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# **Autism and Parental Blame: A Systematic Literature Review**

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## Executive Summary

Parents and carers of autistic children experience blame from multiple sources including from professionals. Parents often describe this professional blame is when their parenting causes child's autistic presentation instead of considering other reasons. This systematic literature review examines the current academic knowledge and evidence about the blame parents of autistic children and/or young people experience when engaging with services (such as education, health and social care). A scoping of the knowledge base suggested the following central research question.

## Research Question

How do parents of autistic children experience parental blame when they approach Health, Education and Social Care services for support?

## Aim/Objectives

Undertake a systematic literature review to determine the current academic knowledge in regard to autism and experiences of parental blame.

## Keywords

Autism, Autistic, Children, Young People, Parents, Families, Professionals, Practitioners, Blame, Judgement, Criticism

## Method

Systematic reviews are robust ways of ensuring a knowledge review is gathering and assessing the best and widest range of literature on a specific topic (Petticrew and Roberts, 2008). Five search terms were generated to gather the related literature:

- Children and young people
- Autism
- Parents and carers
- Parental blame
- Fabricated and Induced Illness

A robust search strategy was developed and adapted for each database. Five databases were searched, in addition to a grey literature search, without date limits. In addition, the project advisory group (including experts by experience) identified additional relevant literature.

The initial search returned a total of 285 papers, with 54 removed as duplicates, leaving 231. Two reviewers screened these to assess relevance to study aims. Any discrepancies were discussed by the research team until agreement was reached. An experienced systematic review academic mentor reviewed 10% of titles and abstracts to verify eligibility. 26 papers were identified from this list as meeting the research question.. A further 33 papers were identified through grey literature search and advisory board providing a total of 59 papers which were relevant to the subject matter and research question. To ensure included papers were of high-quality, we used the Critical Skills Appraisal Programme, with 14 papers identified for full critical analysis.

## Findings

Analysis of included papers revealed evidence that parents of autistic children and young people across the globe experience blame from multiple sources which intersect and compound the impact on parents and their families. Parental blame originated from several sources throughout the literature:

- From societies and communities
- From family and friendship groups
- From professionals and service providers

Professionals and service provider blame included three distinct expressions:

- Poor parenting accusations or criticisms
- Professional disbelief of or not listening to parents
- Accusations of neglect or Fabricating or Inducing Illness

Finally, we identify two further themes of note for this review:

- Professional perceptions of parental blame – evidence was limited, with only two of the fourteen papers
- The impact of parental blame on parents and their families. This is described as:
  - Guilt
  - Knowledge, resilience, and advocacy
  - Trauma

## Discussion and Conclusions

Parents of autistic children experience blame from multiple sources, which includes professionals. Professional blame is often experienced as parents feeling they are to blame for their child's autistic presentation rather than considering other issues. Blame is also described as professionals not listening to or believing parents, particularly about the child's presentation and behaviour. Included studies describe 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.

Throughout the literature parents identified that autism is widely misunderstood, including by professionals working within health, education, and social care. There is limited understanding about how professionals perceive parental blame with only two of the fourteen papers 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. Parents in the included studies found these interlocking blame experiences traumatic with some developing symptoms of Post Traumatic Stress Disorder. When confronted by parental blame, many parents seek to become informed and knowledgeable so that they can advocate for their children.

Regardless whether the studies recruited parents or professionals, the included studies show a clear pattern of parental blame by professionals. This outlines that parents experience blame for their child's autistic presentation by professionals, and that some professionals are aware they are doing this.

Experiences of blame in connection to parenting have a negative impact on the health and well-being of parents and potentially a wider impact on the whole family, including a known increased risk of depression, anxiety and social isolation amongst mothers of children with ASD. Courcy and des Rivières (2017) state that *"...it is highly relevant for health providers and professionals to support mothers without blaming them for their child's development"* (2017, p.246). Establishing trust in every encounter is important as negative experiences accumulate leading to greater distress, lack of trust (Boshoff et al., 2019; Jackson et al., 2020) and eventually the possibility of Complex Post Traumatic Stress Disorder (Baker et al., 2021).

## 1. Introduction

Parents of autistic children report experiencing a complex set of interlocking and related blame that comes from a range of sources. These sources include professionals and clinicians, wider society, and even themselves. Blame by professionals can impede obtaining timely and effective support for autistic children. It may also reduce parents' confidence in their ability and competence as parents.

This systematic literature review forms part of a larger study to explore the experiences of parental blame that parents of autistic children and young people in England have encountered when approaching services (e.g., Education, Health, and Social Care) for help and support. An overview of relevant UK policies and service provision as they apply to autistic children, young people and adults in the UK can be found in Appendix 1. The study was commissioned by NHS England and was prompted by the particular experiences of a group of parents in the West Midlands. The study explores the extent to which parents experience parental blame, the ways in which blame is communicated and the impact this has on parents, their children, and their families. In addition to this literature review, the larger study includes an extensive online survey of parents of autistic children and young people across England and a series of focus groups. Recommendations for policy and practice change will be included in the final report.

A systematic literature review has been undertaken to identify the current research knowledge about parental blame as it relates to parents of autistic children and young people. This enables us to identify common themes and gaps in knowledge which we can explore in the subsequent phases which include the survey and interviews.

When writing this report, we have at times reflected the language used to describe autism in the reviewed studies. It is important to note that some of the language used can be regarded as ableist, with the research often conducted by non-autistic (allistic) people, describing autism as something problematic which needs to be fixed. This perspective forms the basis for the medical model of disability, which frames disability as an illness requiring intervention from a professional (Barnes and Mercer, 2003). This stands in contrast to the social model of disability, which rejects the idea that disability is an impairment of the individual, reframing the argument to articulate that people are disabled by societal structures and values (Oliver, 2013; Shakespeare, 2006). The use of ableist language does not reflect the views of the research team working on this project. Future researchers can draw lessons from Bottema-Beutel, et al.'s (2021) findings which describe substantial negative effects for autistic people as a result of the context and language used; the authors make suggestions to adjust how autism is framed, contextualised, and described, and recommend alternatives.

The use of language is an important consideration when we reflect on the way we talk about autism. The Diagnostic and Statistical Manual of Mental Disorders Fifth edition (DSM-5), now refers to Autism as a single category, having removed the diagnosis of Aspergers Syndrome, which described a separate group of autism characteristics. Consultations with autistic people, their families and networks reveal a breadth of opinions and perspectives about the language that should be used to refer to or define autism (Kenny, et al., 2015; Keating, et al., 2022). This includes the terms Autism, Autistic, person/people with Autism and Autistic person/people.

Keating, et al. (2022) advise that the best approach is to ask people what their preference is. We acknowledge that this approach is not within the scope of this review. Throughout this

review, therefore, wherever we have ownership of the language, we adopt an identity first approach and use the term autistic person/people as this term is widely, although not unanimously, endorsed by autistic people (Kenny, et al., 2015).

## 1.1. Autism

### 1.1.1. What is autism?

#### Definitions, characteristics, and prevalence

The National Autistic Society (2023a) describes autism as “a lifelong developmental disability which affects how people communicate and interact with the world”. This straightforward definition is expanded on by The National Institute for Clinical Excellence (2013, p.5).

*“The term autism describes qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours, often with a lifelong impact. In addition to these features, children and young people with autism frequently experience a range of cognitive, learning, language, medical, emotional and behavioural problems, including: a need for routine; difficulty in understanding other people, including their intentions, feelings and perspectives; sleeping and eating disturbances; and mental health problems such as anxiety, depression, problems with attention, self-injurious behaviour and other challenging, sometimes aggressive behaviour. These features may substantially impact on the quality of life of the individual, and their family or carer, and lead to social vulnerability.”*

As Autism is a spectrum condition (Havdahl, et al., 2021), it is perhaps unsurprising that people’s individual experience of autism differs. The presentation of autism can vary significantly from person to person, and each individual will have varying support needs, with some autistic people requiring full time care and others, whose disability may be hidden, seemingly able to live independent lives (National Autistic Society, 2023). A commonly used phrase, attributed to Dr. Stephen Shore “if you meet one person with autism, then you have met one person with autism” (Flannery and Weisner-Carlson, 2020) underscores the unique presentation and experience of each autistic person.

There are over 700,000 autistic people in the United Kingdom – more than 1 in every 100 individuals (Department of Health, 2021). When families and carers are taken into consideration, this statistic means that autism is a part of daily life for almost 3 million people. Growing awareness and understanding of autism has resulted in a steady increase in the numbers of people diagnosed (Havdahl et al., 2021), although Brugha, et al. (2011) found a connection between autism diagnosis and birth year, demonstrating that the older a person is the less likely they are to be diagnosed as autistic.

A large-scale study by the University of Cambridge (Roman-Urrestarazu, et al., 2021), analysing UK school census data of more than 7 million children found that around 1.78% of UK children are recorded by schools as autistic, higher than previously thought. The report further identifies differences in prevalence between ethnicities, with higher rates of autism identified in Black and Chinese pupils and lowest rates in pupils from Roma/Irish Traveller communities (0.85%). The report confirms a higher prevalence of autism amongst boys (2.8%) than girls (0.65%). This gives a boy-to-girl ratio of 4.3:1. Findings from this review also reveal 18.1% of autistic pupils have additional learning disabilities.

Lai, et al. (2014) suggest diagnostic screening instruments and assessment processes may have a male gender bias and that this bias could explain the gender imbalance in autism diagnoses. 'Masking' could also contribute to underdiagnosis in females; masking is described as behaving to fit in with the expectations of non-autistic people and is a recognised unconscious strategy that many autistic people deploy, particularly females (Ratto, et al., 2018). Boys and girls present different signs of autism and, as a result, girls can be misdiagnosed or missed (Havdahl et al., 2021; Loomes, et al., 2017; Mandy and Lai, 2017).

### **1.1.2. What causes autism?**

Autism is a neurodevelopmental condition (Baker J., et al., 2019; Chen, et al., 2022) and is now broadly accepted as genetic in origin, with a high probability of multiple genes being involved, rather than one single autism gene (Smalley, et al., 1988, Havdahl, et al., 2021). However, from the earliest identification of autism as a diagnosable condition, parents have frequently, been blamed for both causing autism in their child through their behaviour (Bettelheim, 1967), and for the ways in which autism presents in a child by their parenting (Walker-Kennedy, 1988; Waltz, 2015).

Mothers have erroneously been described as causing autism, with Waltz (2015) describing mothers being repeatedly blamed as the cause of autism in children has resulted in parents blaming themselves and often seeking a cure, rather than inclusion and acceptance. Present day anecdotal evidence suggests that this view persists within society. For example, a BBC news article (Rees, 2017) draws attention to parents of autistic children being referred inappropriately to parenting courses to help parents manage their autistic children's behaviour. The article attributes these referrals to poor professional understanding about autistic presentation. Parents interviewed for the report described being fearful that their parenting and their children will be misunderstood.

## **1.2. Assessment and Diagnosis**

There are substantial waiting lists in the UK for autism assessments. Both parents and professionals report dissatisfaction with the diagnostic process (Crane, et al., 2016; Crane, et al., 2018; Rogers, et al., 2016).

The most recently published NHS England (2023) statistics (July 2022 – June 2023) identify over 143,119 people with an open referral for an autism assessment; 83% of these have been waiting longer than the National Institute for Clinical Excellence (2013) recommended timeframe of 3 month. In many areas of the UK the wait time for an assessment can be several years; a 2022 report in *The Guardian* identified a wait time of over five years following a GP referral for a child to access an autism assessment in Coventry and Warwickshire (Jayanetti, 2022).

The length of time children and families have to wait for an autism assessment is problematic for parents (Crane, et al., 2016; Crane, et al., 2018). Official waiting lists do not take in to account the period in which parents have concerns about their child but have yet to approach a professional, or the time it takes for the first professional contacted to make a referral for an assessment (Rogers, et al., 2016). Crane, et al., (2016) identify an average wait of four and a half years from *parent's first concerns* about their child until diagnosis is made. Professionals



may underestimate the length of time parents and children have been waiting for an assessment and/or the impact that the wait has had on the family (Rogers, et al., 2016). Crane, et al., (2016) found a negative correlation between the length of wait and parental satisfaction with the diagnostic process.

Clinical multi-disciplinary diagnosis of autism is key to identification and access to support; however, assessment processes are not easily or readily accessible (Crane, et al., 2018; Clements and Aiello, 2021). As there is no biological test for autism, diagnosis is made on the basis of clinical observations, preferably drawn from multiple sources (Rogers, et al., 2015). The relationship between practitioners and parents is critical in ensuring parental satisfaction with the diagnostic process (Crane, et al., 2016) but parents often feel their opinions and experience are not given due consideration (Crane, et al., 2018). Furthermore, parents perceive that some professionals, particularly GPs and teachers lack knowledge about autism (Crane, et al., 2018). Clear explanations, treating parents as co-experts and being knowledgeable facilitate greater parental satisfaction (Crane, et al., 2016)

A further tension between parents and professionals arises in the expectation of what support can be accessed once a diagnosis of autism is made (Crane et al., 2018). Support is either non-existent, or inappropriate (Crane et al., 2018). In a survey of UK professionals, over half identified that they were unable to offer post-diagnostic support in line with National Institute for Clinical Excellence guidelines (Rogers, et al., 2015). Clements and Aiello (2022) found that families who approached Social Care services for support were frequently assessed from a child protection perspective rather than support from a disabled child in need perspective. Representatives from parent/carer-led organisations suggest that non-specialist social workers have limited understanding of disabled children and/or autistic children, and therefore make assumptions that parents are to blame for any difficulties their family experiences due to their child's condition Clements and Aiello (2022).

### **1.3. Parental Blame**

From the identification of autism in 1940's until 1980, when the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) first included criteria for a diagnosis of infantile autism; attempts have been made to understand the root causes of autism and how it should be categorized. (Kenny, 2015; Rosen, et al., 2021). Parents were initially blamed, by both professionals and the wider society, firstly for causing autism and then for the autistic behaviours that many considered undesirable (Bettelheim 1967; Kenny, 2015; Waltz, 2015).

Waltz (2015) identifies that blaming mothers originated in the child guidance movement of the early 20th century. Early pioneers, like Ernest Groves, a sociologist, suggested that all mothering "*was pathological, and in need of scientific improvement*" (Waltz, 2015, p. 354). It was in this environment that Kanner opened the first child psychiatry unit in the United States (Waltz, 2015) and here studied a small group of autistic children (Kenny, 2015; Waltz, 2015).

Kanner's initial observations of autistic children led him to conclude autism was an inborn condition (Bettelheim 1967). Despite this early view, his work is often identified as instrumental in suggesting that parents are to blame for autistic behaviours of their children, describing the mothers of the autistic children he studied as cold, un-empathic and distant (Waltz, 2015). Bettelheim concurred with some of Kanner's statements, promoting the idea that parents, and mothers specifically, caused autistic behaviour by inappropriate parental responses to their children, particularly in the early development stages (Bettelheim, 1967; Kenny, 2015).

Later researchers, including parent-researcher Lorna Wing, are credited with changing the narrative around mothers being blamed for causing autism in their child (Happé and Frith, 2020; Waltz, 2015). However, despite the shift in understanding the causes of autism, this has not completely resolved the outdated notion of parent blaming. An online survey carried by Running and Jata-Hall (2023) of 1,016 families of autistic children reported widespread blame, gaslighting and safeguarding investigations by professionals of parents of autistic children. 88% of parents/carers completing the survey said that they had felt blamed for some aspect of their child's presentation (Running and Jata-Hall, 2023). The study focused on pathological demand avoidance (PDA), which is characterised by an extreme resistance to everyday demands and can be a characteristic of some people autistic presentation (National Autistic Society, 2023b). The survey found that neurodivergent, single mothers appeared to be most susceptible to parental blame from supporting professionals (Running and Jata-Hall, 2023), which suggests complicated intersectional issues contributing to these situations.

The advisory group for the Autism and Parental Blame Project, of which this literature review forms a part, included members who are experts by experience, that is, people with lived experience of being parents of autistic children. Feedback from the advisory group corroborates the examples above, with experts by experience describing multiple occurrences of parents seeking help for their child and feeling that the health/education/social care systems failed to provide the right support to their child. When parents challenged the provision and complaining or advocating several reported professionals escalated expressions of parental blame. The parents cited numerous personal accounts of professionals criticising parenting skills, accusing them of child abuse, or, even more distressing, professionals initiating child protection procedures. Similar experiences are reported by Clements and Aiello (2022).

Reports of barriers to diagnostic assessments are commonplace, and many parents and families have the perception that the barriers serve to act as a filter to service demand (Clements and Aiello, 2021). Parents report that they are more likely to have their parenting ability called into question by professionals than receive an autism assessment for their child (Clements and Aiello, 2021). A personal account of this battle to obtain an assessment is described by parents, Julia Carter, Tracy Moon and Tracey Harrison (Carter, et al., 2020). The parents describe the hurdles and gatekeeping tactics adopted by services, which includes a requirement for parents who believe their child may be autistic to attend a parenting course. Carter, Moon and Harrison suggest that there is an immediate assumption by professionals that parenting techniques are the only factor responsible for a child's behaviour, rather than considering whether the child's behavioural presentation could be an indicator of autism. Julia Carter and Tracy Moon's determination to bring attention to this situation has led directly to this review into experiences of parental blame, commissioned by NHS England.

#### **1.4. Accusations of Fabricated and Induced Illness (FII) as a form of parental blame**

An emerging sub-theme of parental blame is parents of autistic children being suspected and accused of Fabricated and Induced Illness (FII). FII (previously known as Munchausen by Proxy), is described by the Royal College of Paediatrics and Child Health as "... a *clinical situation in which a child is, or is very likely to be, harmed due to parent(s) behaviour and*



*action, carried out in order to convince doctors that the child's state of physical and/or mental health and neurodevelopment is impaired (or more impaired than is actually the case). FII results in physical and emotional abuse and neglect, as a result of parental actions, behaviours or beliefs and from doctors' responses to these. The parent does not necessarily intend to deceive, and their motivations may not be initially evident"* (Royal College of Paediatrics and Child Health, 2021, p.11).

The intention to deceive is an important factor in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) definition of FII, however Bass and Glaser (2014) claim this is too narrow and should be widened to include erroneous and mistaken reporting of symptoms by parents because of the potentially harmful impact on the child's health regardless of the motivation or intent of the parents. In their article *"Early recognition and management of fabricated or induced illness in children"* published in the Lancet, Bass and Glaser (2014) use autism as an example of a condition that may be fabricated by a parent and also suggest that a parent who is autistic themselves may be prone to erroneous reporting of symptoms in their child *"Some parents with this disorder might present with beliefs about their child's health that are difficult to corroborate"* (Bass and Glaser, 2014, p.1417). The Royal College of Paediatrics and Child Health (2021) Guidelines on FII suggest that parents who struggle with their child's behaviour may seek justification through an inappropriate diagnosis of ADHD or autism. The guidelines further suggest that some parents are motivated to fabricate symptoms by the potential financial gain that a diagnosis may secure *"Material gain includes financial support for care of the child, improved housing, holidays, assisted mobility and preferential car parking"* (Royal College of Paediatrics and Child Health, 2021, p.13).

Parents of autistic children, and autistic parents, express a growing concern about accusations of FII and there are numerous accounts from parent-led support groups attesting to an increase in accusations (Autism Eye, 2014; Gray-Hammond and Adkin, 2022; Wadlow, 2019). Experiences range from professionals misunderstanding the presentation of the autistic child (Eaton, 2018), to parental concerns that FII and child protection are used as a punishment when parents complain about service provision (Clements and Aiello, 2021).

Bilson (ca.2020) criticises the *Royal College of Paediatrics and Child Health Guidelines* as not being evidence based and suggests that previous epidemiological research is flawed; a view echoed by Gullon-Scott and Long (2022). Bilson (ca.2020) criticises the lack of evidence regarding the accuracy of diagnostic tests for FII, arguing that these issues substantially increase the likelihood of false positive FII cases. Long, et al., (2022) in writing a practice guide for Social Workers acknowledge the increase in referrals to social workers for suspected FII. (Long, et al., 2022, p.5). advocate that whilst safeguarding children should be of primary concern, social workers *"have a duty to ensure parents/caregivers are appropriately supported, rather than them being subjected to unnecessary child protection proceedings, when inappropriate and wrongful accusations of FII are made"* (Long, et al., 2022, p.5).

Gullon-Scott and Long (2022) highlight that FII is not a diagnosable condition, and a lack of evidence means that the guidelines around FII and Perplexing Presentations (PP) have broadened the concept of abusive behaviour to include anything that leads to a parent presenting frequently to professionals with concerns about their child and where the professionals are unable to identify a cause.

## 2. Methods

This systematic review has broadly followed guidance from the Cochrane Collaboration (Higgins et al., 2020). The review sought to answer the central research question, ‘What is the evidence base about how parents of autistic children experience parental blame when they approach health, education and care services for support?’ In order to further improve the strength of the review findings, papers were quality assessment using the Critical Skills Assessment Programme (CASP, 2018)

### 2.1. Sources and search strategy

We searched the international evidence base for sources related to our central research question using five search terms:

- Children and young people
- Autism
- Parents and carers
- Parental blame
- Fabricated and induced illness

Key word and search terms were developed to reflect the research question (Table 1), and the search strategy adapted for each database. Five databases were searched, in addition to a grey literature search, without date limits. In addition to this robust search strategy, we sought input from the project advisory group, including experts by experience, who identified relevant literature.

**Table 1. Outlines the search terms and provides an example search string.**

<b>Search code</b>	<b>Search String</b>
S1	Autism OR Autistic OR ASD OR Neurodivergent OR Asperger* OR Aspi OR Autistic Spectrum Condition OR ASC OR Neurodiversity OR Pathological Demand Avoidance OR PDA Or Childhood Disintegrative Disorder OR Pervasive Developmental Disorder OR Non-Specific Pervasive Disorder OR Developmental Disability
S2	Young People OR Young Person OR Child* OR Young Adult OR Teenager OR Youth OR Adolescent OR Teen
S3	Parent OR Guardian OR Foster Carer OR Family Member OR Kinship carer OR Connected Person OR Grandparent OR Main Carer OR Carer* OR Care Giver
S4	Blame OR Fault OR Judge* OR Criticised OR Undermined OR Hostile* OR Misunderstood OR Fabricated and Induced Illness
S5	Fabricated and Induced Illness OR Munchausen’s by Proxy

## 2.2. Study selection process

Two reviewers screened all titles and abstracts to assess relevance to study aims. Any discrepancies were discussed until agreement reached. An experienced systematic review academic mentor reviewed 10% of titles and abstracts to verify eligibility.

We screened papers to select those with populations that included parent/carers and autistic children and/or young people. Texts were included that focussed on the interaction between parents and professionals within health, social care and education. This included blame experienced from professionals as well as others. Although not a part of our original research question, during review and selection these experiences of blame by “others” were identified as important in understanding the context in which blame can occur.

Our methodological approach is reported according to the PRISMA guidelines (Moher, et al., 2009) (Figure 1). The initial search returned 241 items. Of these 34 were removed as duplicates, leaving 207 items. We undertook an initial screening for primary papers where the main populations were parent/carers and autistic children and/or young people. The context for inclusion was a focus on the interaction between parents and professionals within health, social care and education. Because we were interested in how parental blame is experienced, we rated as high papers that described this from the parents’ perspective. This included blame experienced from others as well as professionals. Although not part of our original research questions, following our initial scoping and discussions with advisory group, these experiences of blame by “others” was seen to be important in understanding the context in which blame can occur.

We assessed these documents for relevance to our research question (see Table 2). Papers were graded from Level 1 – very relevant to the subject to Level 4 – off topic or no indication of relevance to the research question. 26 papers were graded Level 1. To these we added a further 33 papers which were identified through a search of grey literature, or by our Experts by Experience or through the researchers’ own knowledge of the subject.

## 2.3. Quality Appraisal

These 59 papers were then assessed against our quality criteria (Table 3) and 23 papers removed which did not meet the threshold. The remaining 32 papers were assessed using the Critical Skills Appraisal Programme (CASP, 2018) (Table 4). This ensured we selected research papers that specifically addressed the research question and enabled us to identify common themes and gaps.

A maximum of 33 points could be awarded. A total of 14 papers scored 19 and above and were selected for a full critical appraisal. 13 papers scored 20 and over and were deemed to have met the standards required for a high-quality study. A further 2 papers scored 19 and were also included in the final review. This lower score generally indicated a lack of information pertaining to ethical considerations or researcher positioning; however, the research design and methods were sufficiently high quality to warrant inclusion.

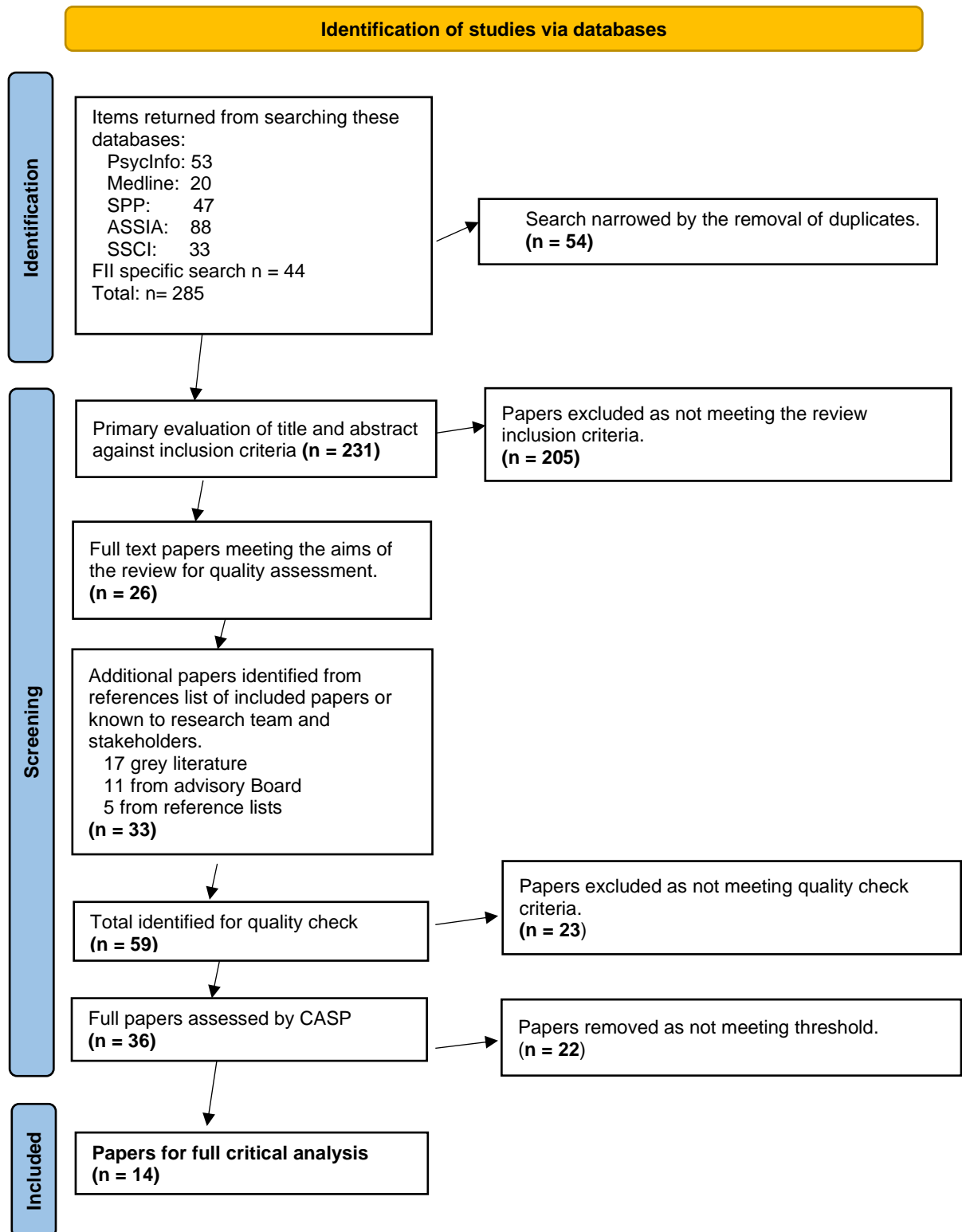
Papers scored lower than 19 generally lacked the academic rigour and quality of data important to create generalisable insights and statements. Some of these papers however, provided knowledge which further informed our understanding of the context for this research

and have therefore been referenced in our introduction. The primary reason for this was not using qualitative methodology and/or a lack of clear aims and research design.

**Table 2: Quality criteria**

Phenomenon of Interest	<ul style="list-style-type: none"> <li>• Parental blame experienced in the context of caring for an autistic child/young person</li> </ul>
Construct	<ul style="list-style-type: none"> <li>• Experiential</li> </ul>
Population	<ul style="list-style-type: none"> <li>• Autistic children and young people</li> <li>• Parents, mother, father, grandparents, carer, guardian</li> </ul>
Context	<ul style="list-style-type: none"> <li>• Interactions between parents and professionals</li> </ul>
Study Design	<ul style="list-style-type: none"> <li>• Qualitative research – this could include questionnaires</li> <li>• Systematic reviews</li> <li>• Themes supported by descriptions or observations</li> </ul>
Other criteria	<ul style="list-style-type: none"> <li>• English language papers only</li> <li>• Peer reviewed publications</li> </ul>

**Figure 1. PRISMA flowchart of identification, retrieval, and inclusion of relevant studies.**



**Table 3. Initial Screening**

<b>Score</b>	<b>N=x</b>	<b>Studies</b>
1	43	Extremely relevant - identified for critical full read of study and analysis
2	37	Indication that some content may be useful but need to identify relevant sections - light reading
3	46	No indication there are relevant references to parental blame - Skimming
4	115	No indications in abstract and conclusion that the content is relevant

## **2.4. Synthesis**

The findings from included papers were synthesised in a multi-step process. Individual reviewers reviewed a portion of the included papers and then discussed emerging themes in a series of workshops, seeking to develop a coherent set of themes generated from the included papers. When nascent themes were developed, these were discussed and refined with the academic mentor to create the final set of themes.

## **2.5. Consultation**

The consultation of experts and stakeholders is an optional but recommended step in reviews and involves a knowledge translation activity (Levac, et al., 2010). The consultation exercise ensured our approach was thorough and provided assurance that the review included a robust search strategy.

We established an advisory group to contribute to this study with a focus upon the East and West Midlands. The advisory group consisting of 18 members. Ten of whom are EbE, the majority are parents of autistic children with in-depth knowledge and experiences of parental blame. Included parents are both autistic and nonautistic. Most members also have a role in a professional capacity with broad ranges of experience including SEND and EHCP expertise, as well as other relevant sector knowledge, such as research or voluntary agencies. In addition, six members work in autism services: providing substantial experience from social care, health and research in roles of influence. It is also noted that the two co-researchers/project leads have both relevant professional backgrounds and are also parents and grandparents of autistic young people.



### 3. Results

#### 3.1. Characteristics of included studies

The below table (Table 4) provides a summary of the studies included following the above screening.

**Table 4.** Summary of included studies.

<b>Author and Title</b>	<b>Year</b>	<b>Location</b>	<b>Methods</b>	<b>Aim and Purpose</b>	<b>Sample</b>
Alareeki, A., Shipton L; Lashewicz B <i>"They're either afraid or ignorant": Experiences of stigma and blame among fathers raising autistic children."</i>	2022	Canada	Qualitative	Explore the concept of courtesy stigma from the perspective of fathers of autistic children from minority ethnic groups	n=11
Baker P., Cooper V., Tsang W., Garnett I., Blackman N. <i>"A survey of complex trauma in families who have children and adults who have a learning disability and/or autism"</i>	2021	America	Qualitative	An exploration of the interactions of families who have children and adults with a learning disability and/or autism and services, considered through a framework of complex post-traumatic stress disorder	n = 214
Boshoff K., Gibbs D., Phillips R. L., Wiles L., Porter L. <i>"A meta-synthesis of how parents of children with autism describe their experience of advocating for their children during the process of diagnosis"</i>	2018	Australia	Qualitative	To consolidate in-depth qualitative data from parents of their experience of advocating for their autistic child during the diagnosis period from 22 studies	n=1178
Broomhead K. <i>"Blame, guilt and the need for labels; insights from parents of children with special educational needs and educational practitioners"</i>	2013	UK	Qualitative	To explore blame within the context of home / school relationships	n=37 (22 parents) (15 professionals)
Clements, L., and Aiello A. L <i>"Institutionalising parent carer blame"</i>	2021	England	Qualitative and Quantitative	Research how Local Authorities in England approach child in need assessments. Obtain views of parent carer support organisations by geographic area seeking good practice and items for improvement	n =92 responses (of 143 LAs and family organisations)

Courcy, I. and des Rivières C <i>"From Cause to Cure" A qualitative study on contemporary forms of mother blaming experienced by mothers of young children with autistic spectrum disorder"</i>	2017	Canada	Qualitative	Explore perceptions of blame and guilt experienced by mothers of autistic children (attending an intervention programme) in relation to their child's development	n=13
Rosenblum-Fishman S.D. <i>"Maternal self-efficacy and perceived stigma among mothers of children with ASD, ADHD, and typically developing children"</i>	2013	USA	Qualitative	To quantify and compare parenting related perceived stigma and maternal self-efficacy amongst mothers of ASD/ADAD/typically developing children.	n=180
Gill, J. and. Liamputtong P. <i>"Walk a mile in my shoes: Life as a mother of a child with Aspergers Syndrome"</i>	2013	Australia	Qualitative	Explore the experiences of mothers of autistic children in relation to perceptions of ideal motherhood and their own physical and emotional health	n=15
Hingley-Jones, H. <i>"An exploration of the issues raised by living with a child with autistic spectrum disorder and a professionals attempt to move beyond pity and blame"</i>	2005	UK	Autoethnographic	To explore the practical and social justice aspects of good casework for practitioners working with families with disabled children	n=1
Jackson, L., Keville S., Ludlow A. K., <i>"Mothers experiences of accessing mental health care for their child with Autistic Spectrum Disorder"</i>	2020	UK	Qualitative	Gain an in-depth understanding of parent's experiences of gaining access to mental health services for their child with ASD and mental health comorbidity	n= 7
Kingston A. K. <i>"Mothering special needs: A different maternal journey"</i>	2007	Ireland	Qualitative	Increase understanding through sharing lived the experiences and personal accounts of mothers of special needs children (ASD/ADHD, Downs Syndrome)	n=18
Mitra B. <i>"It's not Autism. It's your parenting. An autoethnographic exploration of the relationships between professionals and parents of an autistic child in the UK"</i>	2022	UK	Autoethnographic	To chart the journey of parenting an autistic child in the UK and explore the traumatization experienced as a result of engaging with professionals through a series of vignettes	n=1

Neely-Barnes, S. L., Hall H. R., Roberts R. J., Graff C. <i>"Parenting a child with Autistic Spectrum Disorder: Public perceptions and parental conceptualizations"</i>	2011	USA	Qualitative	Explore public perceptions of autism and parents' conceptualisations of themselves and children. it considers how public/parent conceptualisations are at odds and the implications of parent's experiences for social workers	n=11
Robinson C.A. York K., Rothenberg A., Bissell L. <i>"Parenting a child with Asperger's syndrome: A balancing act"</i>	2015	USA	Qualitative	Enhance understanding of the parenting experience unique to AS and inform the provision of services and supports to this population.	n=13

## 4. Findings

### 4.1. Introduction

Parents experience blame from multiple sources, which intersect and compound the impact on parents and their families. We identified several sources of parental blame throughout the literature:

- **From societies and communities**
- **From family and friendship groups**
- **From professionals and service providers**

Given the impact of the final theme, and the power of professionals over family's lives, the professional blame required further examination. This theme included three different formations of parental blame:

- **Formations of professional blame of parents**
  - **Criticism of parenting**
  - **Not listening to or not believing parents**
  - **Accusations of neglect or Fabricating or Inducing Illness (FII)**

Finally, we identify two further themes that are of note for this review:

- **Impact of parental blame on parents, children and families**
  - **Guilt**
  - **Knowledge, resilience and advocacy**
  - **Trauma**
- **Professional perceptions of parental blame**

The majority of papers reviewed explored the views and experiences of mothers in particular. One paper dealt specifically with fathers' experiences and two did not specify the breakdown between mothers and fathers. In research about families, mothers are studied more frequently than fathers (Alareeki, et al., 2022; Broomhead, 2013). Kingston (2007) suggests that this is because mothers are usually the primary carers for their children, especially when their child is disabled.

The following section will describe these themes and outline the knowledge base and critique across each.

### 4.2. Parental Blame from Society and Communities

Societal and community blame was a prominent issue in the papers selected for this review. Parents experienced societal and community blame particularly in relation to their child's behaviour (Alareeki, et al., 2022; Broomhead, 2013; Courcy and des Rivières, 2017; Gill and Liamputtong, 2013; Neely-Barnes et al., 2011). For example, Broomhead (2013, p.14) suggests that the UK has a "*governmental focus on 'parental determinism'*", where parenting is viewed as the most important factor that determines a child's future. Furthermore, mothers are frequently blamed for ineffective parenting if their children display behavioural, emotional and social difficulties. Gill and Liamputtong (2013, p.51) found that mothers in their study felt society blamed them for their children behaviour, "*Their 'parenting practices' were seen to make their children behave inappropriately*". As a result, mothers would internalise this blame,

seeing themselves as “bad mothers”, with one mother stating “... *I thought that must be true, it’s obviously true*” (Gill and Liamputtong, 2013, p.51).

Alareeki, et al. (2022, p.2) examined experiences of “*stigma by association*” in fathers of autistic children, which includes fathers feeling blamed for their child’s autism and/or behaviour. Alareeki, et al. (2022) note that fathers report that their children’s behaviour, and therefore by association their parenting, are judged as inappropriate by strangers. Fathers identify that this is because autism is a hidden disability and their children do not present as disabled. One father commented “*Some people just give you unsolicited advice ... they’ll say something like, that is not very healthy what you’re feeding your kid...Like this is all he’ll eat!*” (Alareeki, et al., 2022, p.6).

The parents in Neely-Barnes et al. (2011, p.212) study echoed this theme of being judged and misunderstood by others, stating that they “*were frequently viewed by others as bad parents*”. Again, this attitude by the public is attributed to autism being hidden. One mother quoted her daughter who has cerebral palsy and uses walking aids, saying of her autistic brother “*People are far more cruel to him than they are to me. No one has ever been that cruel to me. If he had something physical people would treat him better*” (Neely-Barnes et al. 2011, p.213).

### 4.3. Parental Blame from Family and Friendship Groups

As well as experiencing blame from strangers, parents also reported blame from friends and family members (Alareeki et al., 2022; Courcy and des Rivières, 2017; Mitra, 2022; Neely-Barnes et al., 2011). Parents describe in several studies how family and friends rejected the child’s diagnosis and how this rejection led to the parents feeling blamed for the child’s behaviour or delayed development rather than autism considered as a contributory explanation. Courcy et al (2017, p.239) state that all the mothers in their study had “*experienced some blame from their friends or family about the child’s diagnosis and ... behaviors*”.

Alareeki, et al. (2022) describes how culture and ethnicity can influence a family’s response to a diagnosis of autism. He found that in some cultures, some parents of a child with autism may end up withdrawing from their community. One father explained “*In some cultures, the diagnosis of autism has no merit. Even if it brings support.... The negative side is bigger. Like stigma. Isolation from their bigger ethnic community*” (Alareeki, et al., 2022, p.6).

In a meta-analysis of the experience of 1,178 parents, Boshoff, et al. (2018) found that some parents felt their concerns about their child were marginalised by family and friends. Other parents chose to only discuss their child’s needs with close family members and one mother sought a diagnosis from three clinicians to convince her family that her child’s difficulties were due to autism and not poor parenting.

Robinson, et al. (2015, p.2314) state that when confronted by their autistic children’s behaviour “*the typical answer [from friends and family] to the persistent question of “Why is this happening?” was inadequate parenting*”. In an autoethnographic account of parenting a child with Pathological Demand Avoidance (PDA), Mitra (2022, p.32) describes how before her child’s diagnosis, she was told, by family as well as professionals, that “*more effective discipline*” was needed to control disruptive behaviour.

## 4.4 Parental Blame from Professionals and Service Providers

Professionals play a critical role in gaining an autism diagnosis; however, many parents report experiences of blame during interactions with practitioners and services. Eleven of the fourteen papers examined acknowledge parents' negative experience of professionals and services and/or service providers. These included Health, Education and Social Services in a range of countries and contexts. In Jackson, et al.'s (2020, p.538) survey of mothers of autistic children accessing UK mental health services "*the resounding narrative from all mothers' accounts were negative experiences accessing services and, once attained, with the professional support on offer*". Blame from professionals is experienced in several ways, including parenting abilities being called into question (Mitra, 2022); being held responsible for causing their child's behaviour (Broomhead, 2013; Gill and Liamputtong, 2013; Jackson, et al., 2020; Mitra, 2022; Robinson, et al., 2015); parents' concerns being dismissed or minimised (Boshoff, et al., 2018; Jackson, et al., 2020; Kingston, 2007; Mitra, 2022; Rosenblum-Fishman, 2013); and in some cases, parents being accused of neglect or fabricating their child's condition resulting in the instigation of child protection procedures (Jackson, et al., 2020; Kingston, 2007; Robinson, et al., 2015).

## 4.5. Formations of Professional Blame of Parents

### 4.5.1. Criticism of parenting

Parents of autistic children and young people frequently feel their parenting ability is called into question by professionals (Mitra, 2022; Broomhead, 2013; Jackson, et al., 2020), particularly when their child presents with behaviour that is disruptive or that others find challenging. The perception is, that it is the parents who have caused the undesirable behaviour and that parents can change their child's behaviour through the use of parenting strategies. Parents refute these views and describe how these strategies often don't work for their autistic children and in some cases do more harm than good. For example, Mitra (2022, p.35) describes how she was frequently told by her child's school that her parenting was at fault, being told "*act like you're cross*" and "*you're not cross enough*". Mitra goes on to describe how when trying to implement the bedtime routines they had been told to use, their son began self-harming and talking about suicide. "*It was traumatic to put a child you care about through such suffering and unhappiness because professionals believed it was all down to our parenting*" (Mitra, 2022, p.38).

Parents suggest that many professionals have an incomplete understanding of autism and the different ways in which autism can present. Clements and Aiello's (2021) survey of parent carer led support organisations received many responses indicating that parents are frequently blamed for their child's difficulties. A typical survey response states "*Social Workers with very little understanding of the nature of disability and or Autism make assumptions that the parents are to blame for the difficulties their family experiences due to their child's condition*" (Clement and Aiello, 2021, p.30). A respondent in Broomhead's (2013, p.16) survey of parents of children with Behavioural, Emotional and Social Difficulties (BESD) reported "*they think that its parents that are going wrong for the child to be how they are...they blamed me and said 'oh we'll put you on parenting courses'...it makes you feel as though it's your fault, you're doing something wrong*".



#### 4.5.2. Not listening to or believing parents

When working with professionals, parents reported that not being listened to, not being believed, and having their experience minimised or dismissed caused significant stress. Some parents felt this slowed down the diagnostic process meaning their child had to wait to get the help they needed (Baker P., et al., 2021; Boshoff, et al., 2018; Hingley-Jones, 2005; Jackson, et al., 2020; Kingston, 2007; Mitra, 2022; Robinson, et al., 2015).

Robinson, et al. (2015, p.2315) report that parents in their study felt they weren't taken seriously and were "*blamed for imagining or exaggerating problems and not parenting 'well enough'*". A participant in Kingston's (2007, p.168) study described feeling judged by professionals when she requested a report that had been written about her child "*I sometimes think they think I'm hysterical*".

In a meta-synthesis of parent's experiences Boshoff, et al. (2018, p.151), referencing Frye (2016), Ryan and Sailsbury (2012) and Bultas and Pohlman (2014), cite numerous accounts of parents feeling unheard throughout the studies they analysed. "*Parents described feeling unheard with dismissal of their concerns, resulting in distress, anger and humiliation, and frustration*". ... "*Marginalisation, silencing of their concerns, and lack of support were reported, as well as health professionals not acknowledging the importance of parents' 'concerns'*".

Parents frequently describe their interactions with services in adversarial terms – a battle, a fight, a struggle, a war (Kingston, 2007). Hingley-Jones (2005, p.117) describes how after a "*two year battle*" to make themselves heard, one couple refused to collect their child from respite care until a referral to a specialist team was made.

#### 4.5.3. Accusations of neglect or Fabricating or Inducing Illness (FI)

Another further concern for those attempting to seek support from professionals is the threat of being accused of neglect and/or FI. Three studies identified how parental blame had been expressed through direct or indirect accusations "*...it was almost like I, as the parent, was making up my child's mental well-being, like it was my fault*" (Jackson, et al., 2020, p.541). For some parents these accusations become formalised through the instigation of child protection procedures. Mitra (2022) explains that a child protection conference was called after her child refused to go to school. Although the child's difficulties were evident at school as well as at home the focus of the meeting was on parental failure.

Challenging the opinions of professionals is seen as problematic with some parents stating that child protection procedures have been instigated following parents making a complaint (Kingston, 2007). Clements and Aiello, (2021) state that many parents are fearful of complaining or raising concerns because of repercussions. One of the parent/carer led organisations who completed the survey could identify at least eight families who had been accused of fabricated and induced illness following a complaint about services and/or individual professionals. Clements and Aiello, (2021, p.32) refer to a 2021 report produced by the Chief Social Workers for Adults and the Chief Social Worker for Children and Families "*which referred to 'families who had been brought into the child protection process because of disagreements with practitioners' – in their opinion, a 'repeated concern that we hear from parents and carers outside of this study in the course of our ongoing communications with families over the years'*".

## 4.6. Impact of parental blame on parents, children and families

### 4.6.1. Guilt

Accusations and criticisms from communities, family members and professionals, can sometimes lead to parents internalising these ideas and blaming themselves for their child's autistic presentation. There are numerous examples throughout the literature of the guilt experienced by parents both before and after their child's diagnosis. Some parents questioned whether they had been the genetic cause of their child's autism (Alareeki, et al., 2022; Broomhead, 2013). Others reflected on whether they had done enough to support their child's development (Courcy and des Rivières, 2017; Jackson, et al., 2020), or agonised that their parenting was inadequate (Gill and Liamputtong, 2013; Jackson, et al., 2020; Robinson, et al., 2015). "*Your first instinct is to blame yourself for doing something that's making the situation the way it is*" (Robinson, et al., 2015, p. 2314). None of the studies reviewed indicated that parents questioned whether they had fabricated their child's condition or presentation, even when they were accused of having done so (Jackson, et al., 2020; Kingston, 2007).

### 4.6.2. Knowledge, Resilience and Advocacy

Many parents looked to their own research to develop an understanding of how best to support their child. "*I've become the specialist just trying to figure it out on my own, and then talking to [Husband], and working as a team to implement it*" (Robinson et al., 2015, p.2317). Mitra (2022) explains that she undertook significant research to understand her child's behaviour and kept concise records and diaries about strategies employed and their outcomes as well recording all interactions with professionals to safeguard herself against accusations.

Several studies refer to the resilience that parents develop and demonstrate in securing support for their child and negotiating with professionals and services (Alareeki, et al., 2022; Boshoff, et al., 2018; Kingston, 2007). As a response to the lack of acknowledgement of their concerns there is evidence that parents take on the role of advocates for their children and themselves, particularly when they feel their parenting ability is viewed negatively (Alareeki, et al., 2022; Boshoff, et al., 2018; Jackson, et al., 2020; Neely-Barnes, et al., 2011; Robinson, et al., 2015).

### 4.6.3. Trauma

For some families, the negative experiences of engaging with services was found to align with symptoms of Complex Post-traumatic Stress Disorder (CPTSD) (Baker et al, 2021). Relevant studies described that some families can attribute higher stress to the interactions with services than to the effects of living with a disabled person, arguing that the cumulative effect of negative experiences, combined with the subsequent worry that their family member is being placed at risk of harm by not receiving the appropriate service, causes symptoms of CPTSD. Mitra (2022, pp.39-40) agrees that "*having to deal with additional concerns from professional, clinicians, and teachers exacerbate that stress, leaving parents in an emotionally weakened state*".

Assessments of disabled children have been found to frequently utilise a child protection lens which focuses on the failings of the parents rather than the needs of the child (Clements and Aiello, 2021). This lens then focusses on preventing harm to the child instead of putting support in place to safeguard the family. The following comments from family support organisations illustrate the impact on parents:

*“The families we support routinely report an overwhelmingly difficult and distressing experience. Any positive outcomes are because of considerable parental effort – often at significant emotional and financial cost”.*

*“Parents described themselves at breaking point and that the battle with the local authority was exhausting just to get an assessment, never mind the services”.*

*“In our case that ended with the suicide of our son, not 1 single professional guided us towards a diagnosis through 16 years of our son’s life. Mild autism possibly. Not convinced it was that.” (Clements and Aiello, 2021, p.32).*

#### **4.7. Professional perceptions of parental blame**

Only two of the fourteen papers we reviewed examined the concept of blame from the perspective of professionals. Of these, one was an autoethnographic single case study; the other surveyed 15 educational practitioners working with children who were in Special Educational Needs provision and were labelled as having behavioural, emotional and social difficulties (BESD).

In both studies, professionals express feelings of blame towards the parents of the children they are working with. Hingley-Jones (2005), in an autoethnographic account, identifies alternating between states of blame and pity as she responds to the emotions of parents and their desperate need for help. She considers if the parents themselves could have created the emotional difficulties their child presents with. As she rejects this feeling of blame by reminding herself that autism is an organic condition, she moves towards pitying the parents for their situation and distress. This pity/blame cycle is repeated throughout subsequent encounters. Hingley-Jones (2005, p.125) reflects that feeling pity for another person should remind us that needing help can be *“demeaning and humiliating”* and that practitioners need to be aware of this so that they can move beyond it to providing creative offerings of support.

All of the 15 professionals in Broomhead’s (2013) survey expressed blame towards the parents of the children they supported with BESD, believing that their difficulties were due to ineffective parenting. Expressions of blame were characterised by judgmental statements such as *“...you can get children where it’s just downright bad parenting and it’s no wonder the child is the way they are because they’re being dragged up...and some of these children’s problems are just down to dysfunctional families”* (Broomhead, 2013, p.16). She goes on to state that *“the phrases ‘chaotic’, ‘dysfunctional’, and ‘no boundaries’”* were common in the interview responses of professionals in her study. Some professionals in this study commented that socio-economic circumstances played a part in the parents’ ability to cope and the children’s behaviour. Even when the child had received a formal diagnosis professionals saw this as further reason to judge the parents *“...some parents want a diagnosis to say “it’s not our fault because they’ve got this condition” ...it’s almost like an excuse...a devoid of responsibility’ (John, headteacher and SENCo at a mainstream school)”* (Broomhead, 2013, p.18). This study contrasted attitudes of blame towards children with BESD with the attitude towards parents of children with learning difficulties. Professionals expressed that these were *“real special needs”*, with a biological cause (Broomhead, 2013, p.17). Parents in this study whose children had learning difficulties did not perceive being blamed by the professionals for their child’s behaviour or learning difficulties.

## 5. Discussion

The influential, historical and inaccurate views of Kanner (1943) and Bettelheim (1967) that parents and, in particular, mothers cause their child's autism (Waltz, 2015), have been widely scientifically debunked (Courcy and des Rivières, 2017; Neely-Barnes, et al., 2011; Robinson, et al., 2015). However, research shows that parents continue to be blamed both before and after their child's diagnosis by family and friends and the wider community (Alareeki, et al., 2022; Boshoff, et al., 2018; Broomhead, 2013; Courcy and des Rivières, 2017; Gill and Liamputtong, 2013; Jackson, et al., 2020; Mitra, 2022; Robinson, et al., 2015). Blame is expressed both directly, through judgemental statements (Alareeki, et al., 2022) and indirectly through resisting or rejecting a child's diagnosis of autism (Courcy and des Rivières, 2017).

That these views should exist amongst the general public is troubling, but of more concern is that professionals working within health, social care and education services also display attitudes of blame towards parents of autistic children. Although there are very few studies where professionals are the subject of research into parent blaming, two of the fourteen papers we reviewed clearly demonstrated that professionals are aware of feelings of blame towards parents (Broomhead, 2013; Hingley-Jones, 2005).

It is unclear from the literature what the drivers for this blame might be, but as Hingley-Jones (2005) demonstrates, an instinctive reaction of blame needs to be challenged swiftly if this is not to lead to negative interactions between professionals and parents. Unhelpful prejudices, evidenced by Broomhead (2013), demonstrate that professionals may lack sufficient understanding of autism and how it can present, particularly when associated with behaviours that others find challenging. Even with a diagnosis, there are indications that some professionals do not shift from a parent blaming perspective (Broomhead, 2013; Jackson, et al., 2020; Mitra, 2022; Robinson, et al., 2015).

Parents of autistic children face significant challenges (Gill and Liamputtong, 2013; Hingley-Jones, 2005; Jackson, et al., 2020) and are at greater risk of experiencing mental ill-health (Baker P., et al., 2021; Gill and Liamputtong, 2013; Jackson, et al., 2020). The assumption is frequently made that these challenges relate to the difficulties inherently caused by having an autistic family member (Baker P., et al., 2021). However, the impact of negative interactions with services, and the experience of professionals blaming rather than supporting parents, exacerbates any inherent challenges (Jackson, et al., 2020; Kingston, 2007; Mitra, 2022) to the point of producing symptoms of CPTSD in parents (Baker P., et al., 2021).

The impact on families of experiencing blame, particularly from professionals, is noted across several of the papers reviewed (Baker P., et al., 2021; Boshoff, et al., 2018; Kingston, 2007; Mitra, 2022; Robinson, et al., 2015). This impact can be more acute when parents are accused of fabricating their child's autism or specific aspects of their autistic presentation. Such accusations, especially when they lead to children being placed on the child protection register or removed from the family home leave deep scars in families (Clements and Aiello, 2021; Mitra, 2022). While protecting children from harm should be of utmost importance for all professionals, the number of unsubstantiated accusations of FII, including the claim that this occurs following a complaint about a professional or service (Clements and Aiello, 2021; Kingston, 2007), is a cause for concern. This specific issue needs further research to establish

the extent to which the anecdotal evidence available within grey literature and news outlets (Autism Eye, 2014; Gray-Hammond and Adkin, 2022; Wadlow, 2019), and the references in the literature we reviewed (Clements and Aiello, 2021; Mitra, 2022) is experienced by families of autistic people.

Many families experience guilt about their child's autism. This can be in relation to querying whether they are the genetic cause of their child's autism (Alareeki, et al., 2022; Broomhead, 2013), not doing enough to give their child the support they need (Courcy and des Rivières, 2017; Jackson, et al., 2020) or not conforming to the idea of good parents (Courcy and des Rivières, 2017; Jackson, et al., 2020; Kingston, 2007; Robinson, et al., 2015). In addition to these feelings of self-blame parents experience anger, rejection, humiliation, frustration, and a breakdown of trust (Boshoff, et al., 2018; Jackson, et al., 2020; Kingston, 2007) in their dealings with professionals and services. This adds to the guilt they feel, particularly when parents experience blame directly from professionals. *“Patronising attitudes from professionals”* ensure that *“instead of feeling supported the majority of the participants felt scrutinized and minimised in their role as mothers”* (Kingston, 2007, p.162).

As mothers are more frequently the subjects of research (Alareeki, et al., 2022; Kingston, 2007) further studies are needed to say conclusively how fathers experience blame by professionals. However, there is evidence that fathers experience blame from family and friends and the wider community, and, like mothers, experience guilt associated with their child's autism (Alareeki, et al., 2022).

## 6. Strengths of the Research

Systematic reviews provide credible comprehensive, precise outcomes which could be duplicated by future researchers following the same process, asking the same research question (Petticrew and Roberts, 2008). The inclusion of a robust critical appraisal process for included papers also significantly strengthen this review.

The process of retrieving, synthesizing, and appraising the existing knowledge of journals written in English relating to the research question, has been enhanced by the addition of an advisory group with 80% representation of parents of autistic children. This has brought additional knowledge including grey literature into the review and provided a unique perspective in relation to the research.

The input of experts by experience is further improved by the positionality of the research assistants (Hollingsworth and Ferguson), as research assistants for West Midlands ADASS, both as parents of autistic children, with professional backgrounds in social care. To mitigate bias the oversight of an independent academic supervisor ensured a balanced approach was used throughout.

## 7. Limitations and Recommendations for Further Research

When considering how parents of autistic children experience parental blame when they approach health, education and care services for support, the literature review has identified some gaps in current knowledge.



There is little prevalence data about how many parents experience parental blame, and this gap remains an issue. The research we reviewed was largely conducted using small sample sizes and could not indicate or recognise the scale of this population within a wider demographic.

Evidence of parental blame from the perspective of the professional is very limited; only two of the fourteen studies examined the concept of blame from the perspective of professionals. We would recommend further exploration of how health, social care and education professionals perceive parental blame to better understand the barriers and drivers which influence professionals and the provision of services.

This review identified a need to agree a clear and robust definition about parental blame is in the context of autism, and how this presents or manifests.

In seeking to determine what influences parental blame such as the sources, systems, and processes in which they occur, it would be necessary to identify practice implications around legislation or system implementation in England over a wider study sample.

Further research should gather key demographic data which would give additional knowledge. This should include:

- Identifying **where the parent is also autistic**, to identify if the prevalence of parental blame is higher of autistic parents.
- Identifying **only children who have autism** so to ensure the sample group is specific to the question.
- Identify **gender of the child** to establish if female masking is linked to a higher prevalence of parental blame.
- Identify **cultural and ethnicity** data to identify if stereotyping or unconscious bias may be additional factors influencing parental blame.
- Breakdown of which **profession or sector** parental blame comes from to determine if there is a higher incidence in Health, Social Care or Education.
- Measure the incidence of parental blame before and after **autism diagnosis** to ascertain if diagnosis reduces parental blame and improves professional understanding.
- Measure incidence of parental blame by **region** to identify examples of good practice.
- Determine the **wider impact** of parental blame on both the parent and the child/wider family.

## 8. Practice Considerations

We have established that parental blame by professionals is a complex phenomenon, which can have immediate and serious ongoing consequences for the parent and child on many levels. At best limiting or delaying access to the right support, and at worst, removal of the child from the family home.

The current evidence demonstrates examples of the juxtaposition between professional and parental perceptions about the presentation of a child's autism and how this is experienced and perceived by different parties. The included papers also found a reasonable mistrust of professionals by many parents, and a connected inconsistent professional approach about



whether parents are experts of their child's presentation, strengths and struggles; with some professionals using a child protection lens to examine the situation. Ironically, the act of seeking help for the child and parent by the parent can have the reverse effect, but it is not clear whether this is fully understood by professionals.

We know that guidelines, policies, training, and organisational culture all produce the professional context and heavily influence their practice. Conversely, experiences of parental blame are not systematically heard, and there is no review process for professionals when the parental blame is proved to be incorrectly applied.

### **8.1. Training and Awareness**

There is a need to improve professional understanding about autism and how it manifests and presents. The current autism strategy is clear about the need for better training for the community, and current SEND improvement plan (see Appendix 1) sets out to be ambitious about autism, but this may not go far enough.

### **8.2. Reflective Practice and Culture**

Professional blame needs to be recognised as a risk, and there is a need to improve professional practice and reduce the negative impact of parental blame on parents and children. This shift will require heightened awareness by practitioners to self-check their practice, and better oversight by experienced managers. The parental blame concept should be included in supervision and reflective practice. Professional curiosity should be balanced and triangulated with available information, ensuring the child is kept at the centre of any process.

### **8.3. Parents as Partners**

Enthusiastically working in partnership with parents should be a commitment from all health, social care and education providers. It is important to note that the culture of an organisation will underpin how the service is delivered by the professionals it employs. Putting aspiration and vision into practice should be compulsory for each sector. Examples of this could be developing a Parents' Charter.

### **8.4. Advocacy and Accountability**

Advocacy should be a routine part of the offer in delivering support to autistic people and their families. Services should have an open transparent approach in their mission to support better outcomes for children (and adults) with autism. This includes recognising family members as key supporters and also as people who may require support too.

Inspectorates for these organisations should develop Key Performance Indicators that embrace working with parents, and audit and measure parental blame in addition to satisfaction and support received by services.

Consideration should be given to serious case reviews when parents are incorrectly accused of child protection concerns, and when unsubstantiated accusations cause serious harm or significant distress to the child and/or family.

## 8.5. Infrastructure

Services historically have not been specifically designed to support neurodiversity. As the numbers of autistic people increase through better awareness and diagnosis, services need to shift their design to address a broader range of approaches. Consideration should be given to develop pathways and support which are designed to meet the needs of autistic people and work in supportive ways with them and their families.

## 8.6. Policy and Professional Guidance

Policy and guidance documents are sector specific, and reference has been made to *Royal College of Paediatric Child Health Guidelines on Perplexing Presentations and Fabricated and Induced Illness* and *Fabricated or Induced Illness and Perplexing Presentations Abbreviated Practice Guide for Social Work Practitioners* during the course of this review.

However, without undertaking an analysis of professional blame from the perspective of professionals and organisations, it is not possible to identify the opportunities to make changes to current national tools or documents. We would suggest this be reviewed, as recommended previously, through further research to explore blame from the perspective of the professionals. This should include a focus on the specific processes and guidance used in each sector. For example:

- Social care assessments (assessment formats and guidance) - both child protection and child disability assessments processes. We note here that research in this area is currently being undertaken by Luke Clements and Ana Aiello.
- Education – Education and Health Care Plan, Boxall Profiling Toolkit
- Health - GP criteria for meeting autism assessment threshold. Child clinicians' guidance.
- Interrelationship between sectors in decision making processes.

## 9. Conclusions/Summary

Across the included studies, evidence shows a complex and interlocking experience of parental blame, often by professionals. Examples can be found in studies focussing on professionals and was reported by parents when they were the focus of the research. This multiple vantage point demonstrates that parents experience blame for their child's autistic presentation by professionals, and that some professionals are aware they are doing this.

Parents are often acutely aware of the blame directed towards them. At best, they find it a hindrance to seeking good health, education, and other care services for their autistic child. At worst, blame manifest towards parents of autistic children has devastating long term impacts on the family, including symptoms of CPTSD. This is especially pertinent when

unsubstantiated accusations of neglect and/or FII result in the removal of the child from the family home.

Experiences of blame in connection to parenting have a negative impact on the health and well-being of parents and potentially a wider impact on the whole family (Courcy and des Rivières, 2017; Hingley-Jones, 2005; Jackson et al., 2020; Mitra, 2022; Robinson et al., 2015). There is a known increased risk of depression, anxiety, and social isolation amongst mothers of children with Autism Spectrum Disorder (Courcy and des Rivières; 2017 Jackson et al., 2020). Therefore *"...it is highly relevant for health providers and professionals to support mothers without blaming them for their child's development"* (Courcy et al. 2017, p. 246).

Parents acting as advocates for their children and as experts in their child's behaviour when not in a formal situation can unfortunately create tension between parents and professionals. In some cases, this knowledge can be viewed with suspicion, and even interpreted as an indicator of FII. Establishing trust in every encounter is important, as the impact of negative experiences between professionals and parents can accumulate, leading to greater distress, lack of trust (Boshoff et al., 2018; Jackson et al., 2020) and eventually the possibility of CPTSD (Baker P., et al., 2021).

## References:

- Alareeki, A., Shipton, L. and Lashewicz, B., 2022. "They're either afraid or ignorant": Experiences of stigma and blame among fathers raising autistic children. *Research in Autism Spectrum Disorders*, 96, pp.101999. doi:[10.1016/j.rasd.2022.101999](https://doi.org/10.1016/j.rasd.2022.101999)
- Al-Beltagi M., 2021. Autism medical comorbidities. *World Journal of clinical Pediatrics*, 10(3), pp. 15-28. doi:[10.5409/wjcp.v10.i3.15](https://doi.org/10.5409/wjcp.v10.i3.15)
- Autism Act 2009 (c.15)*. [online]: Available at: <https://www.legislation.gov.uk/ukpga/2009/15/contents>
- Autism Act 2009, Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy, 2015*. (Issued by the Department of Health and Social Care in accordance with section 2 of the Act) [online] Available at: <https://www.gov.uk/government/publications/adult-autism-strategy-statutory-guidance>
- Autism Eye, 2014. Parents Accused of Fabricated Illness. *Autism Eye*, [blog] 23 January. Available at: <https://www.autismeye.com/parents-accused-of-fabricated-illness/>
- Autistica, 2019. *Building Happier Healthier Longer Lives: The Autistica Action Briefings*. [online]: Autistica. Available at: <https://www.autistica.org.uk/news/autism-strategy>
- Baker, J.K., Fenning, R.M., Howland, M.A. and Huynh, D., 2019. Parental criticism and behavior problems in children with autism spectrum disorder. *Autism*, 23(5), pp.1249-1261. doi:[10.1177/1362361318804190](https://doi.org/10.1177/1362361318804190)
- Baker, P., Cooper, V., Tsang, W., Garnett, I. and Blackman, N., 2021. A survey of complex trauma in families who have children and adults who have a learning disability and/or autism. *Advances in Mental Health and Intellectual Disabilities*, 15(5), pp.222-239. doi:10.1108/AMHID-07-2021-0032
- Barnes, C. and Mercer, G., 2003. *Disability*. Cambridge, UK: Polity Press.
- Bass, C. and Glaser, D., 2014. Early recognition and management of fabricated or induced illness in children. *The Lancet*, 383(9926), pp.1412-1421. doi:10.1016/S0140-6736(13)62183-2
- Bettelheim, B., 1967. *Empty fortress*. New York: The Free Press, Simon and Schuster.
- Bilson, A., ca.2021. Response to RCPCH draft guidance on FII. *Bilson*. [blog] Available at: <https://bilson.org.uk/home/response-on-fii/>
- Boshoff, K., Gibbs, D., Phillips, R.L., Wiles, L. and Porter, L., 2018. Parents' voices: "Our process of advocating for our child with autism." A meta-synthesis of parents' perspectives. *Child: Care, Health and Development*. 44(1), pp.147-160. doi:[10.1111/cch.12504](https://doi.org/10.1111/cch.12504)
- Bottema-Beutel, K., Kapp, S.K., Lester, J.N., Sasson, N.J., Hand, B.N., 2021. Avoiding Ableist Language: Suggestions for Autism Researchers. *National Library of Medicine*, 3(1), pp.18-29. doi:[10.1089/aut.2020.0014](https://doi.org/10.1089/aut.2020.0014)
- Broomhead, K., 2013. Blame, guilt and the need for 'labels'; insights from parents of children with special educational needs and educational practitioners. *British Journal of Special Education*, 40(1), pp.14-21. doi:[10.1111/1467-8578.12012](https://doi.org/10.1111/1467-8578.12012)

- Brugha, T. S., McManus, S., Bankart, J., Scott, F., Purdon, S., Smith, J., Bebbington, P., Jenkins, R., & Meltzer, H., 2011. Epidemiology of autism spectrum disorders in adults in the community in England. *Archives of General Psychiatry*, 68(5), pp.459–465. doi:[10.1001/archgenpsychiatry.2011.38](https://doi.org/10.1001/archgenpsychiatry.2011.38)
- Care Act 2014 (c.23) [online] Available at: <https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>
- The Care and Support (Assessment) Regulations 2014*. 2014 SI 2014/2827. [online] Available at: <https://www.legislation.gov.uk/uksi/2014/2827/regulation/5/made>
- Care Quality Commission, 2022a. *Who I am matters – Experiences of being in hospital for people with a learning disability and autistic people*. [online] Available at: <https://www.cqc.org.uk/publication/experiences-being-hospital-people-learning-disability-and-autistic-people/report>
- Care Quality Commission, 2022b. *Right support, right care, right culture: How CQC regulates providers supporting autistic people and people with a learning disability*. [online]: Care Quality Commission. Available at: <https://www.cqc.org.uk/guidance-providers/autistic-people-learning-disability/right-support-right-care-right-culture>
- Carter, J., Moon, T. and Harrison, T., 2020. It's definitely not autism it's.... *Luke Clements*, [blog] 5 November. Available at: <https://www.lukeclements.co.uk/its-definitely-not-autism-its/>
- Chen, Y., Cheng, T. and Lv, F., 2022. Sense of Parenting Efficacy, Perceived Family Interactions, and Parenting Stress Among Mothers of Children With Autistic Spectrum Disorders. *Frontiers in Psychology*, 13, p.878158. doi:10.3389/fpsyg.2022.878158
- Children and Families Act 2014 (c.6) [online] Available at: <https://www.legislation.gov.uk/ukpga/2014/6/contents>
- Children and Families Act 2014, SEND Code of Practice, 2014*. (Issued by the Department for Education and the Department of Health and Social Care in accordance with part 3 of the Act) [online] Available at <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>
- Clements, L., & Aiello, A. L., 2021. Institutionalising parent carer blame. The Experiences of Families with Disabled Children in Their Interactions with English Local Authority Children's Services Departments. *Cerebra*. University of Leeds.
- Clements, L., & Aiello, A. L., 2022. Challenging Parent Carer Blame: Interim implementation research report 1: Disability and human rights training and guidance for disabled children's assessors. *Cerebra*. University of Leeds.
- Courcy, I. and des Rivières, C., 2017. "From cause to cure": A qualitative study on contemporary forms of mother blaming experienced by mothers of young children with autism spectrum disorder. *Journal of Family Social Work*, 20(3), pp.233-250. doi:[10.1080/10522158.2017.1292184](https://doi.org/10.1080/10522158.2017.1292184)
- Couteur, A.L., 2003. *National autism plan for children (NAPC): Plan for the identification, assessment, diagnosis and access to early interventions for pre-school and primary school age children with autism spectrum disorders (ASD)*. London, UK: The National Autistic Society for NIASA

- Crane, L., Chester, J.W., Goddard, L., Henry, L.A. and Hill, E., 2016. Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*, 20(2), pp.153-162. doi:10.1177/1362361315573636
- Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L.A. and Hill, E.L., 2018. Autism diagnosis in the United Kingdom: Perspectives of autistic adults, parents and professionals. *Journal of autism and developmental disorders*, 48, pp.3761-3772. doi:10.1007/s10803-018-3639-1
- (CASP) Critical Appraisal Skills Programme, 2018. CASP Qualitative Checklist. [online]: Critical Appraisal Skills Programme. Available at: <https://casp-uk.net/casp-tools-checklists/>
- Department for Education, 2023. *Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) Improvement Plan*. [online]: Department of Education. Available at: <https://www.gov.uk/government/publications/send-and-alternative-provision-improvement-plan>
- Department for Education and Department of Health and Social Care, 2021. *National Strategy for Autistic Children, Young People and Adults: 2021 to 2026*. [online]: Department of Education and Department of Health and Social Care. Available at: <https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026>
- Department of Health and Social Care, 2010. *Fulfilling and rewarding lives: the strategy for adults with autism in England*. [online]: Department of Health and Social Care. Available at: <https://webarchive.nationalarchives.gov.uk/ukgwa/20130104203954/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH113369>
- Department of Health and Social Care, 2018. *Think Autism strategy governance refresh*. [online]: Department of Health and Social Care. Available at: <https://www.gov.uk/government/publications/think-autism-strategy-governance-refresh-2018>
- Department of Health and Social Care, 2022. *Building the right support for people with a learning disability and autistic people*. [online]: Department of Health and Social Care. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1092537/Building-the-Right-Support-for-People-with-a-Learning-Disability-and-Autistic-People-Action-Plan-accessible.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1092537/Building-the-Right-Support-for-People-with-a-Learning-Disability-and-Autistic-People-Action-Plan-accessible.pdf)
- Eaton, J., 2017. *A guide to mental health issues in girls and young women on the autism spectrum: Diagnosis, intervention and family support*. London, UK: Jessica Kingsley Publishers.
- Flannery, K.A. and Wisner-Carlson, R., 2020. Autism and education. *Child and Adolescent Psychiatric Clinics*, 29(2), pp.319-343. doi:10.1016/j.chc.2019.12.005
- Gray-Hammond, D. and Adkin, T., 2022. Creating Autistic Suffering: Fabricated or Induced Illness, state sanctioned bullying. *Emergent Divergence*, [blog] 25 June. Available at: <https://emergentdivergence.com/2022/01/25/creating-autistic-suffering-fabricated-or-induced-illness-state-sanctioned-bullying/>



- Gill, J. and Liamputtong, P., 2013. Walk a mile in my shoes: Life as a mother of a child with Asperger's Syndrome. *Qualitative Social Work*, 12(1), pp.41-56. doi:[10.1177/1473325011415565](https://doi.org/10.1177/1473325011415565)
- GOV.UK, 2023. *Special educational needs in England: Academic Year 2022/23*. [online] Available at: [https://explore-education-statistics.service.gov.uk/find-statistics/special-educational-needs-in-england?fbclid=IwAR2oIOn1VCNZM1D8Iz2E6wR8e\\_MJ8nFWSmo5gVS1ioKz1VqKIY-ZpzhTUco](https://explore-education-statistics.service.gov.uk/find-statistics/special-educational-needs-in-england?fbclid=IwAR2oIOn1VCNZM1D8Iz2E6wR8e_MJ8nFWSmo5gVS1ioKz1VqKIY-ZpzhTUco)
- Gullon-Scott, F. and Long, C., 2022. FII and perplexing presentations: What is the evidence base for and against current guidelines, and what are the implications for social services?. *British Journal of Social Work*, 52(7), pp.4040-4056. doi:10.1093/bjsw/bcac037
- Happé, F. and Frith, U., 2020. Annual Research Review: Looking back to look forward—changes in the concept of autism and implications for future research. *Journal of Child Psychology and Psychiatry*, 61(3), pp.218-232. doi:10.1111/jcpp.13176
- Havdahl, A., Niarchou, M., Starnawska, A., Uddin, M., van der Merwe, C. and Warriar, V., 2021. Genetic contributions to autism spectrum disorder. *Psychological medicine*, 51(13), pp.2260-2273. doi:10.1017/S0033291721000192
- Higgins, J.P.T., Thomas, J., Chandler, J., Cumpston, M., Li, T., Page, M.J., Welch, V. A. (eds.) (2019) *Cochrane Handbook for Systematic Reviews of interventions*. 2nd ed. Chichester, UK: John Wiley and Sons.
- Hingley-Jones, H., 2005. An exploration of the issues raised by living with a child with autistic spectrum disorder and a professional's attempt to move beyond pity and blame. *Journal of Social Work Practice*, 19(2), pp.115-129. doi:[10.1080/02650530500143677](https://doi.org/10.1080/02650530500143677)
- Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S., 2016. Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*, 208(3), pp.232-238. doi:10.1192/bjp.bp.114.160192
- House of Commons Education Committee, 2019. *Special educational needs and disabilities, First Report of Session 2019*. [online]: House of Commons. Available at: <https://committees.parliament.uk/work/2311/special-educational-needs-and-disabilities-inquiry/publications/reports-responses/>
- Jackson, L., Keville, S. and Ludlow, A.K., 2020. Mothers' experiences of accessing mental health care for their child with an autism spectrum disorder. *Journal of Child and Family Studies*, 29, pp.534-545. doi: 10.1007/s10826-019-01662-8
- Jayanetti, C., 2022. *Autistic children wait up to five years for an NHS appointment*. [online]: The Guardian. Available at <https://www.theguardian.com/society/2022/apr/02/children-with-autism-wait-up-to-five-years-for-an-nhs-appointment>
- Kanner, L., 1943. Autistic disturbances of affective contact. *Nervous child*, 2(3), pp.217-250.
- Keating, C.T., Hickman, L., Leung, J., Monk, R., Montgomery, A., Heath, H. and Sowden, S., 2023. Autism-related language preferences of English-speaking individuals across the globe: A mixed methods investigation. *Autism Research*, 16(2), pp.406-428. doi:10.1002/aur.2864



- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C. and Pellicano, E., 2016. Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), pp.442-462. doi:10.1177/1362361315588200
- Kingston, A.K., 2007. *Mothering special needs: A Different Maternal Journey*. London, UK: Jessica Kingsley Publishers.
- Lai, M.C., Lombardo, M., Baron-Cohen, S., 2014. Autism. *The Lancet*, 383(9920) pp. 896-910. doi:10.1016/S0140-6736(13)61539-1
- Lai, M. C., Kasse, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & Ameis, S. H., 2019. Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *The Lancet Psychiatry*. 6(10), 819–829. doi:10.1016/S2215-0366(19)30289-5
- Levac, D., Colquhoun, H. and O'Brien, K.K., 2010. Scoping studies: advancing the methodology. *Implementation science*, 5, pp.1-9. doi:10.1186/1748-5908-5-69
- Long, C., Eaton, J., Russell, S., Gullon-Scott, F. and Bilson, A., May 2022. *Fabricated or Induced Illness and Perplexing Presentations: Abbreviated Practice Guide for Social Work Practitioners*. Birmingham: British Association of Social Workers, BASW.
- Loomes, R., Hull, L., & Mandy, W. P. L., 2017. 'What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis'. *Journal of the American Academy of Child & Adolescent Psychiatry*, 56(6), pp. 466-474. doi:10.1016/j.jaac.2017.03.013
- Mandy, W. and Lai, M.C., 2017. Towards sex-and gender-informed autism research. *Autism*, 21(6), pp.643-645. doi:10.1177/136236131770690
- Mitra, B., 2022. It's not Autism. It's Your Parenting. An Autoethnographic Exploration of the Relationships Between Professionals and Parents of an Autistic Child in the UK. *OUHGT: The journal of autistic culture*, 3(2), p.6. doi:10.9707/2833-1508.1091
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G. and PRISMA Group\*, 2009. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Annals of internal medicine*, 151(4), pp.264-269. doi:10.7326/0003-4819-151-4-200908180-00135
- National Autistic Society, 2023a. *What is autism?* [online] Available at: <https://www.autism.org.uk/advice-and-guidance/what-is-autism>
- National Autistic Society, 2023b. *Demand avoidance (sometimes known as 'PDA')* [online] Available at: <https://www.autism.org.uk/advice-and-guidance/topics/behaviour/demand-avoidance>
- National Institute for Clinical Excellence, 2013. *Autism spectrum disorder in under 19s: support and management*. London: NICE
- Neely-Barnes, S.L., Hall, H.R., Roberts, R.J. and Graff, J.C., 2011. Parenting a child with an autism spectrum disorder: Public perceptions and parental conceptualizations. *Journal of Family Social Work*, 14(3), pp.208-225. doi:10.1080/10522158.2011.571539
- NHS England, 2017. *Transforming Care: service model specification*. [online] NHS England. Available at: <https://www.england.nhs.uk/publication/transforming-care-service-model-specification-january-2017/>

- NHS England, 2019. *The NHS Long Term Plan, Chapter 3 Learning disability and autism*. [online]: NHS England. Available at <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>
- NHS England, 2021. *Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) policy 2021*. [online]: NHS England. Available at <https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf>
- NHS England, 2023. *Autism Waiting Time Statistics; Autism Statistics July 2022 to June 2023*. [online]: NHS England. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/autism-statistics/july-2022-to-june-2023#resources>
- Oliver, M., 2013. The Social Model of Disability: Thirty Years on. *Disability & Society*, 28(7), pp.1024–1026. doi:10.1080/09687599.2013.818773
- Petticrew, M., & Roberts, H. (2008). *Systematic reviews in the social sciences: A practical guide*. John Wiley & Sons.
- Ratto, A. B., Kenworthy, L., Yerys, B. E., Bascom, J., Wieckowski, A. T., White, S. W., Wallace, G. L., Pugliese, C., Schultz, R. T., Ollendick, T. H., Scarpa, A., Seese, S., Register-Brown, K., Martin, A., & Anthony, L. G., 2018. What About the Girls? Sex-Based Differences in Autistic Traits and Adaptive Skills. *Journal of Autism and Developmental Disorders*, 48(5), pp.1698–1711. doi:10.1007/s10803-017-3413-9
- Royal College of Paediatrics and Child Health, 2021. *Perplexing Presentations (PP) / Fabricated or Induced Illness (FII) in Children RCPCH guidance*. [online]: Royal College of Paediatrics and Child Health. Available at <https://childprotection.rcpch.ac.uk/resources/perplexing-presentations-and-fii/>
- Rees, J., 2017. 'Parents 'blamed' for children with autism's behaviour'. *BBC*. [online]: Available at <https://www.bbc.co.uk/news/uk-wales-40717652>
- Robinson, C.A., York, K., Rothenberg, A. and Bissell, L.J., 2015. Parenting a child with Asperger's syndrome: a balancing act. *Journal of Child and Family Studies*, 24, pp.2310-2321. doi:10.1007/s10826-014-0034-1
- Rogers, C.L., Goddard, L., Hill, E.L., Henry, L.A. and Crane, L., 2016. Experiences of diagnosing autism spectrum disorder: A survey of professionals in the United Kingdom. *Autism*, 20(7), pp.820-831. doi:10.1177/1362361315611109
- Roman-Urrestarazu, A., van Kessel, R., Allison, C., Matthews, F.E., Brayne, C. and Baron-Cohen, S., 2021. Association of race/ethnicity and social di:10.1001/jamapediatrics.2021.0054
- Rosen, N.E., Lord, C. and Volkmar, F.R., 2021. The diagnosis of autism: from Kanner to DSM-III to DSM-5 and beyond. *Journal of autism and developmental disorders*, 51, pp.4253-4270. doi:10.1007/s10803-021-04904-1
- Rosenblum-Fishman, S.D., 2013. *Maternal self-efficacy and perceived stigma among mothers of children with ASD, ADHD, and typically developing children*. PhD. University of Massachusetts Boston
- Running, A. and Jata-Hall, D., 2023. *Parental Blame and the PDA Profile of Autism*. [online]: Available at: <https://www.pdasociety.org.uk/resources/parental-blame-and-the-pda-profile-of-autism/>

- Shakespeare, T., 2006. The Social Model of Disability, in L.J. Davis (ed.) *The Disability Studies Reader*. 2nd edn. Abingdon, Oxon: Routledge, pp. 197–204.
- Smalley, S.L., Asarnow, R.F. and Spence, M.A., 1988. Autism and genetics: A decade of research. *Archives of general psychiatry*, 45(10), pp.953-961. doi:10.1001/archpsyc.1988.01800340081013
- Special Educational Needs and Disability Regulations 2014*. 2014 SI 2014/1530. [online] Available at: <https://www.legislation.gov.uk/uksi/2014/1530/contents/made>
- Wadlow, C., 2019. FII – When Professionals Fabricate the Truth.... *Sunshine Support*, [blog] May. Available at: <https://sunshine-support.org/fii-when-professionals-fabricate-the-truth/>
- Walker-Kennedy, S., 1988. Autism from a Freudian and a Kleinian point of view. *The Journal of the Melanie Klein Society*, 6(1), pp.35-57.
- Waltz, M.M., 2015. Mothers and autism: the evolution of a discourse of blame. *AMA Journal of Ethics*, 17(4), pp.353-358. doi:10.1001/journalofethics.2015.17.4.mhst1-1504
- Ying, K.O., Browne, G., Hutchinson, M., Cashin, A., Binh, B.U., 2012. Autism in Vietnam: The Case for the Development and Evaluation of an Information Book to be Distributed at the Time of Diagnosis, *Issues in Mental Health Nursing*, 33(5), pp. 288-292, DOI: 10.3109/01612840.2011.653039

## Appendices

### Overview of UK Policies and Service Provision

#### 1. Legislation

The Health, Education and Social Care policy context for autism has changed significantly over the last 20 years with an increased recognition of autism. Several policy developments seek to improve the lives of autistic people and their families. The most relevant of these policies are listed below.

#### **The National Strategy for Autistic Children, Young People and Adults: 2021 to 2026** (Department for Education, Department of Health and Social Care, 2021)

This is the UK governments most ambitious policy to date in relation to autistic people. It places a statutory duty on local authorities to work in partnership with the NHS, the voluntary sector, and autistic people to implement actions about services for autistic people. The key priorities from this strategy are (Department of Education, Department of Health and Social Care 2021, p.10):

- *“Improving understanding and acceptance of autism within society*
- *Improving autistic children and young people’s access to education, and supporting positive transitions into adulthood*
- *Supporting more autistic people into employment*
- *Tackling health and care inequalities for autistic people*
- *Building the right support in the community and supporting people in inpatient care*
- *Improving support within the criminal and youth justice systems”*

#### **Special Education Needs and Disability Code of Practice: 0 to 25 years** (Children and Families Act, 2014)

This provides statutory guidance in relation to children and young people aged 0-25 years.

#### **Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) Improvement Plan** (Department for Education, 2023)

Published in March 2023, this publication sets out the Governments plans for improving the outcomes for children and young people who access SEND services and/or Alternative Provision. New National Standards are aimed at making mainstream provision more accessible, which will reduce the number of children requiring an Education Health and Care Plan.

Other key legislation and policy documents which show an increased attention on this topic over the last two decades, include:

- *National Autism Plan for Children* (Couteur, 2003)
- *The Autism Act 2009*
- *National Autism Strategy ‘Fulfilling and Rewarding Lives’* (Department of Health and Social Care, 2010)
- *Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy* (Department of Health and Social Care, 2015)
- *Think Autism Strategy Governance Refresh* (Department of Health and Social Care, 2018).

## 2. Health Care Services

Autistic people experience significant health inequalities when compared to non-autistic people (Lai, et al, 2019; Al-Beltagi, 2021). The Autistica Action Briefings (Autistica, 2019) identify that Autistic people in the UK experience some of the greatest social and health inequalities, compared to non-autistic people. They are up to three times more likely to experience mental health anxiety issues, they have some the lowest employment opportunities (only 3 in 10 are in employment) and poorer quality of life outcomes compared to non-autistic people. They have significantly higher premature mortality rates, dying on average 16 years younger than the general population, with 66% contemplating suicide and 35% reporting a suicide attempt. Suicide is a leading cause of early death for autistic people with autistic adults with no additional learning disability being over 9 times more likely to commit suicide than the general population and autistic children experiencing suicidal thoughts 28 times more compared to children in the general population.

The Learning Disabilities Mortality Review (LeDeR) Programme (NHS England, 2021) reviews all deaths of adults and children with a learning disability, and from 2021 was extended to investigate the deaths of autistic adults and children. It seeks to understand people's lived experience and the issues that contributed to their death. The programme was established to support local areas to learn from those deaths and take forward that knowledge and understanding into service improvement initiatives. As yet they have not reported specifically on the deaths of autistic people, however early LeDeR findings echo reports regarding high suicide rates for people who are autistic.

A lack of training and understanding of special needs and neurodivergence means adequate support is not always available for autistic people in a hospital setting (Care Quality Commission 2022a). This sometimes leads to autistic people being admitted to inpatient care during crisis situations due to being unable to access care in a community health care setting before crisis intervention was needed. The National Autistic Society (2023a) found that 41% of autistic patients admitted into hospital did not need to be there as their needs could have been met in the community. They also found that of those admitted to hospital, 57% of autistic patients were taken to out of area hospitals away from their families, homes, and familiarity. This highlights the importance of increased training within health services to improve the services available and reduce unnecessary admissions to hospital, in addition to keeping individuals close to home.

Current healthcare revisions are focussed on improving the pathway for autistic people in crisis who have become inpatients, through national programmes such as the Transforming Care Programme (NHS England, 2017). This programme aims to reduce the number of autistic and/or learning disabled people who display behaviours that others may find challenging and have been, or are at risk of being, admitted to a specialist hospital. The Transforming Care Programme failed to reach its 2020 target for a 35% reduction in the number of in-patients with learning disability and/or autism to be living in the community, and the current target is for a reduction of between 35-50% by 2024 (Care Quality Commission, 2022b). Policies such as Building the Right Support for People with a Learning Disability and Autistic People (Department of Health and Social Care, 2022) and the NHS Long Term Plan – Learning Disability and Autism (NHS England, 2019) are an attempt to address this failure and meet the ambitions of the TCP.

### 3. Social Care Services

Social care provision for autistic people is fraught with challenges for both service users and service providers. Although the Care Act 2014, updated in 2022, recognises and strengthens the rights of autistic people and their family carers by promoting fairer, more personalised care, most local authorities only provide services to people whose needs meet the eligibility criteria.

Local Authorities retain a duty under the Care Act 2014 to promote wellbeing through signposting to appropriate services in the community. Regulation 5 of the Care and Support (Assessment) Regulations 2014 says that local authorities are required to ensure a person carrying out a social care needs assessment has the skills, knowledge, and competence to carry out the assessment in question and is appropriately trained. Local Authorities must therefore ensure assessors carrying out assessments of autistic people have the skills, knowledge, competence, and training to carry out such assessments.

### 4. Education Services

The Children's and Families Act 2014, supported by The Special Educational Needs and Disability Regulations 2014 was introduced with the aim of improving services and outcomes for vulnerable children and young people, which includes children with special educational needs and disabilities. Part 3 of the Act requires Health, Education and Social Care agencies to work together, and places a duty on Local Authorities to identify children who may have SEND and provide an assessment of a child's needs when requested by the child, their parent or school. Children and young people with special educational needs and/or disabilities (SEND), whose needs cannot be met by the existing SEN provision in their school can request an Education, Health and Care Plan (EHCP) assessment. As of January 2022, 103,4000 (31.3%) of completed EHCP plans had autism listed as the primary relevant issue, making autism the most common type of need listed on EHCPs in the UK (GOV.UK 2023).

The House of Commons Education Select Committee in 2019 (p.3) found that the ambitions of the Childrens and Families Act 2014 had not been realised. *“Let down by failures of implementation, the 2014 reforms have resulted in confusion and at times unlawful practice, bureaucratic nightmares, buck-passing and a lack of accountability, strained resources and adversarial experiences, and ultimately dashed the hopes of many”.*