Member

“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, Advisory Group Member

Overview of Phases 1 and 2

Phase 1: 'Blamed Instead of Helped'

The first phase of the project set out to explore the how parents of autistic children and young people experienced blame when they had sought support for an autism assessment. There were three stages: a systematic literature review, an on-line survey of 685 parents of autistic children and two focus groups, one with autistic parents and one with parents who did not identify themselves as autistic. Full reports for each stage, with details of methods, results, analysis, and conclusions can be found on the WM-ADASS webpage Parents' perspectives: research findings.

Throughout Phase 1 we found compelling evidence that parents of autistic children experience blame from multiple sources, which includes professionals. Professional blame is described as professionals not listening to or believing parents, particularly about the child's presentation and behaviour. A systematic literature review revealed that this was a global phenomenon. The literature review, survey and focus groups included reports from many parents who describe being accused of making up or exaggerating their child's autism - for some parents this situation includes a child protection review, and removal of their children from the family home. Professional blame towards parents of autistic children and young people occurs within education, health, and social care systems.

Eight key areas were identified regarding parents' experiences of parental blame. With input from parents in the focus groups a set of recommendations was developed which could improve the experiences of autistic children, young people, and their families when they approach services for help and support.

Key Areas for Consideration:

Autism is widely misunderstood by professionals - 86% of parents said they experienced parental blame before an autism diagnosis. Parents felt many practitioners relied on outdated stereotypes and were ill equipped to recognise autism’s diversity and complexity. When parents raised concerns, professionals often responded first with blame rather than curiosity, overlooking that perplexing presentations could reflect autistic traits, reactions, or coping strategies. When children presented differently at home than in settings such as school or GP surgeries, this was often seen as evidence that parents were exaggerating concerns or struggling to manage behaviour.

> *“[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 respondent

Accusations of blame result in trauma, long term damage and increased risk of suicide - 1 in 4 parents said their child was at increased risk of suicide as a result of the impact of parental blame, and 94% of parents experienced stress and anxiety. Parents who were wrongly accused of Fabricated or Induced Illness (FII), parents who children became the subjects 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 surveyed, reported receiving 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.

> *“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

Autistic parents may be at higher risk of parental blame - Autistic parents in the survey 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. Autistic parents reflected that professionals often didn’t work in a way which was helpful for them. They identified that communication, parenting resources and strategies were not adapted for autistic parents.

Parents of autistic children have a high level of mistrust in services and professionals - 73% of parents told us poor experiences had caused them to lose faith in services and professionals. Over a third of parents told us they experienced parental blame after making a complaint about a service or professional. Parents described seeking support for their child as a battle or a fight to be heard. Many reported a fear of interaction with professionals, describing a power imbalance weighted towards professionals.

Parents of autistic children may be at higher risk of child protection proceedings - One in four parents (27%) who had requested an autism assessment for their child were subsequently subject to a safeguarding referral. One in six (16%) were accused of Fabricated and Induced Illness (FII).

Parental knowledge is not recognised or valued - 81% of parents who had experienced parental blame said they weren’t believed about their child autistic presentation with their experience ignored or dismissed and their motives questioned by professionals. Parents identify a need to become highly knowledgeable so that they can advocate for their children. 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.

> *“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.

Parental blame is more likely before a child is diagnosed as autistic - 86% of parents participating in our survey felt their parenting was criticised prior to a formal autism diagnosis. Blame is directed at parents from all sides, including themselves (22%), partners (22%), friends and family (46%), education practitioners (77%), health practitioners (63%), social care practitioners (26%). Across all areas the confirmation of a diagnosis resulted in a reduction in blame for most parents. Parents did not identify delayed access to diagnosis as a key issue of concern, but they did describe 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.

Current support offered is often unhelpful and sometimes does more harm than good - 65% of parents reported they were not offered any support whilst waiting for an autism diagnostic assessment. Less than 2% of participants said they get the help they need from services. Parents described positive experiences when they were supported by neurodiverse professionals 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.

Phase 2: Who’s to Blame for Parental Blame?

The first phase of the project revealed limited understanding about how professionals perceive parental blame, with only two of the fourteen papers, identified in the systematic literature review exploring this. However, these two papers found that professionals do blame parents and may interpret a child’s behaviour or presentation as a result of poor parenting. 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 phase included an online survey of 96 practitioners working within health, education and social care services and 3 focus groups, one for each of the three sectors. Reports for the survey and focus groups with details of methods, results, analysis, and conclusions can be found on the WM-ADASS webpage Exploring Perspectives on Autism.

The main aims of Phase 2 were 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 (FII).
- **Analyse practitioner experience:** Explore what factors, if any, might impact a practitioner's professional insights.
- **Explore practitioner understanding of parental blame:** Investigate practitioner responses to parents’ descriptions of blame and explore potential conditions and drivers for blame.
- **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.

Key Findings

Practitioners feel knowledgeable about autism in theory, but confidence falls as judgement becomes more interpretive and potentially adversarial - Over 80% of survey respondents said they understood autism and how masking can affect behaviour, but only 60% felt able to identify masking in practice. Confidence fell to 40% when distinguishing autistic presentation from concerns linked to parenting or the environment. Focus group participants said outdated assumptions about autism persist across services, leading professionals to misread autistic communication, emotional presentation, or advocacy as suspicious or resistant. Education practitioners noted that children who appear to cope in school may miss out on support despite significant needs elsewhere. Practitioners noted the lack of specialised support for autistic parents and the possibility of professionals making judgments about their parenting or communication.

Lived experience of autism increases practitioner confidence - Practitioners with personal, familial or lived experience of autism were 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.

There is a significant knowledge and training gap - only 6% of practitioners had formal FII training, although 29% had encountered FII concerns. Of the 13 who had investigated FII, only 3 had received formal training. Overall, over 60% of respondents had no FII training.
Only 20% of autistic respondents agreed they had clear guidance on autism, compared with 48% of non-autistic respondents.
Focus group participants also highlighted discomfort about misinterpreting autism-related presentations, especially when making high-stakes decisions under uncertainty.

Children’s needs and voices are lost in adult/system-led responses - practitioners described systems that struggle to engage meaningfully with children’s lived experience. Social care participants said assessments often frame the child’s voice around pre-existing concerns or risk, rather than a broader understanding of their experiences. Health and education practitioners highlighted masking and how autistic children may present very differently across settings. Participants also noted that professionals can rely too heavily on observable behaviour, missing distress as communication. They raised concerns that trauma, attachment, or other neurodivergent traits such as ADHD may be confused with, or overlooked because of, autism. Across sectors, participants recognised that autistic children who mask well are especially at risk of having their needs missed.

> *“Even when they’re gathering children’s voices, it’s very much about ‘how does that fit around the worry?’”*
> - social care focus group participant

Systems prioritise process and risk management over relationships and understanding - Participants described highly pressured systems shaped by limited resources, weak accountability, and fear of missing risk. Social care practitioners highlighted defensive practice and safeguarding cultures that favour risk-averse decisions and premature conclusions when systems cannot hold uncertainty. Heavy workloads, large caseloads and classes, time pressures, and targets reduce opportunities for reflection, relationship-based work, and meaningful family engagement. Practitioners recognised that these conditions discourage curiosity and create pressure to reach certainty quickly, even when presentations are complex or unclear.

> *“...you’re almost taught in this field that...it’s better to be wrong [about a safeguarding concern] than to have missed it and have a serious case review”*
> - social care focus group participant

Service capacity and system constraints create obstacles to effective support - Over 60% of respondents identified long waits for autism assessments as the most pressing issue when working with families. Children may wait years for assessment, and diagnosis does not guarantee support.

Practitioners said support often depends on diagnosis, so long waits increase pressure on families and services, especially where resources and staffing are limited. They also noted that early intervention improves outcomes, while delayed diagnosis and support can have serious consequences.
Fragmented, siloed services and poor collaboration can disrupt assessment pathways and delay support.

Several respondents also highlighted schools’ central role in assessment, and the problems that arise when school evidence is given more weight than parents’ or other practitioners’ views.

Parental expectations, understanding, and beliefs can be challenging for practitioners - practitioners described difficulties when discussing views parents may find challenging. Some felt parents were focused on obtaining a diagnosis and reluctant to consider other explanations, such as parenting, environment, trauma, or attachment. They also reported that some parents were unwilling to try parenting strategies before diagnosis. Participants suggested that needs-led support could help reduce this diagnostic focus and manage expectations.

> *"... 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

Practitioners may recognise parental blame from other practitioners while also unconsciously demonstrating blame - across the survey and focus groups, practitioners identified blaming attitudes, values, and language in others, and sometimes in themselves. Some recognised this when reflecting on past responses to parents; others seemed unaware that their language could be experienced as blaming. Around 20% of survey respondents made comments that coded positively for parental blame.

> *"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

There was strong agreement that parental mistrust of services is often a rational response to repeated negative experiences. Participants recognised that language, tone, and professional attitudes can shape family experiences and either build or damage trust. Education practitioners also described tensions when home and school accounts differ, especially where masking is poorly understood.

Advocacy was seen as a possible solution for families navigating complex systems alone, and one respondent gave a clear account of the support autistic children and their families need.

Synthesis of Findings Across Phase 1 and 2

Where and How Parental Blame Occurs

The findings from both phases of this project suggest that parental blame occurs within four interconnected domains (*Figure 1*).

- **Social, Cultural, and Political Environment**
- **System Pressures and Constraints**
- **Professional Knowledge and Practice**
- **Parent/Practitioner Interactions**

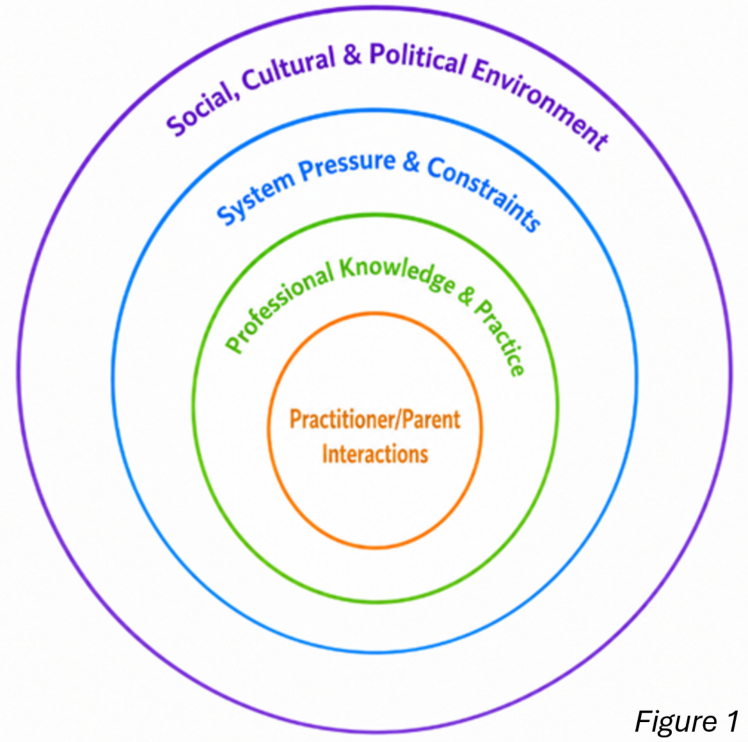


Figure 1

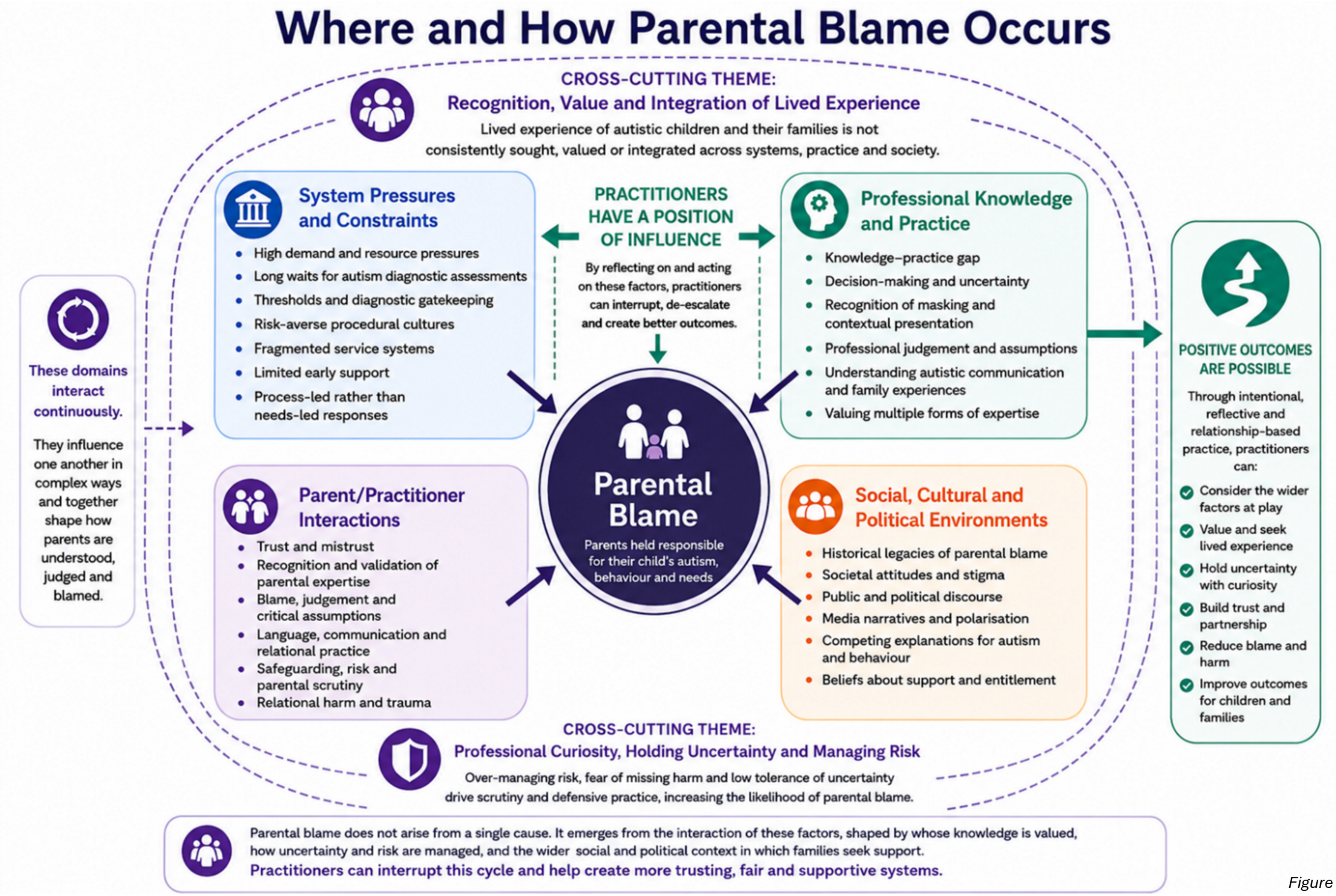
Within each of these domains parental blame occurs as a result of various factors. These include practice and policy decisions, values, gaps in autism knowledge and understanding, communication choices etc. Each one of these can contribute to a parent’s experience of being blamed for their child’s autism.

In addition, we found cross cutting themes which sit across all domains:

- **Recognition, value and integration of lived experience.**
- **Professional curiosity, holding uncertainty and managing risk.**

Parental blame does not come from any one area. Pressure in any one area can increase the likelihood of blame occurring. Conversely making positive changes in any one area might improve outcomes for autistic children and their families and reduce the harm of parental blame (*Figure 2*).

- **Pressure in any one area can lead to negative outcomes.**
- **Pressure across multiple area can increase the likelihood of impact of blame.**
- **Strength in any one area can improve outcomes for families.**



Where and How Parental Blame Occurs

CROSS-CUTTING THEME:
Recognition, Value and Integration of Lived Experience

Lived experience of autistic children and their families is not consistently sought, valued or integrated across systems, practice and society.

These domains interact continuously.

They influence one another in complex ways and together shape how parents are understood, judged and blamed.

System Pressures and Constraints

- High demand and resource pressures
- Long waits for autism diagnostic assessments
- Thresholds and diagnostic gatekeeping
- Risk-averse procedural cultures
- Fragmented service systems
- Limited early support
- Process-led rather than needs-led responses

PRACTITIONERS HAVE A POSITION OF INFLUENCE

By reflecting on and acting on these factors, practitioners can interrupt, de-escalate and create better outcomes.

Professional Knowledge and Practice

- Knowledge–practice gap
- Decision-making and uncertainty
- Recognition of masking and contextual presentation
- Professional judgement and assumptions
- Understanding autistic communication and family experiences
- Valuing multiple forms of expertise

Parental Blame

Parents held responsible for their child’s autism, behaviour and needs

Parent/Practitioner Interactions

- Trust and mistrust
- Recognition and validation of parental expertise
- Blame, judgement and critical assumptions
- Language, communication and relational practice
- Safeguarding, risk and parental scrutiny
- Relational harm and trauma

Social, Cultural and Political Environments

- Historical legacies of parental blame
- Societal attitudes and stigma
- Public and political discourse
- Media narratives and polarisation
- Competing explanations for autism and behaviour
- Beliefs about support and entitlement

POSITIVE OUTCOMES ARE POSSIBLE

Through intentional, reflective and relationship-based practice, practitioners can:

- ✓ Consider the wider factors at play
- ✓ Value and seek lived experience
- ✓ Hold uncertainty with curiosity
- ✓ Build trust and partnership
- ✓ Reduce blame and harm
- ✓ Improve outcomes for children and families

CROSS-CUTTING THEME:
Professional Curiosity, Holding Uncertainty and Managing Risk

Over-managing risk, fear of missing harm and low tolerance of uncertainty drive scrutiny and defensive practice, increasing the likelihood of parental blame.

Parental blame does not arise from a single cause. It emerges from the interaction of these factors, shaped by whose knowledge is valued, how uncertainty and risk are managed, and the wider social and political context in which families seek support.
Practitioners can interrupt this cycle and help create more trusting, fair and supportive systems.

Figure 2

Discussion of Findings

Where blame occurs: **Social, Cultural and Political Environment**

How blame occurs:

- **Poor understanding of lived experience.**
- **Stigma towards autistic people.**
- **Polarised media narratives.**
- **Beliefs about entitlement and support.**

Parental blame has its origins in the earliest identification of autism as a distinct condition, when emotionally distant mothers were initially thought to be responsible for causing an autistic presentation in their child. Despite a now well-established understanding of autism as a genetically linked condition, blame towards parents continues. Parents report that this blame frequently comes from close friends and family as well as professionals and the wider society. Many parents say that they often hold themselves responsible, worrying that they haven’t done enough to support their child.

As autism awareness and diagnostic criteria improve, diagnosis rates have soared and the waiting time for an assessment now stretches into multiple years. In the UK, policy makers at all levels of government struggle to balancing demand for services against the cost of providing those services. Reviews into SEND provision and welfare spending are often regarded as cost cutting opportunities by families concerned about support for their child. As the political conversation has centred more on the cost of autism to the public purse, a division in sympathies has arisen. In mainstream and social media, the discourse about the validity and necessity of an autism diagnosis has become increasingly fractious and polarised.

Within this highly charged, contentious atmosphere, practitioners, parents, indeed all of society, form views and opinions about how autism is caused, whether autism is being used as an excuse to be treated differently, or as an excuse for poor parenting, whether parents can or should try to change their child’s behaviour and whether autistic children and young people are deserving of additional support.

Opportunities for change:

While societal change may be beyond the scope of this project there are many opportunities that would support a shift towards autism informed, relationship-based practices.

Be curious not judgemental - every person is in part shaped by their environment and experiences. By questioning our own perspectives and seeking to deepen our understanding of the lived experience of others we can hold ourselves accountable when needed.

Challenge stereotypes and discrimination - We share a collective responsibility to challenge parental blame and harmful stereotyping when we see or hear it.

Where blame occurs: **System Pressures and Constraints**

How blame occurs:

- **Long waits for assessment without support.**
- **Diagnostic gatekeeping.**
- **Risk averse procedural cultures.**
- **Fragmented services.**
- **High service demand, low resource and capacity.**

Practitioners described systems under pressure from high demand, long waits, fragmented services, and fear of missing safeguarding risks. These conditions promote process-driven, risk-averse responses and leave less room for reflection, uncertainty, relationship-building, and early support.

Parents also described systems that failed them. Assessment pathways are long, support often depends on a diagnosis, 65% received no support while waiting, and fewer than 2% felt their child ultimately got the help they needed.

Families reported that too often a first response to a request for help was scrutiny of their parenting rather than an assessment of their child’s needs. As a result, diagnosis became both a route to support and a validation mechanism to counter accusations of poor parenting. Practitioners likewise recognised that diagnosis often legitimises both children’s needs and parents’ credibility.

Overall, the findings suggest current systems remain overly dependent on behavioural evidence, thresholds, and procedures rather than needs-led, relationship-based support.

Opportunities for change:

De-couple early intervention from diagnosis - create needs-led pathways that provide support before a formal diagnosis, enabling practitioners to meet immediate needs and helping families use strategies tailored to the child.

Update assessment and safeguarding processes - systems should help practitioners work safely with uncertainty and keep the child’s voice central to decision-making.

Improve safeguards against system-led abuse and trauma - update policies so children and families receive support when FII or child protection concerns are not upheld.

Provide advocacy for families - child and parent advocates can help families navigate complex assessments, improve communication, and ensure all voices are heard.

Prioritise relational ways of working - for example, named worker models that reduce repetition for parents, build trust, and improve continuity across services.

Where blame occurs: **Professional Knowledge and Practice**

How blame occurs:

- **Knowledge - practice gap.**
- **Decision making constrained by need for certainty.**
- **School centric assessment process.**
- **Poor understanding of autistic parents.**
- **Lived experience of parents and colleagues not valued.**

Practitioners said they understood autism and masking in theory, but were less confident recognising them in practice, especially in more nuanced cases such as when considering whether parenting might influence a child’s presentation. Confidence was higher among those with lived experience of autism, either personally or through close family ties (82% of those with a close familial relationship, compared with 55% of those without).

Parents reported gaps in practitioners’ understanding of masking, contextual presentation, communication differences, and autistic parenting. Many said they were not believed about their child’s autism, with 81% reporting dismissal or disbelief. As a result, autistic children who mask well may be overlooked, especially when they appear to cope in school.

Parents and practitioners saw schools as central to the assessment process, with school views often treated as more reliable than parents’ observations. Social care participants also noted that assessments can frame the child’s voice around existing concerns or risk, rather than a broader understanding of their experience.

Practitioners and parents also identified that autistic parents may be especially vulnerable to misunderstanding and escalation, particularly when their communication or advocacy is interpreted negatively.

Opportunities for change:

Improve autism and FII training - training that affects autistic people and their families, including FII training, should be developed and led by people with lived experience. It should cover masking, contextual presentation, communication differences, co-occurring needs, and autistic parenting, and be mandatory for practitioners involved in neurodevelopmental pathways or complex safeguarding, especially those investigating FII concerns.

Promote reflective, curiosity-led practice in all sectors - support practitioners to examine unconscious bias so decisions about families are grounded in shared perspectives and a sound understanding of the child’s lived experience.

Recognise neurodiverse workforce experts - value autistic colleagues lived experience and, where appropriate, draw on their expertise to develop policy and practice.

Where blame occurs: **Parent/Practitioner Interactions**

How blame occurs:

- **Parents knowledge and expertise not valued.**
- **Power imbalance weighted towards practitioners.**
- **Assessing need through safeguarding lens only.**
- **Judgemental and critical language or tone.**
- **Disbelieving parents accounts.**

For many parents, interactions with practitioners were marked by blame, judgement, and critical language. Parents’ knowledge and lived experience were not consistently valued and were sometimes treated with suspicion. Most said they were not believed about their child’s autism; some were accused of exaggerating or fabricating it. A small but notable number of families had children removed from their care.

Most practitioners felt knowledgeable about autism and masking, but were less confident identifying them in practice, and less confident still distinguishing autism from presentations they linked to parenting. Even so, many saw parents’ reluctance to accept professional views before diagnosis as a key challenge. Parents, practitioners, and the literature review suggest that seeking an autism assessment is often seen by practitioners as deflecting from poor parenting or environmental concerns.

Practitioners showed insight into how language and assumptions about parents can shape family experiences and recognised that mistrust often reflects repeated negative interactions. While some could identify blaming attitudes in themselves and colleagues, others seemed unaware of their language, tone, or impact on families.

Parents described blaming interactions as traumatic, with long-term effects, especially when a child was removed from their care. Families received no support or aftercare, when concerns are proved unfounded. The reported impacts are consistent with complex post-traumatic stress disorder. Safeguarding creates an inherent power imbalance: professionals must remain alert to abuse or neglect, but if every interaction is filtered through suspicion, trust is likely to break down and may be hard to restore.

Opportunities for change:

Increase awareness of the harm caused by parental blame - help practitioners understand its long-term impact and support conversations rooted in curiosity and compassion, so families feel heard and trust can grow.

Encourage care-filled conversations across practice - raise awareness of how language, tone, and assumptions affect families, and promote transparent, collaborative communication that avoids suspicion.

Value parents’ lived experience - treat parental expertise as a legitimate source of knowledge and seek to understand differences in presentation without defaulting to suspicion or disbelief.

Summary and Conclusion

Parental blame emerges at the intersection of system pressures, professional practice, and parent-practitioner interactions, within a wider socio-political climate where recognition of and support for autism and other neurodivergent conditions has become increasingly divisive and politicised. It arises from multiple failures: societal attitudes to disability, systems that prioritise process over care, and frontline practitioners balancing rising demand against shrinking resources and consciously or unconsciously using language and displaying values that are consistent with parental blame.

The challenges described by parents and practitioners do not exist in isolation. Poor system design, fragmented services, limited resources, outdated diagnostic criteria, and gaps in autism knowledge all make it harder to provide effective support. Long waits for assessment leave children’s needs unmet; when support is only available through a diagnostic gateway, delays can allow needs to escalate into crisis.

Parents who ask for help should be listened to, respected as experts by experience, and treated as equal partners in understanding and meeting their child’s needs. Practitioners must remain alert to safeguarding concerns, but this should happen within a reflective, collaborative, and non-adversarial approach. Without that, trust between families and services is likely to break down.

Individual practitioners are well placed to improve outcomes for autistic children and their families. Compassionate, reflective practice, professional curiosity, respect for lived experience, and collaborative working can all help reduce harm and build trust.

There are many opportunities to improve families’ experiences. Parents described positive encounters with practitioners and services that took time to listen, understand their perspective, and value both parental lived experience and the child’s voice. Every practitioner therefore has a role in shifting families’ experiences from blame to help. By using autism-informed approaches, staying curious rather than sceptical, and being willing to hold uncertainty, services can restore trust, prevent blame, and improve outcomes for children and 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

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. This is because our advisory board recommended that only using the term autistic behaviour could be construed negatively and correlated with bad behaviour.

Fabricated and Induced Illness (FII) - FII is a rare form of child abuse (approximately 0.5 cases in 100,000 cases annually) that occurs when a parent or carer exaggerates or deliberately causes symptoms of illness in their child. Doctors are likely to see only 2 cases of FII in their lifetime; however, evidence suggests that disabled parents are four time more likely to be accused of FII, and over 80% of allegations are not pursued (Clements and Aiello, 2023).

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 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.

Limitations of the Project

All participants in this project were self-selecting, and the research population was small. Therefore, caution should be exercised in interpreting these results as representative of all practitioners working within Health, Education and Social Care or of all parents of autistic children and young people.

There was significant underrepresentation of certain groups in the study, particularly practitioners from minoritised ethnic groups and male practitioners. Additionally, there was a disproportionally high number of autistic respondents in the practitioner survey (10% vs ~1% of general population), and respondents with a close familial relationship to an autistic person, compared to the general population. The study relied on respondents’ subjective self-reported views and experiences and self-assessment of their knowledge, understanding and confidence. It was not designed to objectively test competency in any of these areas.

It was beyond the remit of this project to explore the experiences and long-term impact of parental blame from the perspective of autistic children and young people. This is a gap that should be urgently addressed through further research.

Additional research is also needed to fully understand the experiences of more diverse practitioner populations, in particular how cultural intersections might impact practitioners’ knowledge and confidence. The experience of fathers of autistic children and the differences that might exist between service areas and roles within those services are other key areas for further research.

Acknowledgments

The project team would like to thank everyone who has contributed to this study, in particular the 685 parent/carers and 96 practitioners who have shared their stories and perspectives, including some very personal and painful experiences for the benefit of raising awareness of the issue of parental blame, to gain more transparency and wider recognition.

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

Thank you to those professionals who offered their time and expertise in helping refine the practitioners survey and help to extend its reach. Thank you to Anna Geyer of New Possibilities for the amazing graphic recording during the focus groups in Phase1, and also to Georgia Powell for her much appreciated attention to detail in shaping the layout and presentation of this report.

To all those parents, professionals and organisations who have supported the project, we hope you will use your influence to share the learning from this project to affect positive change.

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 go some way to better understand the interplay between the barriers and challenges but also provide some inspiration for change. We know from our research the power of one person's positive intervention and support and we hope to provoke and challenge everyone engaged in providing services and support to parents and children to ensure they practice with curiosity, integrity, insight, care and respect.

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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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.

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Exploring Perspectives on Autism

“Who’s to Blame for Parental Blame?”

A study on the prevalence, causes, and impact of parental blame from parent and practitioner perspectives.

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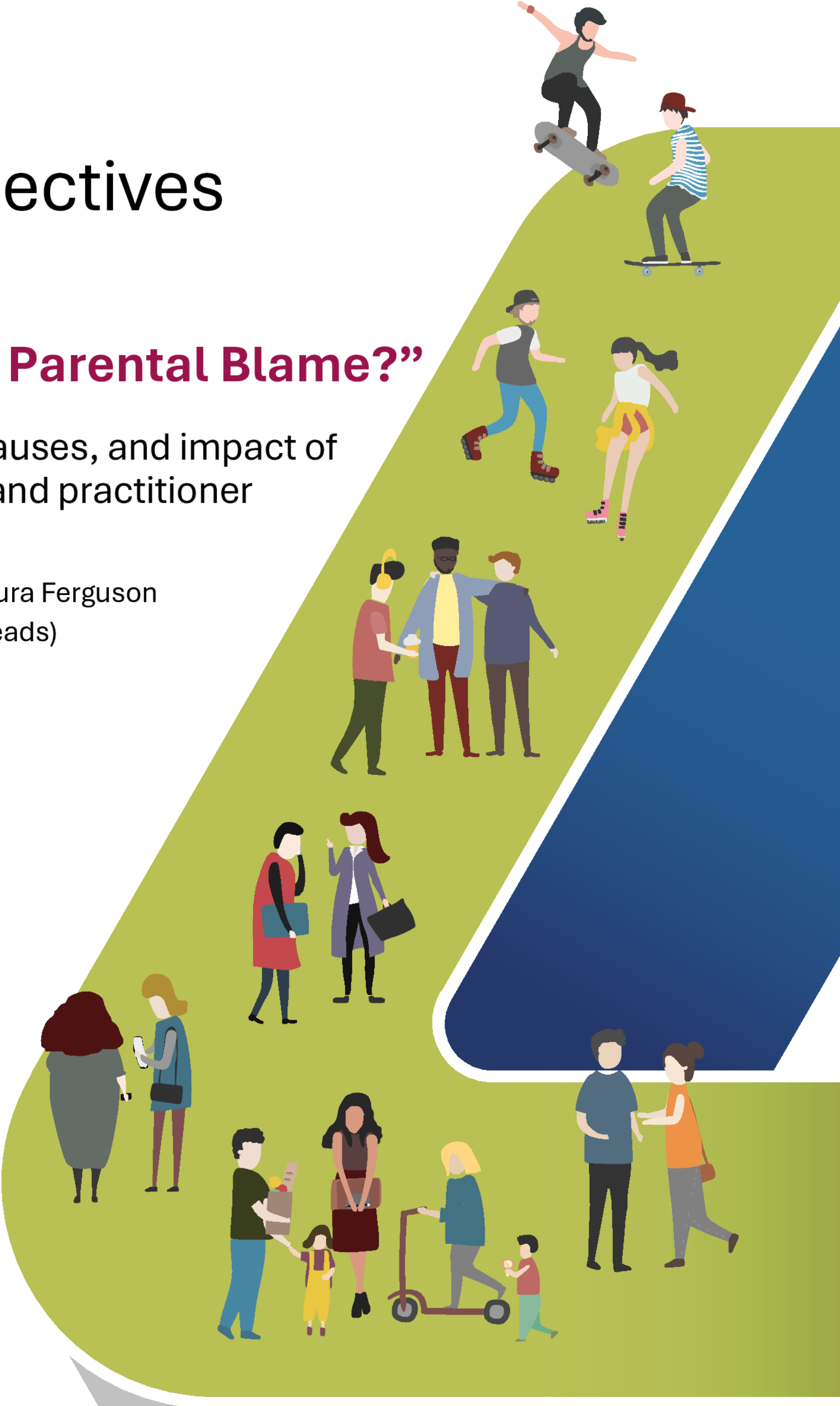

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