# research in practice





# Working with Autistic parents: An introduction to autism

NATIONAL CHILDREN'S BUREAU

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# About this briefing

This frontline briefing is intended for child and family social care practitioners and other professionals, such as occupational therapists, who work directly with Autistic parents or carers and their families. Additionally, it serves as a valuable resource for senior managers, aiding decision-making and enhancing practices that support their social care workforce.

This briefing introduces autism as it relates to practice with Autistic parents. It explores the necessity and responsibility for all social care practitioners to work relationally and inclusively with Autistic parents and their families. This briefing outlines a neuroinclusive approach to practice rooted in the values of the neurodiversity paradigm and social justice models.

# How we developed this briefing

This resource has been developed in collaboration with Autistic parents and child and family practitioners across England and reflects the realities and experiences of families and providers. It includes insights from focus groups, including the voices of Autistic parents who have experienced involvement with social care services.

The author is an Autistic parent, registered social worker and researcher.

With grateful thanks to the Autistic parents who helped shape and contribute to this resource: Helen Butterfield, Kathryn Curtis, Naomi Moksha and Emma Whittaker.

# A note on language and terminology

**Identity-first:** Respecting author preference, the term 'Autistic' is capitalised to signify Autistic identity, while 'autism' is presented in lowercase to denote a diagnostic category.

These resources adopt identity-first language. This means that expressions such as 'I am Autistic' or 'Autistic parent' are preferred to phrases such as 'I have autism' or 'a parent with autism'. This aligns with the majority preference expressed within Autistic and many other neurodivergent communities (see Botha et al., 2021). However, individual preferences do vary. It is important always to ask Autistic individuals how they wish to be identified when being referred to (Keating et al., 2023).

Autistic parents and carers: Autistic parents and carers are individuals who are Autistic and have a caring role for a child or children. Throughout these resources, when we use the term 'Autistic parent' we are referring to an Autistic person who is in a caring role for a child. Autistic parent is therefore intended as a collective term that can include birth parents, members of blended families, stepparents, family carers, foster carers or adoptive parents.

The term Autistic parents is distinct from the concept of 'autism parenting', which typically refers to non-autistic parents raising Autistic children. Unlike those parents, Autistic parents experience the world through an Autistic lens, which shapes their parenting in unique ways. However, Autistic parents frequently care for an Autistic child.

# How to use this briefing

Throughout this briefing, you will see different coloured text boxes or symbols. These sections aim to inform and expand your understanding as you progress.



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# Key messages

- > Autism: Autism is a lifelong neurodevelopmental difference that influences how a person experiences, processes and responds to the world. These differences may manifest in areas such as communication, cognitive processing, sensory processing and behaviour.
- > Not a uniform experience: Autism is not a uniform experience. Autistic people are different to each other, and each Autistic person will have their own unique set of strengths and challenges. Avoid using 'low functioning' and 'high functioning' labels because they fail to reflect the complexity of autism.
- > **Difference not deficit:** Autistic differences are not synonymous with deficit. This doesn't mean Autistic people cannot and do not experience impairments but how we approach these needs to be from a strengths-based perspective. When individual strengths and needs are recognised and supported, Autistic differences can be seen as part of the natural diversity of human experience. Societal attitudes and institutional systems, including services, remain heavily and negatively influenced by deficit models.
- > Practitioners' knowledge and understanding: Research suggests that knowledge and understanding of autism among social care practitioners is limited. Currently, there is little focus on Autistic parents in formal social work education and minimal integration of Autistic perspectives into social work theory.
- > Myths and misunderstanding: Limited public and professional understanding of autism are marked by stereotyping and some persistent myths. One misconception is that autism is a learning disability. Autism is not a learning disability, although autism and learning disabilities can co-occur. A particularly harmful myth is that Autistic people lack empathy.
- > 'Insider' vs 'outsider' perspectives: When working with Autistic parents, it is important for practitioners to understand the distinction between 'outsider' and 'insider' perspectives. For many Autistic people the diagnostic framework is an 'outsider' perspective that does not reflect their lived experience or their Autistic identity.
- > Strengths in Autistic parenting: Being Autistic does not prevent someone being an excellent parent. Like other parents, Autistic parents care for their children with love, dedication and skill. Many Autistic parents see some of their parenting strengths as related directly to their autism. For example, some point to their love of learning as enabling them to commit to parenting as a 'focused interest'; others highlight their preference for routine as beneficial for their children.
- > Challenges in Autistic parenting: Autistic parents can experience a range of challenges. These can include sensory sensitivities (e.g. difficulties with breastfeeding, and distress generated by loud play or crying) and the danger of Autistic 'burnout'. Autistic parents also commonly experience stigma and harm if practice is based on assumptions or services are deficit focused and do not operate in a neuroinclusive way.
- > Conceptual frameworks: Key frameworks such as the <u>neurodiversity paradigm</u>, the <u>double</u> <u>empathy problem</u>, and <u>Diversity in Social Intelligence</u> can help practitioners understand how Autistic parents engage with their children and the world around them. They offer valuable insight for how to support Autistic parents respectfully and more effectively.
- > Intersectionality: Autistic parents can be of any gender, sexuality, race, ethnicity, culture or socioeconomic status. These intersecting identities can amplify or mitigate their experiences, potentially leading to compounded disadvantage. An intersectional approach is essential to recognise the multiple aspects of parents' identities and then dismantle biases in terms of how Autistic parents are treated so that effective support is provided.
- > Heritability: Given the high heritability of autism, practitioners who are working with an Autistic parent or Autistic child should be alert to the possibility of unidentified needs within the family.

# Introduction

As a profession rooted in social justice, equity and anti-oppressive practice, we must confront an uncomfortable truth: research consistently shows that Autistic parents and their children often experience social care systems as judgmental, exclusionary and sometimes harmful. So, we must ask – why is this happening? And what needs to change – in us, in our practice, in our organisations and in our systems?

This briefing outlines a neuroinclusive practice approach rooted in the values of the <u>neurodiversity</u> <u>paradigm and social justice models</u>. A solid understanding of autism and the lived Autistic experience is crucial to challenge these harmful experiences and promote anti-discriminatory practice.

#### This briefing:

- > Introduces autism as it relates to practice with Autistic parents.
- > Explores the necessity and responsibility for all social care practitioners to work relationally and inclusively with Autistic parents and their families.

Its aim is to assist child and family social care practitioners to deepen their understanding of Autistic parenting within the framework of social care assessment, support and intervention. How can we apply an autism lens when working with Autistic parents? And what does cultural consciousness in practice mean when we're working with Autistic parents and Autistic families?

In this briefing we will look at:

- > Understanding autism as a neurodevelopmental difference, including 'insider' (vs outsider) perspectives and Autistic identity.
- > Strengths associated with Autistic parenting.
- > Challenges associated with Autistic parenting, including stigma and systemic trauma.
- > Conceptual frameworks for supporting neuroinclusive practice with Autistic parents.
- > Autism and intersectionality.

# How confident do practitioners feel about autism?

I think a lot of people say they're aware of autism, but have a very small view, or are using old evidence and not listening to lived experience ... They need to know about ... different ways of being, that being autistic is not something wrong. (Autistic parent)

Research indicates that knowledge and understanding of autism within health and social care professions remains limited and in need of significant development. A recent study involving social workers in adults' services found that practitioners recognised the importance of autism awareness and expressed a clear desire for more training (Heslop & Bushell, 2023). Yet in terms of both formal education and research, there is very little focus on Autistic parents in the field of social care (Blakemore, 2015) and minimal integration of Autistic perspectives into social work theory (Guthrie, 2023). See <u>Additional resources</u> for some training options.

In our practitioner focus group, we asked practitioners to reflect on their understanding of autism and how confident they felt in working with Autistic parents. The word cloud in Figure 1 sets out their responses.



Fig 1: Practitioners' self-reported levels of autism knowledge

# Reflective activity

Take a moment to reflect on your understanding of autism within the context of your social care practice.

Use the questions below to guide a self-assessment of your current knowledge, attitudes, and confidence in working with Autistic parents. Then rate yourself using the provided scale and make a note of your responses.

#### Where do you place your knowledge of autism?

I know nothing a little some knowledge a good amount I know everything

#### Where do you place your confidence in working with Autistic people?

I have no confidence a little fairly confident very confident totally confident



#### Reflective questions

- **1.** What has motivated you to explore Autistic experience?
- 2. What would help you feel more confident about working with Autistic people?

After reading the briefing, return to this exercise and revisit your responses. Reflect not just on how much you know about autism, but on the nature of that knowledge - what shaped it before, and what you've gained since. Even extensive knowledge can be influenced by outdated, deficit-based, or medical-model perspectives. This isn't about assuming your understanding is wrong — it's about continually updating our thinking, listening to Autistic voices, and embracing neurodiversity-informed approaches.

#### A reflective checklist for neuroinclusive practice

Keep this checklist in mind as you read about understanding autism, the theories and how they relate to parenting strengths and challenges.

Return to this checklist to reflect on and develop your practice when supporting Autistic parents.

#### > Strengths-based and person-centred practice

- Am I actively identifying and building on this parent's strengths and wishes?
- Am I viewing the parent as an expert in their own experience and parenting?
- Am I aware of my own (as well as systemic) biases and assumptions around Autistic parenting? Such as when it comes to bonding with and understanding their children.

#### > Contextual understanding

- Do I know, and am I taking fully into account, all the relevant contextual factors in this parent's life including their identity, environment, relationships and social barriers?
- Am I sufficiently adapting my approach to reflect the parent's communication (e.g. expressions of love and concern), sensory and support needs?

#### > Language and framing

- Am I avoiding clinical or deficit-based language in how I talk with and about this parent?
- Am I consistently using respectful, affirming and person-centred language?
- Am I taking steps to minimise demands during assessments and interventions?
- During meetings, do I allow sufficient processing time? And do I always provide clear agendas and predictable transitions?

#### > Identity and culture

- Do I recognise autism as a valid identity, not just a diagnosis?
- Am I aware of the cultural, social and community dimensions of being Autistic?
- Do I support parents' rights to express and live their Autistic identity without pressure to conform to neurotypical norms?
- Do I always recognise Autistic ways of relating as valid and meaningful, and not judge them against neurotypical norms?

# Understanding autism

This section looks at what autism is, focusing on the lived experience of Autistic individuals. It is important that practitioners understand 'insider' perspectives and acknowledge autistic differences as part of the natural diversity of human experience.

#### What is autism?

Autism is a lifelong neurodevelopmental difference that influences how a person experiences, processes and responds to the world. These differences may occur in areas such as:

- > Communication: Autistic people may have different communication preferences and/or needs to non-autistic people. For example, they may use or understand tone of voice, gestures and facial expressions differently. A lot of Autistic people may also use alternative communication methods to speech either permanently or situationally.
- Cognitive processing: For example, Autistic people may process all information, including details, over the bigger picture. Autistic people may also experience processing speeds that relate to the information being processed. For example, an Autistic person may develop hyper-focused attention in a task or interest in a particular subject which may present as a challenge when switching tasks (see 'Monotropism' section). Autistic people (as well as some non-autistic people) can have difficulty in the identification, processing and describing of their emotions. Alexithymia is a clinical term for this.
- > Behaviour: For example, Autistic people may need order and routine (e.g. preferring fixed mealtimes), as it provides a sense of control and predictability. Predictability can lessen sensory overload, and in turn, distress. Autistic distress or trauma may present differently to how it does in non-autistic people and could appear as an intense response to overwhelm ('meltdowns') or withdrawal ('shutdown'). Autistic people may respond to emotions or social expectations differently to the anticipated societal norms.
- > Sensory processing: Sensory differences can significantly impact on an Autistic person's emotional regulation and overall wellbeing. Autistic people may process or interpret internal bodily sensations and cues (e.g. hunger, thirst, nausea, pain, fatigue) differently to non-autistic people. This is our interoception sense. Autistic people may perceive the position and movement of their body (our proprioception sense) differently. Autistic people may also have a relatively heightened or reduced sensitivity to particular sounds, smells, tastes and textures. Such sensitivities may vary at different times and in different situations. See 'Additional resources' section.

The number of adults being diagnosed in the UK with autism has increased, with the biggest increase among females. This could be due to several factors such as increased public awareness, expanded diagnostic criteria and greater understanding of who can be Autistic (Russell et al., 2022). And yet there are significant barriers to adult diagnosis. Evidence suggests these include: social anxiety, fear of not being believed, stigma, mistrust of professionals, language and cultural differences, and that a focus on deficits can make autism assessments too negative a process (ConnectED, 2024).

In thinking about neurodevelopmental traits and characteristics that are common among Autistic individuals, it is important also to acknowledge what autism is not. Unfortunately, limited understanding has contributed to stereotyping and some enduring myths about autism. Some prevailing myths are:





Autism is a learning disability

It isn't, although autism and learning disabilities can co-occur (see 'Co-occurring health conditions or disabilities' section).

Autistic people often lack empathy

A particularly damaging myth (see our later discussion of the <u>double empathy problem</u>). A study found that Autistic adults sometimes reported hyper-empathy (Kimber et al., 2024).

Autism is a male or childhood diagnosis

Autism is a lifelong neuro-developmental difference. Gender bias has influenced how autism has traditionally been framed (Lockington & Gullon-Scott, 2025), leaving women at increased risk of misdiagnosis, late diagnosis or non-diagnosis (see Gender section).





#### To find out more:

Visit this NHS <u>webpage</u> which gives a general overview of autism. It includes a 15-minute video by Autistic people offering their insights into the lived experience of autism.

See Additional resources for more films and websites

# Insider vs outsider perspectives: Understanding the lived experience of autism

#### The diagnostic framework is an outsider perspective

There are differences between an 'outsider' diagnostic understanding of autism and 'insider' lived experience.

Autism diagnosis is based on a set of clinically defined characteristics, identified through behavioural observations which are interpreted by professionals. Yet, the lived experience of being Autistic is far more nuanced. It encompasses a complex interplay of body and mind, and involves elements that may be visible as well as invisible to outside observers.

According to the National Institute for Health and Care Excellence (NICE) guidelines for under 19s, an autism diagnosis should be based on criteria outlined in either the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5-TR), or the International Classification of Diseases, Eleventh Revision (ICD-11). The equivalent NICE guidance for adults does not include reference to the DSM-5-TR or ICD-11. These diagnostic frameworks often emphasise difficulties, such as navigating social norms and behaviours, but they frequently miss the broader picture. Diagnostic criteria traditionally defined autism through a 'triad of impairments' – social communication, social imagination and social interaction (Wing & Gould, 1979). These have more recently been refined (including by the World Health Organization in ICD-11) into a dyad: (i) 'persistent difficulties in social interaction and communication', and (ii) 'the presence of stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests' (NICE, 2012, p. 5).

Recent autism research refutes the medical classifications and argues for a more experiential and strengths-based perspective (e.g. Woods & Estes, 2023).

#### Difference not deficit

Recent research on Autism has challenged the deficit focus of current medical classifications and diagnostic evaluations. Researchers argue for strengths-based measures during diagnosis (e.g. Woods & Estes, 2023).

Increasingly, Autistic individuals and scholars are challenging the deficit-focused perspective (e.g. Kapp et al., 2013). They advocate for a view that acknowledges both the strengths and challenges of Autistic experiences.

When individual strengths are recognised and supported – and when needs are understood and accommodated – these differences can be reframed as part of the natural diversity of human experience.

Nonetheless, societal attitudes and institutional systems remain heavily influenced by deficit models. This often results in barriers that restrict opportunities for Autistic people and negatively impact their quality of life (McConachie et al., 2018).

#### Recognising Autistic identity

I consider autism to be a value neutral, innate part of my identity and do not feel a need to separate myself from it discursively to remind others of my personhood. (Benson, 2023, p. 1447)

Many Autistic people see autism as central to who they are: it is integral to their identity. Dugdale et al. (2021) undertook a study with a small number of Autistic mothers, all of whom were diagnosed after becoming a mother and many of whom had previously been misdiagnosed. Mothers reported that receiving a diagnosis had led to a positive re-processing of their experiences. 'For many, this reduced feeling guilty, increased self-acceptance, and gave an explanation that was felt to fit with their identity.' Mothers were more able to 'accept' being 'different' as not 'wrong'. They reported being given 'permission' or the understanding of themselves to prioritise 'self-care, accept support, or access more appropriate support' (Dugdale et al., 2021, p. 1979).

I now see it [autism] as a difference to be celebrated – I'm proud of my autism now. (Autistic father <u>Jude Morrow</u>)

Autistic parents also experience a number of challenges, which commonly relate to professional attitudes and lack of understanding. Hwang and Heslop (2023, p.279) found that Autistic parents often had to 'renegotiate misunderstandings by professionals.' They felt 'the need to mask their identity as an autistic person' (p. 280). In their systematic review of qualitative literature on the lived experience of Autistic mothers (629 Autistic mothers across 23 primary studies), Lockington and Gullon-Scott (2025) report that almost all participants felt 'othered' by professionals and their practice. They found that 'this occurred most frequently during interactions with health, education and social care professionals' (p. 16).

In her study with Autistic mothers who had experience of parenting-related social work intervention, Benson (2023) reports one mother's description of a social worker's response to her son saying he thought he was Autistic:

What's written on the paperwork is 'we're very concerned that he thinks he's autistic'. As if it's the worst thing in the world to see yourself as autistic. So my perception of social workers and the word 'autism' is that they actually think it's some really bad thing to have, and they've got a really negative opinion on what autism is. And I think that's a really negative thing for our community. (Benson, 2023, p. 1452)

# Reflective activity: Moving towards strengths-based practice

Consider the research and quotes above.

- 1. How have prevailing narratives impacted the way you describe Autistic parents in your writing? Is there anything you would change?
- 2. What's one change you could make to *draw out* the strengths and needs of the Autistic parents you work with?

# Autism is dynamic

In the past, people thought the spectrum was a straight line between 'more' and 'less' autistic. This isn't right. Today we understand the spectrum to mean each autistic person has a unique combination of characteristics.

(National Autistic Society, What is autism?)

Autism can be described as dynamic; an Autistic person's needs can fluctuate depending on context, the environment and demands being made of them. What may appear manageable one day may be less so the next.

Sometimes I can't speak at all. It's fine with people I know. But with new people or stress, especially with judgement ... I can't form words. And then you're judged as being stupid and incapable on top of everything else. (Autistic parent)

While everyone has strengths and challenges, Autistic individuals may show greater variation in their abilities across different tasks (Doyle, 2020). Significant variations in people's abilities or skills are often described as 'spiky profiles'. These variations help illustrate why some Autistic people may need regular support with day-to-day activities, and others may not.



**Spiky skills profiles** Read this resource page by <u>Spectrum Gaming</u> to understand how spiky profiles may relate to Autistic experience.

# Is autism a disability?

Many Autistic people don't see autism as a disability. However, in legal terms it is. The way we conceptualise disability significantly shapes our language, beliefs, behaviours, and ultimately, our professional practice. While not all Autistic individuals identify as disabled, autism is recognised under the *Equality Act 2010*. As such, its legal status – and the societal implications that come with it – cannot be overlooked in social care work.

The Equality Act 2010 places a requirement on public services to anticipate and prevent discrimination against people who are disabled, which includes Autistic people (with or without a learning disability). Many people have support and communication needs that, if left unmet, will put them at a significant disadvantage when trying to navigate institutions such as children's social care or the criminal justice system, making it less likely that a fair, just and appropriate outcome will be achieved.

# Heritability

There is a body of research looking at heritability, genetics and environmental factors associated with autism. Many of these studies are reliant on medical diagnosis and therefore have a deficit focus. This can perpetuate outsider only perspectives of autism and be distressing for some readers.

The main point for practitioners is that given the high heritability of autism (e.g. Sandin et al., 2017), many Autistic children (with or without a diagnosis) are likely to have a neurodivergent parent, many of whom may be undiagnosed. Equally, an Autistic parent may have a neurodivergent child.

Practitioners should be alive to the possibility of undiagnosed neurodivergence in the families they visit, both in terms of understanding how to support them, but also exploring whether they may benefit from adult social care assessment and support.

### Reflection point

In this section we've thought about what autism is and what it isn't. Before moving on consider:

- > What did you already know?
- > Is there anything that you didn't know or that has surprised you?
- > What are you taking away from this section?

# Autistic parenting: strengths and challenges

Being Autistic does not stop someone from being an excellent parent. Like other parents, many Autistic people care for their children with love, dedication and skill. But while Autistic parenting can be effective, the parenting preferences of Autistic parents can sometimes be different to other neurodiverse and neurotypical parents (Dugdale et al., 2021; Hwang & Heslop, 2023). This can contribute to misunderstanding and judgmental attitudes among practitioners and others with limited understanding of autism.

Research into Autistic parenting is relatively limited, but over the past ten years Autistic researchers have offered some important insights into the lived experience of Autistic parenting. In this section, we look at some of the strengths and challenges experienced by Autistic parents.



# Strengths and challenges of Autistic parenting:

Advice and guidance from support organisations, including blogs and articles by Autistic parents themselves, can offer valuable insight into the lived experience of Autistic parenting, including its strengths and challenges. See for example:

- > <u>Becoming an Autistic parent</u> (Autism Awareness Australia, n.d.)
- > The strengths and struggles of being an Autistic parent (Brown, 2025)
- > Autism and parenting Unexpected strengths and challenges (Owen, 2023)
- > Autism and fatherhood: Challenges, triumphs, and strategies for success (NeuroLaunch, 2024)

# Autism, parenting approach and social care bias

We don't hug. But when my child sits in the same room as me or comes up to me and talks at length about something they have found, or have read, I know this is done with love. They have chosen to share something special to them, with me. That is special. Even if it is just being in the same space. Another of my children constantly wants to touch me by tapping, to show their affection and communicate. Sometimes I forget that others don't understand what we are saying to each other, and I need to translate. (Autistic parent)

Autistic parents' approach to parenting may look different to neurotypical parents, at least in some respects.

Hampton et al. (2022) compared perinatal experiences of Autistic and non-autistic mothers of two to three-month-old infants and found, that while there were specific challenges, there were no self-reported differences in measures of parenting anxiety, involvement, nurturance or routine. The Autistic mothers in the study felt they had a good understanding of their baby's needs.

What is the difference between a neurodivergent and a neurotypical parent? Well, nothing. You know, we're still, we're still trying to raise our children. It's just we do things differently. But culturally, people do things differently. (Autistic parent)

Social work sometimes mistakes Autistic parenting approaches as signs of abuse and/or neglect. It is important that practitioners exercise professional curiosity to allow for the possibility that a shared understanding could be reached. It is important to explore the family's perspective and situation to determine whether anything is of actual concern or not.

Without a shared understanding to draw on, there was a tendency to interpret perplexing presentations using a neuronormative lens through which autistic traits were reconfigured as 'suspicious', suggestive of harm or damage. (Benson, 2023, p. 1453).

In their systematic review of qualitative studies with Autistic mothers, <u>Lockington and Gullon-Scott</u> (2025) report that mothers speak about:

- > Being 'policed and pathologized' by professionals who tended to favour a 'one size fits all' approach to parenting (p. 16).
- > How professionals sometimes viewed their Autistic differences and parenting approaches as 'dysfunctional' or 'suspicious' (p. 16).
- > How their interactions with professionals were traumatising and the cause of anxiety.
- > A fear of disclosing their autism due to anticipated stigma from professionals. They felt they would be treated negatively, be questioned due to the 'invisibility' of autism or that autism would be seen as posing risks to their child/ren (p. 17).

Attendance at school can be a particular source of friction between Autistic families and social workers, with conflict between parents' approach and that of schools and social care (Benson, 2023). Social care practitioners can see attendance as 'a meaningful end in itself' even though a school may be contributing to an Autistic child's difficulties. In alignment with Benson's study, Autistic parents told us that professionals appear to have different objectives to them, and that their parental perspectives were persistently dismissed on schooling and other decision-making. Strong, trusting relationships between education settings and families are possible when Autistic parents feel safe and when their knowledge, including Autistic expertise, is valued (Rabba et al., 2024).

Parents - due to hyper-empathy, shared sensory experiences and pattern spotting - are often able to know when their child is becoming dysregulated, entering sensory overload or approaching Autistic burnout, often before professionals can.

(Autistic parent)

Autistic parents can feel understandably frustrated when their strengths are misunderstood or misinterpreted as deficits instead of recognised as assets or valuable differences.

Routines work! Neurotypicals can't cope with change. Did you see how many people freaked out in lockdown and had to panic buy, start new hobbies and buy pets to cope?' (Autistic parent)

# Strengths in Autistic parenting

Autistic parents often see their strengths as a parent as being rooted in their autism. Autism is not a singular or uniform experience, and there is not one 'Autistic parenting style'. Nonetheless, research and lived experiences have identified several strengths common among Autistic parents:

#### > A strong empathic connection with their children:

 Autistic parents often form a profound emotional connection with their children – especially when children feel misunderstood or face social pressure. Their lived experience enables them to empathise deeply with non-conformity or misunderstanding.

# > A strong motivation to research and gather knowledge to develop a deeper understanding of their child's needs:

- In this context, some Autistic parents' sustained focus and attention to detail can be a particular asset. In their study with Autistic mothers, for example, Hwang and Heslop (2023) found that mothers often described parenting as 'a special interest', which led to them researching how best to meet and support their child's needs.

#### > A commitment to prioritising their child and their needs:

- Some Autistic parents may demonstrate commitment and perseverance in overcoming challenges. For example, if we consider challenges in relation to executive functioning such as task initiation and completion, a person may plan for clear transition periods between activities to recognise that transitions can create significant neural demand.
- A preference for structure and routine means Autistic parents can be particularly skilled at developing highly organised and stable family routines and environment.

#### > An ability to recognise concerns in relation to their child:

- For some Autistic parents, a heightened sensitivity and instinctive understanding of their child can make them especially attuned to recognising their child's needs.

(Dugdale et al., 2021; Hwang & Heslop, 2023; Lockington & Gullon-Scott, 2025; Radev et al., 2024; Thom-Jones et al., 2024; Westgate et al., 2024).

These strengths are related to some characteristics and skills commonly associated with autism:

- > attunement
- sensory awareness
- > critical analysis
- > hyperfocus and attention to detail
- > problem-solving
- determination and perseverance.

Interestingly, in Thom-Jones et al., (2024) review of the literature, which identified many strengths and positive aspects of Autistic parenting, they noted that authors of quantitative studies in particular have often reported such findings as 'unexpected':

'This reflects a bias in the underlying assumptions about autistic people and therefore in the focus of research into their parenting experiences' (p. 17).1

<sup>1</sup> In their systematic review of qualitative research on the lived experience of Autistic mothers, Lockington and Gullon-Scott (2025) note that quantitative measure are 'increasingly contested' in autism research; they are often 'designed for Autistic people not with them' and can increase the risk of researcher bias, misinterpretation and inaccurate conclusions. Qualitative methods are recommended 'for and by the autism community' as they 'directly capture Autistic people's voices, their nuanced experiences, and leverage their strengths, leading to individualised understanding'.

# **Reflection points**

> Which practice skills and approaches could you use to identify and build on the strengths of the Autistic parents you work with?

For example, you might use strengths-based interviewing. Open-ended questions which explore abilities, preferences and successes could be useful such as:

- > What are some of the things you feel proud of as a parent?
- > What do you enjoy doing with your child?

# Challenges in Autistic parenting

Although Autistic parents have many strengths, they can also face a range of specific challenges when parenting. Practitioners need to understand the significance of these challenges when assessing and providing support to Autistic parents and their children. Here, we discuss some of the challenges that Autistic parents may face.

#### Sensory sensitivities

Sensory sensitivities are a prominent and often challenging aspect of parenthood for many Autistic parents. These can range from discomfort during breastfeeding (e.g. overwhelm from the physical sensations of nursing) to pain and distress caused by auditory stimuli like crying or loud play (Grant et al., 2022; McDonnell & DeLucia, 2021; Samuel et al., 2022; Stuart & Kitson-Reynolds, 2024). Interestingly, Grant et al. (2024) found that Autistic women evidenced more perseverance with breastfeeding than other parents.

#### Communicating needs and wishes

We do have... resting bitch faces sometimes. That is quite a common theme with Autistic individuals. I think they [practitioners] should be aware that they may assume that we are coming across as aggressive or angry, but we're just trying to make our voice heard. That's one thing that I've struggled with. Apparently, I'm really aggressive and, I'm like, but I'm not. You're not listening to me. (Autistic parent)

Being able to convey to others how you are feeling or what you need and why, is a struggle commonly experienced by Autistic people. This can be compounded by misunderstandings and different communication needs. Autistic parents may have this experience with social workers (Benson, 2023), healthcare professionals (Pohl et al., 2020) or other parents (Libster et al., 2024). Autistic parents relate their frustration and distress at not being believed or having their knowledge misunderstood as leading to:

- > missed opportunities for support and the provision of inappropriate support (Benson, 2023)
- > child protection proceedings (Benson, 2023; Gullon-Scott & Long, 2022)
- > wrongful child removal, such as in parent <u>Esther Whitney's case</u> (Ferguson & Hollingsworth, 2024; UK Parliament, 2024).

#### Managing energy demands

Autistic people can expend considerable energy processing sensory stimuli and managing daily demands. Parenting involves many functions and requires constant multi-tasking and rapid responses, which can challenge different processing speeds and capacity, especially when children's needs or other expectations arise unexpectedly (Grove et al., 2023).

In our focus group, Autistic parents emphasised the importance of recognising when sensory or physical overwhelm depletes their energy reserves. Social care practitioners should be mindful of this and support families to find balance to minimise distress. For example, predictability and control were important considerations for Autistic mothers during labour and birth (Westgate et al., 2024).

#### Competing needs

My child will not be with anyone else since a negative short break experience. So we have someone who we go for a walk with as my kid can't take people in their space or the house [...] For me, another adult being around, even for going for a walk, is big as I don't have to be on hyper alert. (Autistic parent)

Parents in our focus group spoke about the challenge of managing the competing needs of their child and themselves. This theme has also been identified in research (Thom-Jones et al., 2024). The needs of child and parent can differ significantly even when both are Autistic. This can result in overwhelm and distress for Autistic parents, while also undermining their confidence that they are parenting in the best way for their family.

#### Parenting Autistic children

Low-arousal parenting focuses on creating a calm and predictable environment, minimising stress and anxiety (e.g. creating quiet environments and establishing routines). Low-demand parenting is a low-arousal approach for children with pathological demand avoidance (PDA – see further reading box below). Autistic parents recognise the value of reducing the number of demands placed on a child and often incorporate that into their parenting approach. However, this often comes at the expense of their own needs, potentially leading to burnout without appropriate support.





**Pathological demand avoidance (PDA)** is considered by some as a form of autism and others as a neurodivergence in its own right. There is <u>debate about the validity of the term</u>, however. PDA has also been framed more positively (by <u>Tomlin Wilding</u>) as 'pervasive drive for autonomy'.

Practitioners should be mindful that some Autistic parents may experience significant 'demand avoidance' or a pervasive drive for autonomy. Although research is limited, the National Autistic Society highlights some <u>support strategies</u> that parents or practitioners have found helpful.

Kristy Forbes's blog and podcast offers free, accessible and helpful information on PDA.



Read <u>Low-demand parenting and why it's important</u> by Dr Megan Neff, an Autistic-ADHD psychologist and parent of an Autistic daughter. She explores what is meant by low-demand parenting and how it can support a child with pathological demand avoidance (PDA), where autonomy equates to feeling safe.



Intersectionality and Low Demand Parenting In this American podcast, Amanda Diekman and Dr Morénike Giwa Onaiwu explore intersectionality and low demand parenting (25 minutes).

#### Masking

Autistic people may use masking as a coping strategy and safety mechanism. Masking means a person alters their behaviour in different ways (consciously or subconsciously) when interacting with others to present as is expected of them (Pearson & Rose, 2021). Masking is exhausting. When masking becomes a prolonged activity, it can lead to emotional, physical and mental distress. Figure 2 shows what masking might involve and illustrates just why it is so exhausting.

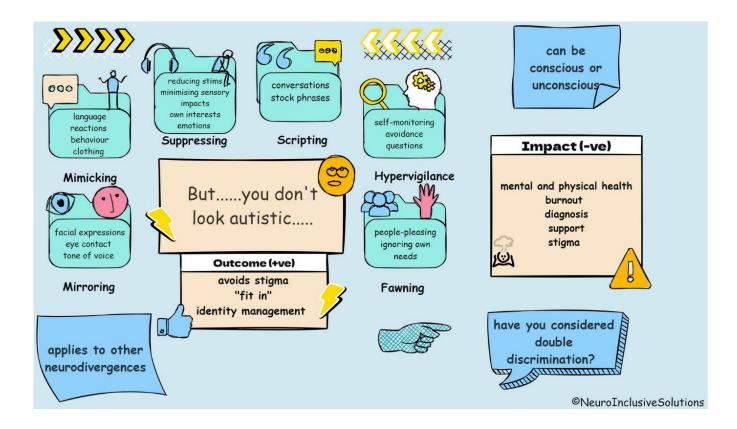


Figure 2: Autistic masking (Oneuroinclusive solutions)



Audio description of the Masking infographics

# Reflection point

What could you change in your practice to enable an Autistic parent to feel safe or included?

#### **Autistic burnout**

Autistic burnout is distinct from occupational burnout or general stress. It is common, recurring and will 'directly and indirectly, impact autistic people's functioning, mental health, quality of life, and well-being' (Mantzalas et al., 2022, p. 53). It stems from prolonged exposure to daily demands without adequate support or resources, can persist for months or even years and is often difficult to recover from (Raymaker et al., 2020).

According to a study analysing more than 1,100 posts on online platforms (by 683 Autistic people), the need to mask was the most frequently cited cause. These burnout cycles were often triggered by others' poor awareness and acceptance of autism (especially by professionals), stigma and discrimination (Mantzalas et al., 2022).

Social care practice can contribute to these cycles; therefore, it is crucial that support is provided in a safe, effective and inclusive manner. When working with a parent experiencing Autistic burnout, adopting a pace that suits them and a trauma-responsive approach may help elicit new strategies, supports and life changes that benefit both the parent and their family.



Read Zoe Williams's account of <u>Autistic burnout in parenthood</u>, published through Autistic Parents UK.

#### Stigma

Another well-documented experience is that the stigma which arises from being misunderstood can adversely impact Autistic people's sense of belonging in communities and cultures (e.g. Ng & Ng, 2022; Sher et al., 2022). For example, stigma can lead to exclusion from support networks, church or parenting groups, and communities (Libster et al., 2024).

When seeking support, Autistic parents may also face stigma from agencies and professionals due to inaccurate understanding or perception of behaviour. This erodes trust in professionals and services, and results in an unwillingness to seek support for fear of discrimination or invalidation (Benson, 2023; Pohl et al., 2020).

#### **Trauma**

Trauma does not cause autism, but being Autistic does increase the likelihood of experiencing trauma. Autistic people face increased risk of experiencing homelessness (Osborn & Young, 2022) and resorting to coping mechanisms such as substance use (Haasbroek & Morojele, 2022). The risk is amplified for those with intersecting marginalised identities. For instance, Autistic people who are women or gender diverse are at increased risk of sexual harm (Cazalis et al., 2022) and adverse mental health outcomes (George & Stokes, 2018). (See 'Intersectionality' section).

Autistic parents may also be grappling with a lifetime's worth of unmet needs due to being undiagnosed or misdiagnosed, excluded or abused (Grove et al., 2023; Smit & Hopper, 2023). Research indicates that these experiences are prevalent and tend to accumulate over time, particularly among those who receive a late diagnosis in adulthood and/or who identify as gender diverse (McQuaid et al., 2024; Tien et al., 2025).

This highlights the importance of trauma-informed practice and care.

#### Systemic trauma

I think, that they [social workers] need to respect the fact that unexpected visits can be a trigger, and that our homes are our safe space. At the time I didn't want her in my safe space, and unfortunately, I got penalised for that. I think, with regards to the visits, making sure that they recognise that for people with autism, unexpected visits can throw them off. It's not that we're trying to hide anything, but this is our safe space. (Autistic parent)

Systemic trauma refers to 'contextual features of environments and institutions that give rise to trauma, maintain it, and impact post-traumatic responses' (Goldsmith et al., 2014, p. 117). Identities are socially constructed, and some have greater power, privilege, and status, while others are pushed to the margins, oppressed, or silenced. These patterns of power and oppression are replicated in systems and organisational structures (Research in Practice, 2024). These reproduced patterns of power and oppression can be traumatic for marginalised groups. If professionals and processes are not informed about autism and Autistic parenting, then the very systems that are meant to provide support can cause

# An example: How systemic discrimination and parental blame affects practice and parents' experiences of care services

In their research with families who had experienced fabricated and induced illness allegations (FII), Clements and Aiello (2023) found that:

- > Disabled parents were four times more likely to be accused of FII than non-disabled parents.
- > Many of these parents had a 'non-visible' disability, including more than 40% who identified as Autistic.
- > More than half (52%) of the allegations occurred after the parent had made a complaint against education, health or social care.
- > The vast majority of FII allegations appear to have been unfounded 84% resulted in no follow-up action or were abandoned.
- > In all but 10 cases (of 291 in which the outcome was evident), the children remained living with the parent who had been accused of FII. In those 10 cases, researchers could not determine (from the survey responses) whether the decision to remove the child was due in whole or in part to evidence relating to the FII allegation.

In their report, the researchers note that 'FII is generally accepted as a very rare condition'. Yet the allegations had often led to 'devastating and life-long family trauma' for those accused (Clements & Aiello, 2023, p. 3).

Building on this, <u>The Autism and Parental Blame Project</u> (a collaborations between NHS England (Midlands), West Midland ADASS, University of Birmingham and parents of Autistic children) explored the experiences of parents raising Autistic children. The report found that **parental blame was traumatic** not only for parents but also for their children (Ferguson & Hollingsworth, 2024).

The findings suggested that being an Autistic parent increased the likelihood of facing traumatic interventions including being wrongly accused of fabricated and induced illness, a child protection investigation or child removal from the family home. Autistic parents were three times more likely than non-autistic parents to report being accused of FII.

Importantly, none of the parents – whether Autistic or not – reported receiving support for themselves or their children following these events, either after a child was removed without warning or when parents were wrongly accused of neglect or harm.

Parents in the study suggested that outcomes could be improved by:

- > **Equipping practitioners** to recognise and work effectively with Autistic adults, ensuring that services are accessible and that reasonable adjustments are made to foster positive relationships.
- > Raising awareness among professionals about the harm caused by parental blame and providing support and aftercare for affected families. Parents were clear that this recommendation is not meant to discourage professionals from acting where there is evidence or strong suspicion that a child is at risk, but rather to ensure that appropriate support is offered when suspicions prove to be unfounded.

I felt gaslighted for ... years, and that has had a huge impact on my mental health, but most importantly, has also meant that my [child] lived in constant pain for far longer than he needed to had I been believed from the start. It has had a huge and terrible impact on our family. (Parent in Clements & Aiello, 2023, p.27)



Read The BASW Practice guide <u>Fabricated or Induced Illness and Perplexing</u>
<u>Presentations: Abbreviated Practice Guide for Social Work Practitioners</u>
(Long et al., 2022)

#### Reflection points: Ways of working

> Are there any ways of working in your team, organisation or as a multi-agency network that you think may be challenging or traumatic for Autistic parents?

It may be useful to ask yourself these questions:

- > Why am I doing it the way I am doing it?
- > Could this way unintentionally cause harm? How?
- > Can things be done differently? If not, what can I do to mitigate against potential harm caused by these ways of working?

# Theories and conceptual frameworks to support neuroinclusive practice

[A]utistic parents ... highlight their parenting can be misunderstood even though parenthood can be highly subjective with diverse parental styles. A key theme is that social care services did not accurately assess the needs of autistic parents. The parents reported feeling unable to seek support, expressed concern about professionals' opinions about autistic parenting and feared they would be negatively stereotyped should they ask for help. (Hwang & Heslop, 2023, p. 290)

In a fast-paced, system-driven environment, it is easy to make assumptions about what people do or do not understand, feel or think, or why they behave as they do. As practitioners, how often do we slow down and genuinely commit to staying curious and understanding Autistic parents **on their own terms**? Yet this is exactly what is needed to move beyond limiting stereotypes about autism, develop our understanding and enable assessments that recognise Autistic parents' strengths as well as their needs in order to provide effective support (Hwang & Heslop, 2023).

In this section, we look at some key theories and conceptual frameworks that support neuroinclusive practice with Autistic parents. These theories challenge the dominance of the 'impairment' mindset that has long shaped clinical views of autism. These 'insider' frameworks can help us understand how Autistic parents engage with their children and the world around them. Crucially, they offer vital guidance for how we as practitioners can support Autistic parents more effectively and respectfully.

# Social justice approach to disability

**Social justice approaches to disability** (often referred to as human rights approaches) recognise that disability is not simply a medical or individual issue but one deeply influenced by systems of power, privilege and oppression.

- > The **medical model** views disability as a personal deficit, as pathological and requiring clinical treatment.
- > The **social model** reframes disability as being the result of barriers created by inaccessible or exclusionary environments (Oliver, 2013).
- > The **social justice approach** builds on this, highlighting the ways in which intersectional identities, societal attitudes and institutional systems shape disabled people's lived experiences and access to rights (Levitt, 2017).

The social justice approach encourages practitioners to critically examine how structural inequalities affect the support that Autistic people – and in this context, Autistic parents – receive.

# Neurodiversity paradigm: A shift from deficit to diversity

The **neurodiversity paradigm** is a framework developed and continuously shaped by Autistic and neurodivergent scholars. It posits that all human brains function differently, and that this diversity in cognitive processing is a natural and valuable aspect of human variation.

While everyone processes the world in unique ways, some individuals experience and interact with the world in ways that diverge from dominant societal norms and expectations. These individuals are described as neurodivergent (e.g. Autistic, ADHD, dyslexic). The neurodiversity paradigm challenges the idea that there is a single 'correct' way to think, feel or behave. Instead, it highlights how concepts of what is considered 'normal', 'desirable' or 'functional' are socially constructed – and often defined by those in positions of power.

From this perspective, Autistic people and other neurodivergent individuals should be respected not only in terms of their rights and needs but also as holding a cultural identity comparable to aspects such as ethnicity, gender or sexuality (Walker, 2021).

Importantly, this paradigm – and related social justice models – **do not reject the existence of medical or biological needs**, nor do they deny the impact of the environment on individuals. Rather, they advocate that disabled and neurodivergent people **should not be judged or supported solely through the lens of normative standards**. Instead, autism should be recognised and affirmed as both a neurological and cultural identity (Dwyer et al., 2024).

For social care practitioners, adopting a neurodiversity-informed approach has wide-reaching implications across all aspects of practice – from assessment and planning to decision-making and long-term support. It calls for inclusive, respectful and person-centred ways of working that move beyond deficit-based models.

A neuroinclusive approach integrates the values of the neurodiversity paradigm and social justice models, emphasising equity, inclusion and the recognition of neurological differences as part of human diversity (Figure 3).

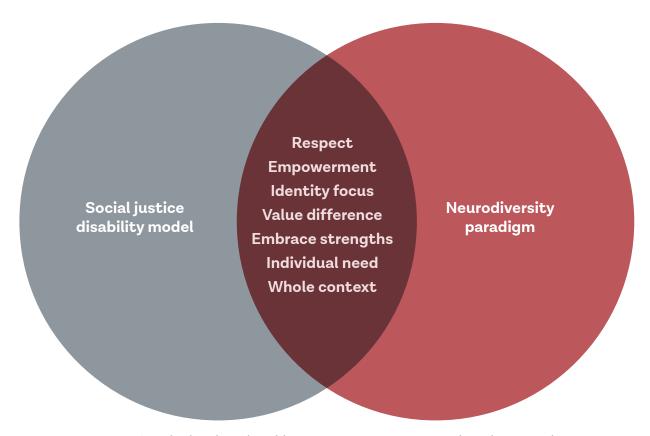


Fig 3: Common values of social justice disability models and the neurodiversity paradigm



Watch Jenni Guthrie and Deb Solomon, two neurodivergent social workers, talk about social justice disability ideas and the neurodiversity paradigm within a social care context (6 mins)

# The double empathy problem (DEP)

An all too pervasive myth is that Autistic people lack empathy. The double empathy problem (DEP) is a concept introduced by Autistic academic **Dr Damian Milton** in 2012. It offers a powerful alternative to the outdated belief that Autistic people inherently lack empathy or 'theory of mind' – i.e. the ability to understand others' thoughts and feelings (see, for example, Baron-Cohen et al., 1985).

The DEP reframes this narrative:

The issue is not a lack within the Autistic person, but rather a **mutual misunderstanding** that arises between people of different neurotypes. (Milton, 2012)

A non-autistic person's perception of a deficiency or lack of understanding in an Autistic person should be understood as a lack of connection with Autistic people's different ways of communicating, expressing and experiencing their perceptions of others and the world around them (Milton, 2012).

Research has shown that Autistic people often communicate and connect effectively with one another. This suggests that the true barrier is often interpersonal misattunement – a socially constructed gap in mutual understanding – rather than an internal individual deficit (Milton et al., 2022). In other words, communication breakdowns are mutual and relational, especially between people of different neurotypes (e.g. Autistic and non-autistic).

Of course, this is not to say people of different neurotypes can never understand and feel empathy for each other. They can.

The DEP is more than being 'lost in translation': it also challenges the assumption that responsibility for bridging communication gaps lies entirely with Autistic people. It argues that non-autistic people may themselves exhibit a lack of empathy towards Autistic ways of being if they are not motivated to 'learn the language' or if they assume that the Autistic person alone has to change for their (non-autistic) benefit.



#### Myth-busting using the double empathy problem

Watch this video by Autistic advocate Kieran Rose as he explains the Double Empathy Problem.

# Diversity in Social Intelligence

This perspective builds on the double empathy problem and highlights that Autistic and non-autistic people may experience challenges in social interaction due to differences in communication styles, rather than deficits.

Research has shown that Autistic people communicate effectively with each other, but they may use different interaction styles which can be misunderstood by non-autistic people (Crompton et al., 2020; Davis & Crompton, 2021). These findings call into question the assumption that neurotypical social behaviours represent the standard by which all others should be measured. Perceived deficits in social communication and intelligence are a result of a normative bias towards non-autistic communication and connection and not inherent impairments within Autistic people.

Aligned with relational and strengths-based social work approaches, this theory emphasises the need to challenge prejudices and misinterpretations surrounding Autistic social interaction. There needs to be a focus on fostering **mutual understanding**, **respect for neurodivergent communication** and inclusive communication models that validate diverse expressions of social intelligence.



#### **Diversity in Social Intelligence**

Read this poster by the Therapist Neurodiversity Collective. It highlights key research findings around Autistic social communication and interaction.

Both theories emphasise the importance of practice bridging this cultural gap, and balancing power so that professional systems don't require Autistic parents to conform to ways non-autistic people behave, simply because this is the larger and more powerful group.

# Monotropism

This theory, developed by Dinah Murray and colleagues, suggests that Autistic people may become deeply immersed in a particular topic, activity or line of thought. They may sometimes find it difficult to disengage, especially if interrupted without warning and can affect task-switching; the process of shifting attention from one activity to an unrelated one (Murray et al., 2005). It may also impact the ability to engage with surrounding conversations or activity.

This intense focus can also be a strength. For Autistic parents it may foster a deep commitment to understanding their child's needs, exploring parenting strategies in detail, and building meaningful connections in ways that align with both the parent's and child's unique ways of relating.



#### **Understanding sensory difference: Monotropism**

Watch Kieran introduce the concept of monotropism from an Autistic perspective (including an example of his own as an Autistic parent). For more information, see Additional resources.

#### Reflective activity: Using theory to understand Autistic strengths and challenges

> Consider these theories and look back to the '<u>Autistic parenting: strengths and challenges</u> section'. What parenting strengths and challenges might these key theories relate to?

# Why intersectionality is integral to effective support

You have the angry Black mum trope when we try to fight for our kids. When we are trying to support our children who face racism, how that impacts us as ADHDers. It just hits differently. So we have loads of barriers as every other person with ADHD has, but then we have the additional barriers of the discrimination. And not being believed is probably the biggest one. ... Differences in behaviours are put down to cultural differences rather than being neurodivergent. Sofia Akbar, Autistic ADHD parent and founder of Scottish Ethnic Minority Autistics (Neurodiversity Natter, 2024)

Autistic people's experiences are shaped not only by their individual neurology and the extent to which society accepts or validates them, but also by other aspects of their identity. Intersectionality recognises how various social identities, such as race, gender and class, can interact to create unique experiences of privilege or oppression (Crenshaw, 1989).

Ignoring or downplaying these intersections can lead to misunderstandings of these complex experiences or even negate them altogether. This risks perpetuating inequities in social care practice as services, research and advocacy may fail to reach or reflect those most marginalised.

Autistic parents may be of any gender, sexuality, ethnicity, culture or background. These identities will intersect with their experiences as an Autistic person, and lead to compounded discrimination or disadvantage. For example, a Black Autistic woman may face racism, sexism and ableism in ways that differ from the experiences of a white Autistic man or a Black neurotypical woman. It is also important to have an awareness of mixed heritage families and the particular differences they may need support with.

Practitioners need to have cultural humility when working with families and communities. See <u>Additional</u> <u>resources</u> section for examples of culturally adapted services.

There is limited research in relation to autism and other marginalised identities. Given this context it is important that practitioners hold in mind the concept of **situated knowledge** – this is the knowledge that people have due to their experiences and identities. It links closely with the idea of person-centred practice but adds to this by recognising that often minoritised people's knowledge is not listened to. An intersectional approach encourages practitioners to listen and hear people's situated knowledge – of being Autistic and black, for example. Seeing people's situated knowledge as expertise in their own life validates their experiences.

# Co-occurring health conditions, neurodivergences or disabilities

Many Autistic people live with co-occurring health conditions or disabilities, which may or may not be related to autism. Autistic people are more likely than non-autistic people to live with multiple health conditions which may include hearing or sight impairment. The following examples commonly co-occur:

- > Hypermobility and joint issues, postural orthostatic tachycardia syndrome (POTS), mast cell activation syndrome (MCAS) or allergies.
- > Other neurodivergences which could be neurodevelopmental, such as ADHD, Tourette's, dyspraxia or dyslexia, or acquired, such as mental health issues.
- > There are also links between autism and epilepsy as well as chronic health conditions such as chronic fatigue syndrome (CFS/ME) and chronic pain (fibromyalgia).

(Lai et al., 2019; NHS England, 2021; <u>SEDS Connective</u>; Ward et al., 2023). See <u>Additional resources</u> section.

Autistic parents told us that their health concerns are sometimes overlooked because their pain and distress don't show up in typical ways, which can lead to serious risks.

Child and family social care practitioners should think holistically and ensure adjustments to practice consider autism alongside any co-occurring conditions. If support is based on a single-disability lens, autism can easily be overlooked, and needs may go unmet.

A related problem is the misconception that autism is a learning disability. It isn't; autism and learning disabilities are distinct but sometimes co-occur. NHS England data published in 2021 found that 28.6% of patients with a learning disability were also diagnosed with autism. Conflating the two can lead, for example, to an Autistic person with a learning disability being referred to as 'severely Autistic', or an Autistic person without a learning disability referred to as 'mildly Autistic', as long as they communicate verbally.

This misconception can mean that Autistic people without a learning disability are seen as 'not Autistic enough' to warrant adjustments or support. Autistic parents told us they felt this belief contributed to practitioners not fully accepting their own or their children's autism diagnoses (i.e. doubting the veracity of the diagnosis). Because their differences may be less visible, their social communication style is sometimes misinterpreted as deliberately inappropriate – such as being rude, awkward, or defiant. These judgments can unfairly influence social work assessments and lead professionals to treat Autistic parents as if they lack understanding or as though their contributions are less valid than the professional's perspective.

This issue can be especially pronounced for non-speaking Autistic parents who use alternative forms of communication, as their voices are even more at risk of being misunderstood or overlooked.

While learning disability and autism are not the same thing, both Autistic parents and parents with intellectual or developmental disabilities face significant challenges in their interactions with children's social care and may be at heightened risk of having children removed from their care (e.g. Atkin and Kroese, 2021; Benson, 2023; Hwang & Heslop, 2023; Slayter and Jensen, 2019). Addressing systemic inequities in social care interventions is essential to ensure fair and supportive practices for all parents and their families.



You can find out more about health conditions and disabilities that are commonly experienced by Autistic people on this <a href="NHS web page">NHS web page</a> and on the <a href="SEDSConnective">SEDSConnective</a> website.

Join the <u>Working Together with Parents Network</u> to learn more about working with parents with learning disabilities and learning difficulties. The network supports professionals working with parents and their children.

# Race and ethnicity

We've had racist harassment here from adults and ableist hate from children. I hadn't really considered the impact of not being white and being Autistic until I moved here where we're in the minority. People are using casual racist everyday language all the time. No one's been pulled up on it. It's people just making instant judgments. Non-informed judgments based on stereotypes. (Autistic parent)

Acquaah and Ville (2024) found that, in policing, education, and mental health services, Black women often face disproportionately harsh treatment. Their report also highlights that these women are frequently perceived as being more resilient than others, which can lead to assumptions that they need less support. However, there is a lack of research on autism in relation to ethnicity, both in general and in relation to parenting more specifically (Malone et al., 2022). This means there is a knowledge gap in practice around how ethnicity and culture interconnect with Autistic identity and need (see for example Fox et al., 2017; Salleh et al., 2022). However, parent accounts illustrate how societal and institutional racism and stigma from their own communities create a double-edged sword.

'Well we're stigmatised on both ends. One is the public services that are supposed to support us. But the other is our own communities. So if you are already traumatised, you are going to behave differently anyway.... You'll have your trauma responses. And that plays out within your own circles and families as well. Then you get stigmatised as well because you're not the typical good girl. You are not the son who is supposed to take responsibility for the whole family. You know, the fact that you are forgetful or you need that extra support with your daily living ... you know the whole gender stereotypes plays a part as well. It's a double-edged sword that we have.'

Sofia Akbar, Autistic ADHD parent (Neurodiversity Natter, 2024)

Much of the research exploring the interconnections between autism and race focuses on diagnosis in childhood. US and UK research shows a mixed, and potentially, changing picture. Black children – especially girls – may experience significant disparities in diagnosis and support, including delayed diagnosis among those diagnosed later in childhood (Habayeb et al., 2021; Nelson & Lichwa, 2025). Practitioners should be mindful that the inequities children face in accessing support do not disappear with age; rather, they reverberate across the life course and continue to impact Autistic parents today. Racial stereotypes can further distort how a person's behaviour is interpreted: race is often seen before autism and differences may be misread through a racial stereotyped lens of aggression (Bobb, 2019; Nelson & Lichwa, 2025).



In this podcast, <u>Melissa Simmonds</u> talks about her experiences as a Black Autistic parent of Autistic children. (approx. 24 mins)

For example, she highlights double empathy and how identities of being a Black Autistic person and parent intersect.



Scroll down this website page to watch a short film (1 minute) trailer for the documentary 'Too Autistic for Black'. Tee Cee Johnson and other contributors talk about their intersectional experience of being Black and Autistic.



Culturally-adapted organisations are much needed but few-and-far between. An example of a culturally adapted organisation is <u>Chinese Autism</u> who provide a range of services to support Chinese-speaking Autistic individuals, their families, and the professionals who work with them. Their work focuses on addressing challenges – such as cultural stigma, language barriers, and systemic exclusion.

#### Gender

There is a deficit of peer-reviewed research beyond the mother perspective. There is little about fathers and gender-diverse parenting. Research on parenting mainly focuses on mothers (Hwang & Heslop, 2023) although some studies aren't clear regarding the gender identity of 'mothers'.

Lau et al. (2016) did find that Autistic fathers in their study may benefit from support around self-efficacy as a parent.

Gender bias and expectations around what autism looks like and gender conformity can contribute to misunderstandings of Autistic individuals (Moore et al., 2022). The gender bias in diagnostic and screening tools has left Autistic women 'at disparate risk' from being:

- > Disproportionately under-diagnosed and tend to be diagnosed later in life (McCrossin, 2022).
- > Frequently misdiagnosed with other conditions such as borderline personality disorder (Lockington & Gullon-Scott, 2025; McQuaid et al., 2024; Tamilson et al., 2024).

Again, this means many parents may have grown up without recognition of their neurodivergent needs, resulting in missed educational, health and social support. Later diagnosis and mis-diagnosis can have negative effects on mental health (Sedgewick et al., 2020). Misdiagnosis can also mean treatments may not address core Autistic needs.

The intersection of autism and gender fluidity, including non-binary and transgender identities, is an under-researched area, but autism diagnoses do appear to be more common among gender-diverse individuals than among their cisgender peers (Bouzy et al., 2023; Gratton et al., 2023; Strang et al 2023). No one is really sure why this is, and there are multiple theories. A neuro- and trans-inclusive theory is that Autistic people are more open to fluid rather than binary definitions and contexts regarding identity. This overlap can amplify the challenges of 'coming out', navigating societal expectations, and finding community. Katie Munday, who is a trans and Autistic parent, writes that they effectively had to 'come out' of two closets, not just once but constantly to new people. One third of respondents to a large 2018 study said their gender identity had been repeatedly questioned due to their autism (Warrier et al., 2020). This may reflect a prejudice towards neurodivergent individuals that assumes they are not competent enough to understand their own sexuality or gender identity, and which contributes to under-diagnosis of autism amongst the LGBTQIA+ community (Gratton et al., 2023).

This reminds us to get to know the whole parent, understand their intersectional experiences, offer holistic support and, where appropriate, support their access to specialist services.



Watch the clip by <u>David Grey Hammond</u> talking about his experience as an Autistic father, especially the impact of internalised ableism on parenting confidence.



Read this short news article about Autistic father <u>Jude Morrow</u> and how he learned to accept his own autism diagnosis through his parenting relationship.

# Socioeconomic disadvantage

Autistic parents may be sole carers or part of a wider family network. Like other disabled people, they may face systemic challenges, including economic hardship. Households that include one or more disabled member are 31% more likely to experience poverty (Francis-Devine, 2022). Although many Autistic people are able and want to work, only around three in ten are in employment and Autistic people face the highest pay gap among disabled groups (Buckland, 2024). As a result, many face socioeconomic hardship due to limited access to income. While some Autistic parents have access to financial and social support, others may experience significant isolation. NHS Autism diagnostic assessment waiting lists are extremely long (up to eight years); people who do not have the option to pay for private assessments can face significant waits and barriers in accessing diagnosis and support.

#### Summary

As always, it's important to:

- > Consider the whole person, using your professional curiosity to understand the parent and family's perspectives, experiences and situation.
- > Explore **parents' experience of their diagnostic and support history**. Many Autistic parents may not have received timely or accurate diagnosis and support in childhood, particularly those from racially minoritised or other marginalised communities.
- > Avoid assuming that a parent's late or absent diagnosis means their needs are less valid. Parents who did not receive appropriate educational or social support when younger may carry forward experiences of exclusion, mistrust, or self-doubt. Sensitivity to this history can help build trust in professional relationships.
- > Reflect on and challenge how bias may affect interpretations of parenting approaches, communication, or behaviour. Racial, gendered, ableist and other stereotypes can shape how Autistic parents are perceived, just as they shape how children are diagnosed.
- Recognise that lived experience is a valuable source of expertise in parenting.
- > Take a life-course perspective and understand that inequities in diagnosis and support accumulate over time, shaping not only childhood experiences but also the contexts in which Autistic people later parent.

#### Reflective point

Holding this in mind:

> What might you show curiosity about when working with a parent? How might you do this?



The Research in Practice Equity Change Project resources explore intersectionality, equity, allyship and justice. While focused on adult social care involvement, the key ideas and many of the tools are transferable. For example, the Drawing the intersection tool can be used to explore the interconnections between different socially constructed identities and experiences of oppression (e.g. the intersection of race and autism).



Monique Botha is a non-binary Autistic parent and researcher. This freely available article by Botha and Gillespie-Lynch (2022) looks at how we can use an intersectional lens to be more flexible in our understanding and promotion of positive Autistic identity.

#### Additional resources

#### **Training**

#### If you are considering training, please ensure that it is led by Autistic people

<u>The Oliver McGowan Mandatory Training on Learning Disability and Autism - elearning for healthcare</u>

This free training option is available for NHS staff:

#### National Autism Trainer Programme (NATP)

This NHS training option is available for adult and children's mental health settings including CAMHS, residential and health and justice settings.

<u>The Autistic Advocate - The Inside of Autism</u> but there are several others lived experience facilitators who can be found online.

#### Studio 3

Studio 3 offer training and resources around the low arousal approach in practice with neurodivergent people.

# Understanding autism

#### Monotropism

This website collated by Fergus Murray includes information in more depth regarding monotropism including original articles by Dinah Murray.

#### **Understanding Social Cognition in Autism**

This 14-minute video captures the Diversity in Social Intelligence project with the lead researchers Dr Sue Fletcher-Watson and Dr Catherine Crompton and research participants Sonny, Fiona and George.

#### Autistic-produced films explaining what it is like to be Autistic

Two short films from Thriving Autistic explore the strengths and possibilities that come with understanding oneself as Autistic. They highlight the diverse ways Autistic people experience, interpret, and navigate the world.

#### Viv Dawes Autistic Advocate on Autistic meltdowns, burnout and recovery

Viv Dawes is an AuDHD advocate and trainer. The website includes links to published books and free information about Autistic burnout, meltdowns and recovery from burnout.

#### Sensory differences: how and why autism affects our senses

The Autism Understood website by Spectrum Gaming is about autism, for Autistic young people. However, this page provides a clear overview of possible sensory differences, including those related to touch, taste, smell, sight, hearing, balance (vestibular), body awareness (proprioception) and internal senses (interoception).

#### Support

#### **Autistic Parents UK**

This charity is led by Autistic parents for Autistic parents. It offers peer support, education through webinars and Q and A sessions, as well as training and project work to enhance understanding and support for Autistic parents and their families across the UK.

#### Autistic Pregnancy, Birth and Beyond

A collaborative project between Autistic Parents UK, Dr Aimee Grant from <a href="Swansea">Swansea</a> <a href="University">University</a>, Autistic UK, and the <a href="Research Wales Innovation Fund">Research Wales Innovation Fund</a> to address a critical gap in understanding the experiences of Autistic parents throughout pregnancy, birth, and the early postnatal period.

Maternity passport and resources for birth: <a href="https://www.autisticparentsuk.org/downloadable-resources">https://www.autisticparentsuk.org/downloadable-resources</a>

#### The Autism-Friendly Guide to Pregnancy, Birth and the Fourth Trimester

A book by Autistic researcher Dr Aimee Grant which provides a guide to navigating pregnancy, birth and the fourth trimester. It includes advice from Autistic pregnant people and registered midwives.

#### **SEDS Connective**

This website offers information and research on links between physical health and disability with neurodivergence.

# Parental blame and FII

<u>Autism and Parental Blame Project</u> - including the <u>Blamed Instead of Helped report</u>

This research project is led by West Midlands ADASS and the University of Birmingham and looks at the experiences of parents of Autistic children and parental blame when they approach health, education and care services for support.

Gullon-Scott, F. & Long, C. (2022). <u>FII and Perplexing Presentations: What is the Evidence Base for and against Current Guidelines, and What are the Implications for Social Services?</u> The British Journal of Social Work, 52(7), 4040–4056.

# Family justice system-related resources

Information relating to neuroinclusive legal services and research on court approaches:

#### **FLANC**

This group of expert lawyers in the family justice system offer information, training and resources regarding neurodivergence within the family court arena.

George, R., Crane, L., & Remington, A. (2020). <u>'Our normal is different': autistic adults' experiences of the family courts</u>. *Journal of Social Welfare and Family Law*, *42*(2), 204–220.

This paper explores experiences of Autistic adults within the family justice system. It highlights the discrimination experienced and makes recommendations for good practice.

#### Intersectionality

#### Autistic While Black in the UK: Masking, Codeswitching, and Other (Non)fictions

This autobiographical essay by Tré Ventour-Griffiths explores the experience of a black, Autistic, and disabled person in the UK.

Please note: this essay contains references to ableism, white supremacy, sexual assault/rape, male violence and racism.

Researchers Mel Green and Dr. Claire Malcom are also Black mothers of Autistic children. Their work to date does not focus specifically on Autistic Black mothers but rather provides detailed understanding of Black mothers' experiences of raising Autistic children, and the racism, misogyny, and ableism they and their children encounter, along with the consequences of these experiences. However, Black Autistic mothers may face many of the same challenges, and implementing these recommendations within services could help improve their experiences as well.

- > Malcolm. C., & Green, M. (2025). <u>Mothering at the margins: Black mothers raising autistic children in the UK</u>. Lives places publishing.
- > Centre for Autism Wellbeing Hub. (2025). Mel Green & Dr Claire Malcolm Black mothers advocating for their autistic children [Video]. Youtube. <a href="https://www.youtube.com/watch?v=EXqiKdo1NPA">https://www.youtube.com/watch?v=EXqiKdo1NPA</a>

Mendes, E. A., & Maroney, M. R. (2019). <u>Gender identity, sexuality and autism: Voices from across the spectrum</u>. Jessica Kingsley Publishers.

This book contains a variety of narratives illustrating intersections of gender identity, sexuality and autistic experience.

Hull, E. (2023). We've Got This: essays by disabled parents. Scribe UK.

This book contains essays from different disabled parents reflecting a wide range of disabilities and experiences, offering additional perspectives to consider where Autistic parents may also have additional physical, sensory disabilities or chronic illness.

Williams, G. (2022). More than words: Supporting effective communication with autistic people in health care settings. Economic & Social Research Council, University of Brighton and boing boing. <a href="https://www.boingboing.org.uk/more\_thanwords/">https://www.boingboing.org.uk/more\_thanwords/</a>

These guidelines were co-produced to share practical ways health care communication/ practice needs to be adjusted to work better for Autistic people.

#### Examples of culturally adapted services:

<u>Chinese Autism</u> is a charity whose mission is 'Changing perspectives about autism in the Chinese Community and turning stigma into strength'. They offer information and resources about autism for Chinese-speaking families and to help professionals understand why Chinese Autistic people may experience inequity and discrimination within Chinese cultures.

Scottish Ethnic Minority Autistics (SEMA) is a charity that works with Scottish racialised communities to make connections, facilitate peer support and improve understanding of autism. Resources include downloadable autism myth-busting booklets translated into a number of languages.

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