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Understanding Healthcare Access for Autistic Children in the UK: Perspectives from Parents and Healthcare Professionals

Autism spectrum disorder (ASD) is a neurodevelopmental condition that affects social interaction, communication, and is often associated with repetitive behaviours and stereotyped actions (American Psychiatric Association, 2013). Global estimates suggest that around 1 in 127 people are autistic (WHO 2025), although reported prevalence varies substantially depending on methodology and setting. In England, survey-based estimates suggest autism prevalence of 1.2% among 5- to 19-year-olds, while recorded diagnosis rates in routine data have risen in recent years (World Health Organization, 2025; Tromans et al., 2025). Research indicates that autism is more frequently diagnosed in males than females, with some studies reporting a male-to-female ratio as high as 4:1 (Levy et al., 2011). Given the significant number of children identified as autistic, and the increased challenges they experience accessing healthcare, this area of research remains highly relevant.

Across settings, autistic children experience poorer healthcare access and outcomes than non-autistic peers, linked to multi-level barriers spanning individual needs, provider capability, and system design (Babalola et al., 2024; Doherty et al., 2022). Prior work highlights inconsistent autism-specific knowledge among clinicians, including general practitioners (GPs), diagnostic overshadowing, limited post-diagnosis support, and variable implementation of reasonable adjustments; particularly for sensory and communication needs (Unigwe et al., 2017; Crane et al., 2018; Ng-Cordell et al., 2022).

The National Health Service (NHS) provides predominantly publicly funded healthcare, with access generally free at the point of use, subject to limited exceptions (Department of Health and Social Care, 2023). Within the UK, organisational arrangements differ by nation.

Participants in the present study were based in England and Wales. In England, healthcare planning and coordination are organised through integrated care systems that bring together NHS organisations, local authorities and other partners (NHS England, n.d.). In Wales, NHS services are planned and delivered through seven Local Health Boards alongside national NHS trusts and special health authorities (NHS Wales, n.d.). These organisational differences are relevant when interpreting the present findings, as referral pathways, coordination between services, information sharing and implementation of reasonable adjustments may vary between local services and organisations.

Previous studies have examined parent and professional/provider perspectives in specific service contexts, including autism services, primary care, emergency departments, and procedural or surgical care (Gholipour et al., 2023; Carbone et al., 2013; Muskat et al., 2016; Hodgetts et al., 2013; Snow et al., 2021; Davignon et al., 2014). While this work is important, to our knowledge, there is little or no qualitative evidence based in the UK that compares parent and HCP perspectives. To address this, the views of both groups are needed to triangulate perspectives and reduce single-informant bias. Including both parents/carers and healthcare professionals enabled us to examine where perspectives converged (e.g., shared recognition of barriers such as time pressure and fragmented services) and where they diverged (e.g., parents' experiences of dismissal versus healthcare professionals' accounts of system constraints), which is important for developing recommendations that are both acceptable and feasible in practice. Although some initiatives have developed and tested interventions to improve healthcare accessibility for autistic children (Kennedy et al., 2016), few have looked at this issue holistically.

Current study

Addressing these gaps requires phenomenologically informed qualitative work that centres parents'/carers' and healthcare professionals' experiences and perspectives, identifies where and why barriers arise, and distils practical adjustments and pathway solutions suited to NHS constraints. The present study responds to this need by analysing interviews with parents/caregivers of autistic children and healthcare professionals to: (i) characterise barriers and facilitators to access, (ii) map convergences and discrepancies between stakeholder perspectives, and (iii) generate concrete, context-sensitive recommendations for policy and practice. Conceptually, this study was informed by the Capability, Opportunity, Motivation-Behaviour (COM-B) model (Michie et al., 2011) and the Theoretical Domains Framework (TDF) (Michie et al., 2005; Cane et al., 2012). COM-B informed the development of interview prompts around behavioural and service-level influences on healthcare access, while TDF was used as an interpretive lens to situate the findings within more specific determinants of behaviour and implementation. However, the analysis itself remained inductive and followed reflexive thematic analysis rather than framework-based coding. Building on our previous systematic review and survey study (REDACTED, 2024/2025), interviews with parents/carers and healthcare professionals were used to generate richer, contextualised accounts of barriers and facilitators to healthcare access.

This paper adopts the term "autistic children" following the preferences expressed by many within the autism community (Kenny et al., 2015), including the first author, who is a mother of an autistic child. This terminology reflects an identity-first perspective, recognising autism as an integral part of an individual's identity rather than a condition they possess. Consistently using these terms also aligns with contemporary discussions on identity and disability.

Research Questions:

1. What are the in-depth perspectives on why barriers and facilitators to healthcare access for autistic children arise?

2. Where there are challenges, how can they be mitigated?

Method

Study design

A phenomenologically informed, descriptive stance centred on parents'/carers' and healthcare professionals' experiences and perspectives guided the study (Hussain & Bandara, 2020). Data collection used one-off semi-structured online interviews (Microsoft Teams; December 2023–April 2024) with open, experience-near prompts, and concrete episode probing. Reflexive bracketing/memos, before and after interviews, were used to manage presuppositions. Analysis followed inductive, phenomenologically informed reflexive thematic analysis: line-by-line coding with horizontalisation (treating each meaning unit with equal value), clustering meaning units into candidate themes, and iterative part–whole movement across the dataset. Brief essence summaries were drafted for each theme. Credibility was supported by an audit trail, peer debriefing, and data-source triangulation parents and healthcare professionals (HCPs) with comparative analysis across groups.

Ethics approval

Ethics approval: Language and Communication Science proportionate review committee (REC ETH2223-0211). Participants received an information sheet and consent form (including consent for use of anonymised quotations) and provided informed consent. Procedural details are given below.

Participants

Participants were recruited across the UK using purposive sampling. Initial recruitment drew on survey respondents who had consented to re-contact, and additional participants were recruited via social media, word of mouth, and snowball sampling.

Inclusion: parents/carers of formally diagnosed autistic children aged 0–18; UK HCPs, including nurses, general practitioners (GPs), dentists, and speech and language therapists (SLTs), with experience working with autistic children/young people in any healthcare setting.

Exclusion: children without a formal diagnosis; parents of children over 18; HCPs without relevant experience.

The final sample consisted of 12 parents/carers of autistic children (11 mothers and one father) based in England and Wales. They represented 17 autistic children aged 4–17 years (12 boys and five girls), with varied communication profiles, co-occurring conditions and support needs. Parent/carer and child characteristics are summarised in Table 1.

Eight healthcare professionals (six female and two male) participated: two GPs, four nurses and two SLTs, representing primary care, hospital, emergency, learning disability and speech and language therapy settings. Healthcare professional characteristics are summarised in Table 2.

Materials

An interview guide was developed from prior work (systematic review and survey: REDACTED et al., 2024; 2025) and structured using the COM-B model to ensure coverage of behavioural determinants of healthcare access. Although COM-B informed the development of the interview guide, the Theoretical Domains Framework (TDF), which elaborates determinants within COM-B domains, was used later as an interpretive

framework. Items targeting Capability examined autism-specific knowledge/skills and communication competence (e.g., recognising sensory needs, adapting interaction), Opportunity items addressed environmental and organisational conditions (e.g., appointment length/continuity, waiting environments, data flow/EHR flags, policies, resourcing), and Motivation items explored beliefs, priorities, confidence, and attitudes toward making reasonable adjustments and avoiding diagnostic overshadowing. Each domain concluded with service-improvement prompts for concrete, context-feasible solutions.

Two parallel topic guides were used; one for parents/carers and one for HCPs, so as to reduce single-informant bias, use role-appropriate language, and explore domain-specific experiences while ensuring triangulation. Full parent/carer and HCP guides are provided in Appendix 1.

Procedure

Piloting

A first draft of the interview topic guide was shared with an expert qualitative researcher, after which minor edits were made to the interview guide protocol. The minor edits included increasing possible response output by revising questions to be more open-ended, allowing participants to elaborate on their experiences, thoughts, and feelings and removing questions that might lead to yes or no answers. The final topic guide was then piloted online by a parent of an autistic child. The participant's level of engagement and satisfaction indicated that the 60-minute duration for each interview was sufficient to gather the necessary information without causing inconvenience.

Data collection

Survey respondents who consented to re-contact were invited by email (two follow-ups, 2-week intervals). Of 12 parents and 8 HCPs who agreed to be contacted, 2 parents (17%) and 3 HCPs (25%) completed interviews. Additional participants were recruited via social media (Facebook, X/Twitter, TikTok, Instagram), word of mouth, and snowball sampling (participants shared the study flyer). Target sampling sought 10 parents and 10 HCPs across settings. Parent recruitment closed 20 Feb 2024 on reaching target; three late reschedules were also interviewed. One parent interview was excluded from the analysis after the interview because language barriers, which became apparent during the interview, meant that substantial parts of the participant's responses could not be interpreted and transcribed with sufficient confidence for inclusion in the qualitative analysis. English-language proficiency had not been specified as a formal eligibility criterion at recruitment. The final parent sample was therefore n=12. Healthcare recruitment closed 30 Apr 2024 when target roles were represented (except dentists), yielding n=8 HCPs.

Interviews were scheduled on receipt of signed consent and conducted online (Microsoft Teams) by the first author, who has personal experience of autism as a parent of an autistic child. Accessibility options were offered (camera off/audio-only, captions, chat responses, brief pre-call check, flexible timing, breaks/stop, supporter present, topic guide in advance). Interviews were video/audio recorded and transcribed by the first author; the first two transcripts were checked for accuracy by an independent researcher. Support-needs descriptors were captured via parent report; no standardised adaptive-functioning measures were administered. Interviews lasted 40–90 minutes; most (18) were within 60 minutes, and two exceeded this.

Data analysis

Reflexive thematic analysis (RTA: Braun & Clarke, 2006) with an inductive, data-driven orientation was applied, with comparative attention across parents and HCPs. COM-B and TDF were not used to generate codes or themes; rather, they were drawn on subsequently as interpretive frameworks to help contextualise the findings. Data were managed in NVivo [14] (QSR International). Coding proceeded line-by-line as open coding, followed by collation of codes into candidate themes, review against coded extracts and the full dataset (including cross-group checks), definition/naming of themes, and reporting with illustrative quotations. Coding was led by the first author in NVivo; co-authors provided peer debriefing on codebooks and theme maps. Trustworthiness was supported by a reflexive audit trail (memos, codebook iterations, theme maps), attention to negative cases, and data-source triangulation (parents vs HCPs). Inter-rater reliability and participant member checking were not undertaken, consistent with RTA; analytic sufficiency was reached when no substantively new codes/themes emerged.

Results

Thematic analysis identified four themes: knowledge and training, reasonable adjustments, communication, and system-level barriers. System-level barriers encompassed a broader range of issues and therefore included more subthemes. For each theme, we first summarise areas of convergence across parents/carers and healthcare professionals, before highlighting points of divergence and then presenting group-specific detail with illustrative quotations. Themes were developed on the basis of patterned meaning and analytic relevance rather than the frequency with which particular views were expressed.

Theme 1: Knowledge and training

Across both parents/carers and healthcare professionals, knowledge and training were described as inconsistent and influential in shaping healthcare access for autistic children.

Both groups recognised that autism-related knowledge varied across practitioners and settings, but they differed in emphasis. Parents mainly described the consequences of insufficient knowledge, including mistrust, misattribution of symptoms, and distressing or inappropriate care, whereas healthcare professionals focused on variability in formal training and the extent to which experience, self-directed learning, and personal connections to autism were used to bridge these gaps.

Parent data

Parents' perception of healthcare practitioners' understanding of autism

Some parents felt the need to seek second opinions due to the lack of confidence in the initial assessments and treatments provided by healthcare professionals. A parent shared his experience about not trusting healthcare practitioners:

> *"...Back in the day, I used to trust medical people. But then I told the doctors that my son is shaking a lot. They said 'Oh, it's anxiety'. They put him on medication...the shakes were getting worse, and it turned out that the shakes were actually epileptic traumas. The doctors had picked them up wrong and the medication that they put him on aggravated the epilepsy…he was turning blue."* (P 08).

Parents described some healthcare professionals as lacking specialised training in autism, which they felt could lead to inadequate or inappropriate care. For instance, they believed that some professionals do not understand the unique needs of autistic patients, such as the necessity for tailored interventions or specific communication approaches. However, not all experiences were negative. Some parents recounted instances of exceptional service from healthcare practitioners, which positively impacted their child's healthcare. For instance, one

parent described their encounter with a radiologist who avoided eye contact and spoke calmly and directly to the child.

However, some parents reported an apparent lack of knowledge about autism and co-occurring conditions among healthcare receptionists and non-medical staff. In one instance, instead of facilitating access to immediate care, the receptionist redirected the parents to call emergency services like NHS 111 (UK's non-emergency medical advice helpline) or 999 (UK's emergency services number) when they were told that the child was autistic and unable to wait in a crowded area, indicating a reluctance to engage with the specific needs of autistic child and their parents. This approach delayed necessary care and added unnecessary steps for caring for the child. Some parents reported how receptionists often display a lack of understanding and flexibility regarding the specific needs of autistic children.

Assumptions & Forceful Interventions

Some parents suggested that healthcare practitioners often attribute a wide range of symptoms and behaviours solely to autism without investigating further potential medical issues, which led to a lack of thorough examinations and an overshadowing of other possible conditions:

> *"…Your child is not speaking, he's just crying. And you'll be requesting for some exams, but they just said 'He's autistic. So, it's normal'. When you say the child is not sleeping. Nobody will ever think about. Maybe he has a digestive problem. They just say, 'it's like that. Autistic children, usually they don't sleep'"* (P 01).

Parents reported how symptoms like non-compliance or behavioural issues were often viewed through the lens of autism alone, ignoring possible medical or psychological causes.

For example, one child's aggressive behaviour was linked to an ear infection, but this was initially overlooked due to the assumption that the behaviour was just part of being autistic.

Two parents told us about their experiences where healthcare professionals who apparently did not know how to deal with autistic children used forceful interventions like physical restraint to conduct medical exams. For example, one child was “pinned down” by five staff to examine his throat. Similarly, another child had a traumatic experience when several doctors and nurses forcibly tried to treat an eye injury. Both parents reported that their children later developed a medical phobia following these experiences.

Healthcare practitioner data

HCP knowledge

Healthcare professionals described drawing on a combination of formal training, prior clinical roles, accumulated experience, and personal exposure to autism when reflecting on how they approached care for autistic children. Several participants felt that these experiences had informed their current practice. For example, one healthcare professional worked in paediatrics and social work before becoming a GP, bringing a broad spectrum of relevant experience to his practice. Some professionals described having many years of experience in areas such as day surgery, emergency medicine, or paediatric healthcare, which they felt had helped them develop skills and insights relevant to caring for autistic children. For example, a GP talked about how they dealt with a child with sensory issues who would not sit still to check their vitals. They described how they had to follow him around the room because they had already planned to accommodate the child’s autistic traits.

Several healthcare professionals described having autistic family members or friends, which they felt informed their understanding of autism and informed their professional practice.

Healthcare professionals reported that their foundational university training included some content on making healthcare more accessible and accommodating for autistic individuals. This training addressed specific sensitivities, such as aversion to loud noises and touch. However, they stated that training often lacked depth in understanding the sensory needs of autistic children. This understanding was felt to sometimes be gained through clinical practice rather than formal training, which most healthcare practitioners interviewed in this study had. Some healthcare professionals stated that additional training opportunities were sometimes available at their workplace but were often optional. Healthcare professionals reported being able to choose to further their knowledge based on personal interest and perceived need and talked about the fact that training was not consistently embedded across all healthcare settings.

Some HCPs stated that their settings mandated ongoing training and have dedicated specialists who disseminate updates, changes, and recommendations related to autism care. Another setting had occupational therapists who provided training on sensory needs. These sessions included practical activities such as sensory warm ups which helped professionals to meet the sensory needs of autistic children. However, not all settings offered this training:

> "*…we don't really have anything specific in place for what we are meant to do to support that access to health care. We're left to just organise ourselves and do it ourselves, which I would hope we're quite good at. But yeah, it doesn't really support with making sure that every child is getting the same level of access*" (HCP 08).

Some professionals engaged in advocacy and feedback to improve autism care policies. They actively sought information, challenged inaccuracies, and pushed for better practices through personal initiatives or community forums. Many healthcare professionals reported relying on

their network of trusted colleagues and local experts to stay up to date with autism care, especially when systematic support is lacking. Some professionals also turned to informal sources like Google to gather information about autism.

Theme 2: Reasonable adjustments

Across both parents/carers and healthcare professionals, reasonable adjustments were viewed as important for making healthcare more accessible and less distressing for autistic children. Both groups recognised that relatively simple adaptations, such as quieter environments, extra time, pre-appointment planning, and less invasive approaches, could improve care experiences and reduce distress. However, they differed in emphasis: parents mainly highlighted the inconsistent availability or absence of such adjustments, whereas healthcare professionals described making ad hoc adaptations within the constraints of time, workload, and service context.

Parent data

<u>Adjustments made at the point of delivery</u>

Parents reported a lack of adaptation to the physical environment of healthcare settings. Reasonable adjustments that could make the experience more manageable for autistic children, such as extra time, a calm environment or less invasive methods, were apparently often overlooked. Parents reported that they felt most healthcare settings were not designed for sensory sensitivities to environmental features like loud noises and bright lights. The lack of these adjustments was seen as a significant gap that, if addressed, could improve the healthcare experience for their children. Some parents reported that some healthcare providers were apparently inflexible and not willing to make the necessary adjustments, which resulted in negative experiences and unmet healthcare needs. A lack of pre-

appointment calls and having to wait for long periods of time were also mentioned as problems. Some parents said even though they told the healthcare providers about their child's healthcare needs, the adjustments promised were not made, leading to distressing experiences.

However, some parents reported instances where suitable, reasonable adjustments were made for their children, which positively impacted their experience. For instance, one parent described a positive experience where a consultant communicated through the parent because the child's social anxiety limited communication with unfamiliar people. Another parent shared their experience with an HCP who wore casual attire instead of a uniform and allowed examinations in a car because the child had a medical phobia.

Healthcare practitioner data

Adjustments made at the point of delivery

Healthcare practitioners consistently acknowledged the impact of sensory issues on autistic children. They discussed how they adapted their practices and environments and how that impacted healthcare services. For example, a healthcare practitioner spoke about how their setting changed their practice by speaking to the parents on the phone before a physical appointment is scheduled to reduce unnecessary healthcare visits. A nurse reduced the time for vital observations to prevent distress. They sometimes used quieter, less clinical spaces to reduce sensory overload and offered alternative medication routes. For instance, one practitioner gave walking boots instead of plaster casts to an autistic child with a broken ankle to avoid sensory distress.

Some HCPs mentioned the importance of parents and carers communicating their child's needs and preferences to help HCPs adapt their approach. Some HCPs also mentioned the

lack of standardised training and guidelines leading to variations in how sensory issues are managed.

Theme 3: Communication

Across both parents/carers and healthcare professionals, communication was described as central to healthcare access for autistic children. Both groups recognised that clear, flexible, and individualised communication could improve care experiences, reduce distress, and support more effective consultations. However, they differed in emphasis: parents mainly highlighted limited post-diagnosis guidance, lack of direct engagement with children, and not being listened to, whereas healthcare professionals focused on adapting their communication styles over time and using flexible, child-led approaches to build rapport and facilitate care.

Parent data

<u>Information dissemination</u>

Parents commonly described difficulties finding specific and actionable information relevant to their children's needs. This was compounded by the generic nature of much of the information provided by healthcare professionals, which is often perceived by parents as insufficient or out-dated:

> *"Once we got a diagnosis, there was a letter to say you can access this and it was like two or three services and then you're left to your own device*" (P 03).

After receiving an autism diagnosis, some parents in the present study reported being left without adequate guidance or support on the next steps. This lack of post-diagnosis support hindered families' ability to manage their child's condition effectively. Online social networks, particularly Facebook, served as vital platforms where parents exchanged

experiences, sought advice, and found support from other parents in similar situations. Parents shared personal experiences and recommendations, which were often tailored and practical.

Communication during consultation

Parents commonly described healthcare practitioners as not engaging directly with their children. However, a contrasting perspective was expressed by two parents, who preferred communication to be directed through them rather than directly to their children; both described their children as having social anxiety disorder. Parents also described occasions when they felt their views about their children were overlooked, resulting in negative healthcare experiences:

> "*I phoned them up to say, xx's got a medical phobia…He's very scared of those tools that you use. So don't have it in the room when he enters because he's just going to have a freak out…we went and the tray was there fully. They hadn't taken it out"* (P 10).

Some parents described their experiences with HCPs who implied that they were lying when they spoke about their children's health issues.

> "*The eating disorder team was horrific…Her whole reasoning for not listening to the parents' view was because my son didn't verbally state to her that he has an eating disorder. She said, "Well, who says he doesn't eat? It's you" (P 03).*

In contrast, some parents recounted good experiences where clear communication of what to expect was given to them and their children. For example, a vaccination centre and dental practice took extra time to explain procedures, which parents described as improving their

children's experiences. Parents often had to advocate strongly for their children's needs to be met. When healthcare providers listened and acted on this input, parents generally considered the outcomes to be better.

Healthcare practitioner data

Healthcare professionals described communication as something that often needed to be actively adapted to the child's preferences, behaviour, and level of comfort. All the healthcare professionals interviewed in this study stated that they had made changes to their communication styles based on the children's preferences and behaviour. For example, an HCP shared a positive experience where they engaged a child by letting them name a life-size paper 3D model of a human body. This helped build rapport and made the consultation process easier. One HCP also emphasised the importance of listening to the parents and understanding the child's interests to frame the interaction accordingly.

The HCPs frequently mentioned the necessity of flexible and individualised approaches and adapting consultation to suit a child's needs. Several healthcare practitioners also mentioned the importance of training and experience in understanding and managing autism-specific behaviours and sensory issues. They described how their approaches to dealing with autistic children have evolved and improved significantly from the beginning of their careers:

> "*From that first bad experience, this was 14 years later into my clinical career…at the end when he approached me and just gave me a toy, and he even looked at me. And I think it was a positive experience because I was able to trust my judgement in that moment and go, okay, I can't overwhelm him even more"* (HCP 08).

Theme 4: System-level barriers

Across both parents/carers and healthcare professionals, system-level pressures were described as major barriers to healthcare access for autistic children. Both groups recognised that limited capacity, long waiting times, fragmented pathways, and inconsistencies across services could delay care and make navigation more difficult. However, they differed in emphasis: parents mainly described the family experience of gatekeeping, delays, and feeling lost within disconnected services, whereas healthcare professionals focused on workload pressures, triage demands, referral complexity, and variation across settings and NHS organisations.

Parent data

Participants described a healthcare system grappling with inefficiency, long waiting times, and insufficient support for children with special needs or mental health issues due to a lack of resources.

Waiting delays & inefficiency

Several parents reported the lengthy waiting periods they encountered between assessments and follow-up appointments. For example, a child waited for a review from December to the following June, which was further delayed until the subsequent December. Immediate support was often not available, which the parents thought worsened their children's condition. Parents expressed frustration over the delays in getting appointments with general practitioners. They complained that the urgency of their children's health issues often clashed with the long wait times. There is also a perceived barrier to accessing medical services due to receptionists acting as gatekeepers. This adds to the frustration, especially when immediate medical attention is necessary:

> *"...you can't get past the receptionist because they know best"(*P 02).

Some parents reported that they felt healthcare professionals deliberately avoided providing treatment due to financial constraints. They felt that the limited financial resources available in the healthcare system influenced the decision-making process of these professionals, leading to insufficient or delayed care for their autistic children. One parent elaborated on her belief regarding the reasons for the long wait:

> *"…if you can catch these things super early, you can avoid it ever being a problem… because of the lack of funding, 'let's ignore it. Let's put it off. Let's not do anything about it until we're at a crisis point'"* (P 04).

Despite the systemic issues, there were instances where individual healthcare providers acted promptly and effectively, such as when a cancellation allowed a child with severe dental issues to be seen sooner. However, the overarching narrative is one of delay and inadequate responses to urgent health needs.

Allocated time

The standard 10-minute GP appointments were often not adequate for addressing complex health issues, which led to rushed consultations and incomplete care. Parents expressed their frustration with the standard GP appointment time, which was too brief and did not allow thorough examination and understanding of the children's issues. The short appointment time increased the challenge for non-speaking children or those who have difficulty expressing themselves, as parents struggle to convey all necessary information and concerns within the limited timeframe:

> "*…And on the front door it is written just one problem ten minutes. when you go to the GP, you don't have more than ten minutes…To talk about your problem. But your child is not speaking, he's just crying*" (P 01).

There were also reported experiences of situations whereby healthcare professionals performed the minimum required and then discharged patients without ensuring that all concerns were addressed, as seen in the case of children with nutritional and developmental needs that were not fully addressed:

> *"…they only have a 10 minutes slot…And he was so upset that we couldn't wait for him to calm down. So, she had to quickly listen to his chest in between his screaming…It's not your fault you had to do it that way….But is your conscience clear enough to send me away now after having to listen like that with your stethoscope to say, 'no, he's fine?"* (P 05).

Parents reported they needed to frequently advocate for longer appointments or additional services to meet their children's needs. This included requesting extended appointment times and persistently following up to ensure their children received the necessary care. In contrast, most parents' experiences with the allocated time for paediatrician appointments have been predominantly positive. Most parents who reported their experiences with the paediatrician felt that the time given to treat their children was sufficient.

Work overload

The limited time allocated for the children's appointments was partly because the healthcare professionals had to see a large number of children within a short consultation time, which affected the amount of time they could spend with each child during consultation. For example, some parents said some specialists did the initial assessment and report but did not have time for follow-up appointments, so care was fragmented. They described the professionals as doing "their bit" and then moving on, which means they only deal with immediate needs and not long term needs due to time constraints:

"…They will do their bit that they are paid to do. They get rid of you. Despite the fact that you may not be sorted with what you went to them for…He is very nutritionally unwell because you can't live on toast. But they can't do anything. They did their bit. They saw him, they did a report. That's all they were paid to do. So that's it" (P 05).

Most parents interviewed believe that practitioners are unable to spend enough time with each patient, not because they do not want to, but because of the time constraints they are under.

Integrated services & referrals

Parents reported that healthcare settings appeared to often work in silos, addressing physical, behavioural and social communication problems separately rather than holistically. Parents, especially those who lack prior knowledge or experience, felt lost and overwhelmed by the complexity of navigating the healthcare system:

"Where do we start? Who do we pick up the phone to? It's hard. It's like you feel lost. You feel like you're at crossroads." (P 12).

Parents reported that referrals often seem delayed or blocked due to systemic issues. Although it is unlikely to be the case, one parent suspected that some services were being withheld to prevent parents from accessing them:

"My son wasn't referred to the occupational therapist... I was led to believe that the occupational therapist was for their physical movement…It wasn't until speaking to other parents that I found out, OT can help with things like toileting because my son's classed as incontinent...I had to do a self-referral to get him seen because none of

the other professionals had even bothered mentioning it…there are services you can access that they're not telling you about." (P 09).

Healthcare practitioner data

Allocated time & work overload

Healthcare practitioners reported the broader systemic issue of time limitations in clinical settings, which can hinder the ability to provide thorough and patient-centred care:

"*Obviously, we'll treat them as needed. But I can't say that we have a huge amount of time to be able to dedicate to them, as well as we may want to. Because we're very busy, a lot of the time we see a lot of children. And those children need that bit of extra time. And sometimes we can't give that to them because of pressures of the ward and the other patients as well. That definitely happens regularly" (*HCP 05).

The HCPs reported on the issue of high caseload numbers impacting the provision of adequate support. The pressured environment within the department meant they had to prioritise life-threatening issues over other essential support.

"*Patients that have those additional needs don't always have those needs met when the department is at capacity and it's full and it's got high acuity because you do unfortunately have to prioritise those medical emergency needs. So it can be frustrating"* (HCP 06).

This perspective was further confirmed by another HCP:

"..Life or death wins over communication. You're going to do that as a priority over the communication support. So yes, it's the answer to your question" (HCP 07).

Integrated service & referrals

The HCPs criticised the inconsistency in the care provided across different NHS Trusts, primary and outpatient care, delays and lack of resources, resulting in disparity in the quality and timeliness of care.

One HCP discussed the disconnect in policy and the lack of joined-up thinking between children's and adult services, which creates delays and barriers to timely care. He illustrated the severe impact of long waiting times in mental health services, comparing the urgency of physical health emergencies to the often-delayed response in mental health care.

Not all HCPs were involved directly in referrals, but those who were able to share their experience highlighted vital themes, which included the complexity of the referral process, accessibility issues caused by system-wide problems, and delays. One HCP talked about the importance of knowledge in processing referrals, especially when professionals do not have an open referral policy.

While some improvements have been made, such as introducing electronic systems like System One, they have not fully resolved the healthcare access challenges, especially in a situation where the systems were not widely used across all Trusts and when some healthcare professionals were not trained to use them effectively. However, one healthcare professional stated that having autism does not impact the referral process. They emphasised that referrals are based on the patient's medical needs rather than autism diagnosis.

Discussion

To our knowledge, this is the first qualitative UK study to compare parents'/carers' and healthcare professionals' perspectives on autistic children's healthcare access across NHS settings, with an explicit focus on areas of convergence and divergence. Similar to our previous studies (systematic review & survey), and as reported in other international studies (Edelson, et al., 2022), the findings reveal a complex interplay of patient, provider and system level influences on healthcare access. The discussion is organised around the themes identified in the analysis, with emphasis on interpreting the findings in relation to existing qualitative literature and on examining areas of convergence and divergence between parents'/carers' and healthcare professionals' perspectives. COM-B and TDF are retained as broad interpretive lenses to help contextualise implementation-related implications, rather than as frameworks that structured the analysis or Results since the interview topics were guided by these.

These findings are broadly consistent with prior qualitative work showing that barriers to healthcare and support for autistic children arise across interpersonal, organisational, and systemic levels (Boshoff et al., 2018; Boshoff et al., 2021; Hodgetts et al., 2013). In the UK, Mason et al. (2021) also qualitatively compared clinician and caregiver/autistic perspectives and similarly highlighted concerns about communication, professional understanding, and the need for more flexible, individualised care. Our findings align with this broader evidence base, but extend it by focusing specifically on autistic children's healthcare access across NHS settings and by examining where parents'/carers' and healthcare professionals' perspectives converge and diverge in relation to barriers such as professional knowledge, reasonable adjustments, communication, and system fragmentation (Gholipour et al., 2023; Carbone et al., 2013; Muskat et al., 2016; Davignon et al., 2014; Snow et al., 2021). What

remains less well understood is how these issues play out across routine NHS healthcare settings for autistic children specifically, and how they are experienced from both sides of the healthcare encounter. The present study addresses this gap by providing a cross-setting, NHS-focused comparative account of these barriers and facilitators in practice.

Some findings may be particularly shaped by the organisation of NHS services, including variation between local services, fragmented referral pathways, limited interoperability of records, waiting times and pressures on appointment capacity. However, other findings, including the need for autism-specific knowledge, flexible communication, sensory adjustments, anticipatory preparation and greater involvement of families, are consistent with qualitative research conducted in other healthcare contexts (Carbone et al., 2013; Muskat et al., 2016; Davignon et al., 2014; Snow et al., 2022). These findings may therefore have relevance beyond the NHS, although the organisational mechanisms for implementing improvements will differ between healthcare systems.

Knowledge and training

Impact of limited knowledge and training

Adequate autism-specific training for healthcare professionals is important to increase their ability to recognise autistic children's unique sensory, communication and behavioural needs that require specialist knowledge (Unigwe, 2017). Lack of training could lead to suboptimal care, missed diagnoses and even traumatic experiences which can lead to negative associations with healthcare and avoidance of necessary care (ibcces.org, 2019). The lack of consistency in training often leads to wide variability in healthcare settings (Unigwe et al., 2017). Relying on informal learning or limited training opportunities means healthcare

providers may not be well equipped to deal with the complexities of autism, which means care might be fragmented and ineffective (Fletcher-Watson et al., 2018).

This pattern is consistent with earlier work showing that families often perceive clinicians as lacking autism-specific understanding, while professionals themselves describe variable confidence, training, and practical preparedness (Carbone et al., 2013; Gholipour et al., 2023; Morris et al., 2019; Mason et al., 2021). It also aligns with research suggesting that parents and providers may recognise similar broad problems but differ in how they interpret their causes and consequences (Carbone et al., 2013; Gholipour et al., 2023).

While existing training in autism-specific issues is a step in the right direction, there is still much to be done to balance the theoretical and practical aspects of autism care. Theoretical knowledge alone is not enough for autistic children who need flexible, adaptable care strategies which can only be learnt through practical experience and hands-on training (Unigwe, et al., 2017). Effective autism training should include simulated interactions, case studies, and practical exercises to help healthcare providers develop the skills needed to manage autism challenges in real-world settings (BMC Medical Education, 2020). Practical hands-on training can also improve healthcare practitioners' competence and confidence, which in turn can increase their ability, by providing exercises that allow them to apply strategies for managing autism challenges (Unigwe et al., 2017; Crane et al., 2018). The positive examples reported in the present study suggest that autism-aware practice can be strengthened when formal training is supplemented by practical, case-based learning and accumulated clinical experience.

Assumption and misattribution of symptoms

Healthcare professionals attributing a wide range of symptoms and behaviours to autism is particularly harmful to autistic children because it could lead to diagnostic overshadowing and neglect (Ng-Cordell et al., 2022). The conventional medical model's deficit-focused approach risks oversimplifying the complexities of autism, which means the HCPs might fail to address the diverse needs of autistic individuals effectively (Pellicano & den Houting 2022). Diagnostic overshadowing is when a person's symptoms are attributed to their primary diagnosis (autism), and co-occurring conditions are overlooked or misdiagnosed (Singh et al., 2023; Ng-Cordell et al., 2022). When healthcare professionals assume all symptoms stem from autism, they may not investigate other medical or psychological conditions and miss diagnoses or interventions with potentially harmful consequences. This could be because of a lack of training in the complexities of autism (Ng-Cordell et al., 2022), communication barriers between healthcare practitioners and the patients (Unigwe, et al., 2017), lack of resources or time constraints, which could make some healthcare professionals rush consultations (Ng-Cordell et al., 2022). To reduce diagnostic overshadowing, commission extended slots for complex cases, mandate “do-not-miss” checklists for common co-occurring conditions and ensure electronic health records carry an autism reasonable-adjustments flag across settings (Ng-Cordell et al., 2022; NHS England, 2019). Enhancing autism-specific knowledge helps HCPs distinguish autism-related behaviours from co-occurring conditions, reducing diagnostic overshadowing and promoting thorough, appropriate care (Singh et al., 2023).

Non-medical staff

A recurring theme in the research is the issues with non-medical staff, such as administrative personnel or receptionists, who are often the first point of contact. Parents reported instances where they may have unintentionally caused distress, trauma or frustration with insensitive

handling of patients and families (Doherty et al., 2022). Empathetic communication is crucial to improving healthcare experiences for autistic patients (Fletcher-Watson et al., 2018; Doherty et al., 2022), however, without proper training, non-medical staff members might not be equipped to respond flexibly to the needs of autistic children, which could result in barriers to accessing healthcare services and delays in critical medical interventions for the children.

Another significant issue raised in the study is the role of non-medical staff acting as gatekeepers to medical services. This is usually to control the scheduling of appointments or how information is shared between workers in healthcare settings. However, if the frontline staff are not trained to recognise autism-specific traits, their co-occurring conditions or how they affect autistic individuals, they might not be capable of providing the right support. They might also unintentionally deny access to care if they believe that the symptoms described by the parent are not important (Doherty et al., 2022). The non-medical staff, in this case, might not understand the urgency of the test result to the autistic child or might not realise why it is important for an autistic child to see a familiar GP rather than go to the accident and emergency department where they would most likely encounter strange faces. This reinforces the need for baseline autism awareness for all frontline roles (Unigwe et al., 2017).

Although the significant role that non-medical staff play in facilitating or hindering access to care and the need for adequate training have been well documented (Doherty et al., 2022; Fletcher-Watson et al., 2018), training all receptionists in autism-specific care might not be feasible because of the high number of non-medical staff, low wages and varying educational backgrounds (Edelson, 2022). Despite these challenges, practical low-burden solutions include brief e-learning, interactive micro-modules (between 10–15 min), onboarding and periodic refreshers, and quick reference guides ("cheat sheets") at reception desks to support

responses to common issues faced by autistic children and their families (Unigwe et al., 2017; Crane et al., 2018; Kennedy et al., 2016; Edelson, 2022; Doherty et al., 2022).

One recent policy response in England is the Oliver McGowan Mandatory Training (Department of Health and Social Care, 2025) on Learning Disability and Autism, which aims to improve staff knowledge and support safer, more informed care. However, the training may still be too general for some roles and does not fully address the more specific communication, sensory, and system-level issues highlighted in the present study.

For example, although it covers reasonable adjustments about sensory and communication issues, it does not offer actionable role-specific guidance or specialised training, particularly in non-speaking or minimally speaking communication strategies. Also, even though it provides training about waiting times, it does not address systemic solutions offered in the present study. Furthermore, the training is long and time-consuming, which could lead to disengagement among non-medical staff (Health Education England & Skills for Care. 2022; Salas et al., 2012). The mandatory nature of the training may also lead to resistance among participants, which could reduce its effectiveness. Furthermore, the "one size fits all" approach may not address the diverse needs of different healthcare roles like receptionists versus clinicians (Unigwe et al., 2017; Crane et al., 2018). Therefore, further evaluation is needed to determine its long-term effectiveness in improving care for autistic children.

Forceful interventions

Forceful interventions were described as particularly harmful for autistic children because sensory sensitivities, communication differences, and anxiety in unfamiliar environments may increase distress and reduce cooperation during care (Hoover, 2015; Wong et al., 2020). Such experiences can be traumatic and may contribute to long-term fear of healthcare

settings, particularly when children do not understand why restraint or coercive procedures are being used (Adams et al., 2018; Hoover et al., 2015). The present findings therefore reinforce the importance of slower pacing, anticipatory preparation, flexible examination approaches, and reliance on parent knowledge as safer and more compassionate alternatives to coercive practice.

Communication

Communication emerged as a central determinant of healthcare access in the present study. This is consistent with broader parent-focused literature showing that families often experience inadequate communication, difficulty navigating services, and pressure to advocate repeatedly for their child's needs (Boshoff et al., 2018; Boshoff et al., 2021; Kerr et al., 2026). However, the present study adds a comparative dimension by showing that, although both parents/carers and healthcare professionals recognised the importance of flexible, individualised communication, parents more often described the consequences of not being listened to, whereas healthcare professionals emphasised adaptation within existing constraints (Carbone et al., 2013; Gholipour et al., 2023).

Communication and information after diagnosis

Parents in the present study described post-diagnosis information and guidance as limited, generic, and often insufficient for managing their child's needs, which is consistent with earlier work on inadequate post-diagnostic support (Crane et al., 2016). Many therefore relied on informal networks such as Facebook for practical, experience-based advice. Although these networks could provide tailored and emotionally relevant support, they also raise concerns about inconsistent or non-evidence-based information (Casagrande & Ingersoll, 2017; Moorhead et al., 2013; Chou et al., 2009). Together, these findings suggest that formal

post-diagnosis support should be more practical, individualised, and responsive to family context (Crane et al., 2016), including for parents who are themselves autistic or otherwise neurodivergent as emerging evidence suggests that autistic parents can face distinct challenges when navigating services for their autistic child, including feeling judged and stigmatised by professionals (Radev et al., 2024).

Reasonable adjustments

Reasonable adjustments and pre-assessment

Healthcare professionals in the present study recognised the value of pre-assessment and anticipatory planning but described these processes as inconsistently implemented in practice. This appeared to reflect a combination of workload pressures, limited capacity, and fragmented systems that made it more difficult to identify and prepare for autistic children's needs in advance (Crane et al., 2018; Exworthy et al., 2011; Unigwe et al., 2017). Although some practitioners had adapted their practice through greater awareness and experience, the absence of more systematic pre-assessment processes limited their ability to make timely and appropriate adjustments. Therefore, implementing pre-admission protocols, continuity of care, and better systems for identifying support needs in advance is essential to better support and improve healthcare outcomes for autistic children (Autism Spectrum News, 2023; ATN, 2023).

The importance of anticipatory preparation, flexible environments, and tailored procedural support is in line with previous studies in emergency, procedural, and surgical contexts, which have similarly highlighted the value of disclosure, preparation, environmental modification, and collaborative planning with families (Muskat et al., 2016; Davignon et al., 2014; Snow et al., 2021). The present study extends those more setting-specific findings by

suggesting that these same principles are relevant across a broader range of NHS healthcare encounters.

Reasonable adjustments and work overload

Work overload due to financial constraints in the healthcare system is another issue that affects healthcare professionals. Overworked healthcare professionals would most likely not be motivated to provide adequate care for their patients, which would disproportionately affect autistic children, whose care is often more resource-intensive (Edelson, et al., 2022). Underfunded services would most likely struggle to provide timely interventions, leading to long waiting lists for critical services (Crane et al., 2018).

The healthcare professionals in the study acknowledged the importance of sensory issues and talked about the reasonable adjustments they had made. However, they also mentioned that there were no standard guidelines across healthcare settings. When there are no systemic supports or guidelines on reasonable adjustment, the HCPs would need to rely on their own judgement and creativity to address these issues which could reduce their willingness or capacity to implement adjustments consistently (Unigwe et al., 2017). Some HCPs, like the participants in the current study might take the initiative to make adjustments, but these are individual initiatives. This means autistic children are more likely to receive varying levels of support depending on the setting or provider. While individual efforts are helpful, they do not ensure consistency across settings which limits the effectiveness of adaptations, therefore standardised guidelines are essential to ensure consistent and effective reasonable adjustments and improved care outcomes for autistic individuals (Edelson, et al., 2022).

<u>System-level barriers</u>

System-level barriers identified in the present study are consistent with previous work showing that fragmented pathways, inconsistent service coordination, and organisational constraints can undermine accessible care for autistic children and their families (Gholipour et al., 2023; Hodgetts et al., 2013; Boshoff et al., 2021). What the present study adds is a clearer account of how these same system pressures are experienced from both sides of the encounter: as delay, gatekeeping, and uncertainty for families, and as workload, triage pressure, and constrained flexibility for healthcare professionals.

Policies and regulations

Inconsistent policies and regulations between providers and settings mean care delivery can be different from one location to another, which can be confusing. This inconsistency can result in delays in accessing services and can worsen the existing health conditions of the children as discussed in our previous studies. The healthcare practitioners emphasised the need for consistent policies across Trusts and improved data management systems to prevent information inefficiencies. This could be because they were frustrated by working in a working environment that is fragmented and under-resourced. Managing a high caseload, especially when dealing with complex and multifaceted health needs like autism, can lead to frustration or professional burnout (Crane et al., 2018).

Dealing with a fragmented system, especially when they do not have the opportunity to thoroughly follow up on each patient's needs could also negatively affect healthcare professionals' job satisfaction and morale (Crane et al., 2018). Research has shown that fragmented care, different policies across Trusts and poor data management are the main barriers to optimal and timely care for autistic children (Babalola et al., 2024; Crane et al., 2018). Current efforts to integrate services, such as multidisciplinary assessments and electronic health records, show some progress but are not consistent (Exworthy et al., 2011).

Although inconsistent, these examples suggest that joined-up systems and interoperable records may provide a useful foundation for reducing fragmentation if implemented more consistently across services. The lack of standardised protocols and siloed services hinder care coordination and can result in significant variation in care (Kennedy et al., 2016; Pratt et al., 2011). These delays can exacerbate health issues and create additional stress for the families. Therefore, commissioners should set cross-Trust service-level agreements and an auditable reasonable-adjustments protocol. Full system-level actions are summarised in Implications for Policy and Practice.

Waiting times, resources and work overload

Parents in the current study highlighted issues with long waiting times (for initial appointments and between assessments and follow-ups). Parents reported that their autistic children need more time during medical consultations due to their communication difficulties, sensory sensitivities and complexity of their conditions (Babalola et al., 2024). Rigid procedures such as fixed appointment lengths might not allow the HCPs the opportunity to address complex autistic children's health issues (Pellicano & den Houting, 2021), leading to rushed consultations, incomplete care and increased anxiety for both the child and their parent (Crane et al., 2018).

The reliance on standard appointment times, regardless of patient needs and lack of continuity of care, increased the challenges faced by autistic children and their families (Babalola et al., 2024). However, the NHS recognises that individualised care is needed and is working to improve healthcare access for autistic people. Some examples of these efforts include the 2024/25 priorities and operational planning guidance (NHS England, 2024) and the Five-year NHS autism research strategy for England (NHS England, 2022), which reflect ongoing efforts to improve healthcare and support for autistic people in England. The

operational planning guidance includes actions relating to autism-specific staff training, diagnostic pathways and the use of reasonable adjustment digital flags (NHS England, 2024), while the research strategy aims to strengthen the evidence base underpinning NHS autism services (NHS England, 2022). However, neither document specifically identifies flexible appointment duration as an autism-related action, despite the importance of sufficient consultation time identified in the present study.

Implications for Policy and Practice

Our findings point to concrete system changes that commissioners and providers can work towards implementing:

Commissioning & training: Embed autism-specific training in contracts and commissioning frameworks for all roles (including reception/administrative staff), with regular refreshers and local sign-off; align content with national standards and the Oliver McGowan model.

Reasonable adjustments as standard: Require service specifications to include longer/flexible appointment times, quiet/low-sensory waiting options, pre-appointment planning calls, and alternatives to clinic rooms (e.g., car or home visits where appropriate), with simple audit indicators.

Integrated pathways & coordination: Commission joined-up pathways across primary care, emergency departments, dentistry, community paediatrics and mental health, with a single point of access, shared care plans, warm handovers, and a named care coordinator.

Capacity & data systems: Invest to reduce waiting times and improve continuity; ensure interoperable records that flag reasonable adjustments so they follow the child across settings.

Post-diagnosis navigation: Resource co-designed information, proactive follow-up, and signposting so families are not reliant on informal networks for crucial guidance.

Measurement & accountability: Set clear commissioning metrics (e.g., proportion of extended appointments provided; time to follow-up; uptake of adjustments) and report performance to drive improvement.

These actions operationalise individualised, flexible care at the system level and are consistent with national guidance and priorities (NICE, 2021; NHS England, 2019; Department of Health & Social Care, 2022; Crane et al., 2018).

Strengths and limitations

A key strength of this study is that it directly compares the perspectives of parents/carers and healthcare professionals, allowing areas of convergence and divergence in healthcare access to be examined across NHS settings. The phenomenologically informed qualitative approach generated rich accounts of parents'/carers' and healthcare professionals' experiences and perspectives, while also identifying practical examples of accessible care and areas for service improvement. These features strengthen the relevance of the findings for policy and practice.

Although the sample included some geographical and professional variation, diversity within both participant groups was still limited. The parent sample was composed almost entirely of mothers. It would have been helpful to hear from more fathers or other carers such as grandparents. This is because their approaches often differ in how they deal with situations and understanding the differences could help healthcare professionals in how they engage with them. For example, fathers are more likely to be practical and less emotional which might affect how they deal with autism-related healthcare challenges (Braunstein et al.,

2013). Fathers are also less likely to be involved in advocacy compared to mothers (Lindgren et al., 2017) which might affect the level of healthcare services the child is able to access. The HCP sample was also small and unevenly distributed across professions, with limited representation of some key groups such as GPs and no dentists. In addition, we did not collect ethnicity, socioeconomic status, or rurality data across either group, which limited consideration of how social location and professional context may shape experiences. The interviews were conducted in English without interpreter support, which may have limited the representation of families with limited English proficiency. Future research should consider multilingual or interpreter-supported approaches to broaden participation. Future studies should purposively recruit a broader and more diverse range of parents/carers and healthcare professionals to enhance the transferability and breadth of the findings. We also did not systematically collect data on whether parents/carers or healthcare professionals identified as autistic, disabled, or otherwise neurodivergent. This may be important, as such identities and lived experiences could shape both service navigation and professional understanding of autism. Future studies should capture these characteristics explicitly and explore how they influence experiences of care. Autistic children were not interviewed, so their experiences were represented indirectly through parent/carer and healthcare professional accounts.

Although the first author's lived experience could be seen as a strength because the parents were able to open up to her once they realised that she was also a mother of an autistic child, it could have affected the reporting of the data because of bias. Also, the fact that the participants had to recall past experiences may introduce recall bias, as current feelings and perceptions can influence their memories. Standardised measures of adaptive functioning were not collected; parent-reported profiles aid context but limit cross-study comparability. Future studies should use prospective research methods, where participants can report their

experiences in real-time or shortly after the healthcare interaction so as to reduce recall bias and get more accurate data. Future research should use accessible and co-produced methods to include autistic children and young people directly in reporting their healthcare experiences and in designing and evaluating adjustments and care pathways (Pellicano & den Houting, 2022).

Conclusion

This study contributes to NHS-wide debates on healthcare equity by showing how access barriers for autistic children are produced at system level, through variable reasonable adjustments, time-limited appointments, and fragmented pathways. In England, several recommendations map onto levers available to integrated care systems, including embedding autism-specific training in contracts, requiring reasonable adjustments in service specifications, commissioning integrated pathways with a single point of access and a named care coordinator, and investing in capacity and interoperable data to support continuity. Implementing these changes would operationalise personalised care and reduce avoidable inequities for autistic children and their families.

References

Adams, C., Lockton, E., Freed, J., Gaile, J., Earl, G., McBean, K., Nash, M., Green, J., Vail, A., & Law, J. (2012). The Social Communication Intervention Project: A randomized controlled trial of the effectiveness of speech and language therapy for school-age children who have pragmatic and social communication problems with or without autism spectrum disorder. *International Journal of Language & Communication Disorders, 47*(3), 233–244. https://doi.org/10.1111/j.1460-6984.2011.00146.x

American Psychiatric Association, DSM-5 Task Force. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5™ (5th ed.).* American Psychiatric Publishing, Inc. https://doi.org/10.1176/appi.books.9780890425596

Babalola, T., Sanguedolce, G., Dipper, L., & Botting, N. (2024). Barriers and facilitators of healthcare access for autistic children in the UK: A systematic review. *Review Journal of Autism and Developmental Disorders.* https://doi.org/10.1007/s40489-023-00420-3

Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & 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), 147–160. https://doi.org/10.1111/cch.12504

Boshoff, K., Bowen-Salter, H., Gibbs, D., Phillips, R. L., Porter, L., Wiles, L. (2021). A meta-synthesis of how parents of children with autism describe their experience of accessing and using routine healthcare services for their children. Health and Social Care in the Community, 29, 1668–1682. https://doi.org/10.1111/hsc.13369

Braunstein, V. L., Peniston, N., Perelman, A., & Cassano, M. (2013). The involvement of fathers in investigations of autistic spectrum disorders. *Research in Autism Spectrum Disorders, 7*(2), 369-377. https://doi.org/10.1016/j.rasd.2013.03.005

Cane, J., O'Connor, D. A., & Michie, S. (2012). Validation of the theoretical domains framework for use in behaviour change and implementation research. *Implementation Science*, 7(1), 37. https://doi.org/10.1186/1748-5908-7-37

Carbone, P. S., Murphy, N. A., Norlin, C., Azor, V., Sheng, X., & Young, P. C. (2013). Parent and pediatrician perspectives regarding the primary care of children with autism spectrum disorders. Journal of Autism and Developmental Disorders, 43(4), 964–972. https://doi.org/10.1007/s10803-012-1640-7

Casagrande, K. A., & Ingersoll, B. R. (2017). Service delivery outcomes in ASD: Role of parent education, empowerment, and professional partnerships. *Journal of Child and Family Studies, 26*(9), 2386–2395. https://doi.org/10.1007/s10826-017-0759-8

Cheak-Zamora, N. C., Teti, M., & First, J. (2015). "Transitions are scary for our kids, and they're scary for us": Family member and youth perspectives on the challenges of transitioning to adulthood with autism. *Journal of Applied Research in Intellectual Disabilities, 28*(6), 548–560. https://doi.org/10.1111/jar.12150

Crane, L., Davidson, I., Prosser, R., & Pellicano, E. (2018). Understanding psychiatrists' knowledge, attitudes, and experiences in identifying and supporting their patients on the autism spectrum: Online survey. *BJPsych Bulletin, 42*(4), 151-158. https://pmc.ncbi.nlm.nih.gov/articles/PMC6469236/

Davignon, M. N., Friedlaender, E., Cronholm, P. F., Paciotti, B., & Levy, S. E. (2014). Parent and provider perspectives on procedural care for children with autism spectrum disorders. Journal of Developmental & Behavioral Pediatrics, 35(3), 207–215. https://doi.org/10.1097/DBP.0000000000000036

Department of Health and Social Care. (2022). *The Oliver McGowan mandatory training in learning disability and autism: Government response.* Retrieved from https://www.gov.uk/government/publications/oliver-mcgowan-mandatory-training-in-learning-disability-and-autism-government-response

Department of Health and Social Care. (2023). The NHS Constitution for England. GOV.UK. https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england

Department of Health and Social Care. (2025). *The Oliver McGowan code of practice on statutory learning disability and autism training.* Retrieved from https://www.gov.uk/government/publications/oliver-mcgowan-code-of-practice

Doherty, M., Neilson, S., O'Sullivan, J., Carravallah, L., Johnson, M., Cullen, W., & Shaw, S. C. K. (2022). Barriers to healthcare and self-reported adverse outcomes for autistic adults: A cross-sectional study. *BMJ Open, 12*(2), e056904. https://doi.org/10.1136/bmjopen-2021-056904

Edelson, S. M. (2022). Understanding challenging behaviors in autism spectrum disorder: A multi-component, interdisciplinary model. *Journal of Personalized Medicine, 12*(7), 1127. https://doi.org/10.3390/jpm12071127

Exworthy, M., & Hunter, D. J. (2011). The challenge of joined-up government in tackling health inequalities. *International Journal of Public Administration, 34*(4), 201–212. https://doi.org/10.1080/01900692.2011.551749

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism, 23*(4), 943-953. https://doi.org/10.1177/1362361318786721

Gholipour, K., Ghiasi, A., Shahrokhi, H. et al. Perceptions of the Professionals and Parents of Children with Autism Spectrum Disorders About Autism Services; A Qualitative Study. J Autism Dev Disord 53, 96–109 (2023). https://doi.org/10.1007/s10803-021-05388-9

Hodgetts, S., Nicholas, D., Zwaigenbaum, L., & McConnell, D. (2013). Parents' and professionals' perceptions of family-centered care for children with autism spectrum disorder across service sectors. Social science & medicine (1982), 96, 138–146. https://doi.org/10.1016/j.socscimed.2013.07.012

Hoover, D. W. (2015). The effects of psychological trauma on children with autism spectrum disorders: A research review. *Review Journal of Autism and Developmental Disorders, 2*(3), 287-299. https://doi.org/10.1007/s40489-015-0052-y

Kerr, J., Nicholson, H., Richards, R., & Anderson, C. (2026). Parents' experiences in accessing services for their autistic children in the United Kingdom: A meta-synthesis. The British journal of clinical psychology, 65(2), 470–491. https://doi.org/10.1111/bjc.70033

Kennedy, R., Binns, F., Brammer, A., Grant, J., Bowen, J., & Morgan, R. (2016). Continuous service quality improvement and change management for children and young people with autism and their families: A model for change. *Comprehensive Child and Adolescent Nursing.* https://doi.org/10.1080/24694193.2016.1178357

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism, 20*(4), 442–462. https://doi.org/10.1177/1362361315588200

Levy, D., Ronemus, M., Yamrom, B., Lee, Y. H., Leotta, A., Kendall, J., … & Wigler, M. (2011). Rare de novo and transmitted copy-number variation in autistic spectrum disorders. *Neuron, 70*(5), 886-897. https://pubmed.ncbi.nlm.nih.gov/21658582/

Lindgren, K., Olin, B., Ringnér, A., & Persson, E. (2017). Being a father to a child with autism spectrum disorder; Experiences of getting a diagnosis and navigating healthcare services. *Scandinavian Journal of Caring Sciences, 31*(3), 627-635. https://doi.org/10.1111/scs.12378

Mason, D., Ingham, B., Birtles, H., Michael, C., Scarlett, C., James, I. A., Brown, T., Woodbury-Smith, M., Wilson, C., Finch, T., & Parr, J. R. (2021). How to improve healthcare for autistic people: A qualitative study of the views of autistic people and clinicians. Autism : the international journal of research and practice, 25(3), 774–785. https://doi.org/10.1177/1362361321993709

Michie, S., Johnston, M., Abraham, C., Lawton, R., Parker, D., & Walker, A. (2005). Making psychological theory useful for implementing evidence based practice: A consensus approach. *Quality and Safety in Health Care*, 14(1), 26–33. shttps://doi.org/10.1136/qshc.2004.011155

Michie, S., van Stralen, M. M., & West, R. (2011). The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science*, 6, 42. https://doi.org/10.1186/1748-5908-6-42

Moorhead, S. A., Hazlett, D. E., Harrison, L., Carroll, J. K., Irwin, A., & Hoving, C. (2013). A new dimension of health care: Systematic review of the uses, benefits, and limitations of social media for health communication. *Journal of Medical Internet Research, 15*(4), e85. https://doi.org/10.2196/jmir.1933

Morris, R., Greenblatt, A. & Saini, M. Healthcare Providers' Experiences with Autism: A Scoping Review. J Autism Dev Disord 49, 2374–2388 (2019). https://doi.org/10.1007/s10803-019-03912-6

Muskat, B., Greenblatt, A., Nicholas, D. B., Ratnapalan, S., Cohen-Silver, J., Newton, A. S., Craig, W. R., Kilmer, C., & Zwaigenbaum, L. (2016). Parent and health care provider perspectives related to disclosure of autism spectrum disorder in pediatric emergency departments. Autism, 20(8), 982–994. https://doi.org/10.1177/1362361315621520

National Health Service. (2019). *The NHS long term plan.* Retrieved from https://www.longtermplan.nhs.uk/

National Institute for Health and Care Excellence. (n.d.). Autism in adults: Prevalence. Clinical Knowledge Summaries. Retrieved August 10, 2025, from https://cks.nice.org.uk/topics/autism-in-adults/background-information/prevalence/

NHS England. (n.d.). What is integrated care? Retrieved August 21, 2026, from https://www.england.nhs.uk/integratedcare/what-is-integrated-care/

NHS England. (2022). Five-year NHS autism research strategy for England. https://www.england.nhs.uk/publication/five-year-nhs-autism-research-strategy-for-england/

NHS England. (2024). 2024/25 priorities and operational planning guidance. https://www.england.nhs.uk/publication/priorities-and-operational-planning-guidance-2024-25/

NHS Wales. (n.d.). About us. Retrieved August 21, 2026, from https://www.nhs.wales/about-us/

Ng-Cordell, E., Howes, S., & Simonoff, E. (2022). Diagnostic overshadowing in children with autism spectrum disorder: A systematic review. *Developmental Medicine & Child Neurology, 64*(6), 703-710. https://doi.org/10.1111/dmcn.15195

O'Nions, E., Petersen, I., Buckman, J. E. J., Charlton, R., Cooper, C., Corbett, A., Happé, F., Manthorpe, J., Richards, M., Saunders, R., Zanker, C., Mandy, W., & Stott, J. (2023). Autism in England: Assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data. The Lancet Regional Health – Europe, 29, 100626. https://doi.org/10.1016/j.lanepe.2023.100626

Pellicano, E., & den Houting, J. (2022). Annual research review: Shifting from 'normal science' to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry, 63*(4), 381–396. https://doi.org/10.1111/jcpp.13534

Radev, S., Freeth, M., & Thompson, A. R. (2024). 'I'm not just being difficult . . . I'm finding it difficult': A qualitative approach to understanding experiences of autistic parents when interacting with statutory services regarding their autistic child. *Autism : the*

international journal of research and practice, *28*(6), 1394–1404. https://doi.org/10.1177/13623613231212794

Singh, A., Amiola, A., Temple, P., & Maplanka, C. (2023). Diagnostic overshadowing and implications on treatment and rehabilitation of people with a genetic syndrome and co-existing psychiatric conditions: A case report of 22q11.2 duplication syndrome. *Journal of Psychosocial Rehabilitation and Mental Health, 10*(4), 443–449. https://doi.org/10.1007/s40737-023-00366-z

Snow, S. L., Smith, I. M., Latimer, M., Stirling Cameron, E., Fox, J., & Chorney, J. (2022). A balancing act: An interpretive description of healthcare providers' and families' perspective on the surgical experiences of children with autism spectrum disorder. Autism : the international journal of research and practice, 26(4), 839–848. https://doi.org/10.1177/13623613211034057

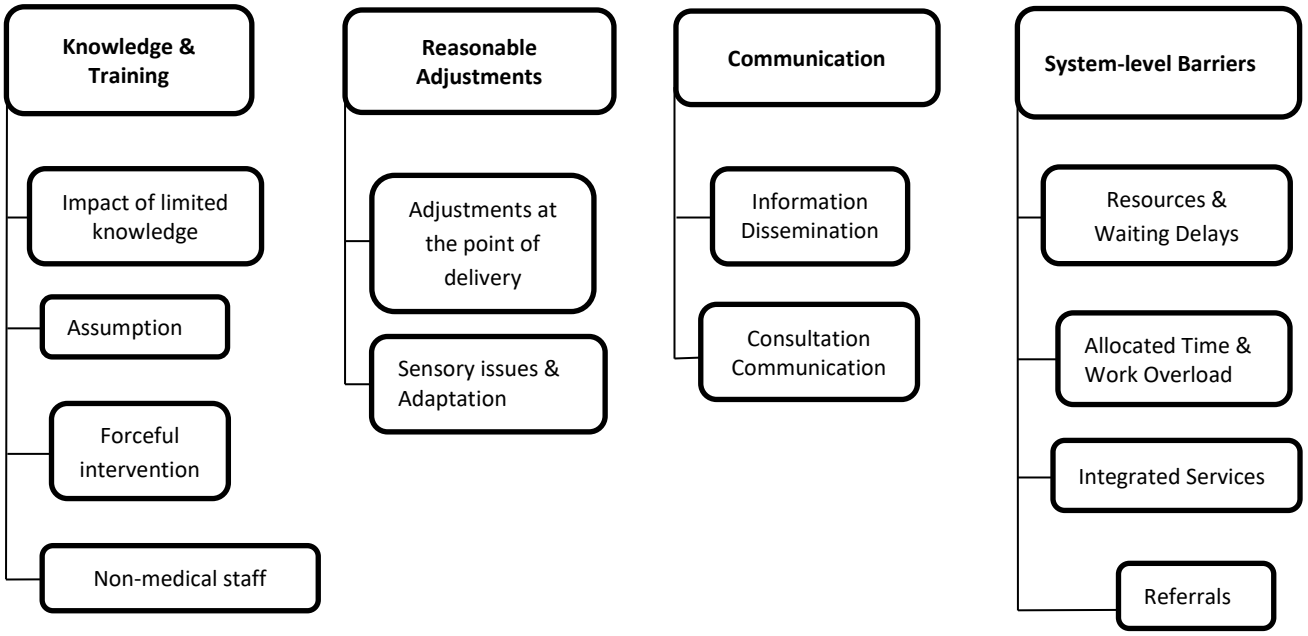
Tromans, S., Clery, E., Randall, E., Morris, S., Gullon-Scott, F., Morgan, Z., McManus, S., & Brugha, T. (2025). Autism spectrum disorder. In S. Morris, S. Hill, T. Brugha, & S. McManus (Eds.), Adult Psychiatric Morbidity Survey: Survey of Mental Health and Wellbeing, England, 2023/4. *NHS England.* Retrieved from https://digital.nhs.uk/data-and-information/publications/statistical/adult-psychiatric-morbidity-survey/survey-of-mental-health-and-wellbeing-england-2023-24/autism-spectrum-disorder

Unigwe, S., Buckley, C., Crane, L., Kenny, L., Remington, A., & Pellicano, E. (2017). GPs' confidence in caring for their patients on the autism spectrum: An online self-report study. *British Journal of General Practice.* https://doi.org/10.3399/bjgp17X690449

World Health Organization. (2025, September 17). Autism. Retrieved from https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders

Wong, A. H., Ray, J. M., Rosenberg, A., Crispino, L., Parker, J., McVaney, C., … & Pavlo, A. J. (2020). Experiences of individuals who were physically restrained in the emergency department. *JAMA Network Open, 3*(1), e1919381. https://doi.org/10.1001/jamanetworkopen.2019.19381

Figure 1



Final thematic structure. *The four main themes are shown in bold text, with associated subthemes connected by solid lines. Lines indicate thematic grouping only and do not imply causal, directional, sequential, or hierarchical relationships.*

Table 1. Parent/carer participants

ID	Parent/carer role	Autistic child/children represented	Communication profile	Relevant co-occurring conditions/support needs
P01	Mother	Boy, 5 years	Non-speaking	No additional diagnosed healthcare condition reported; eating and sleep difficulties discussed
P02	Mother	Two boys and one girl: 13, 15 and 17 years	All verbal	Both boys had dyspraxia; daughter had ADHD
P03	Mother	Boy, 12 years	Verbal, but may not speak with unfamiliar people because of social anxiety	Eating difficulties/eating disorder, OCD and tic discussed
P04	Mother	Girl, 11 years	Verbal	Anxiety and sensory difficulties discussed
P05	Mother	Three boys, aged 4, 9 and 13 years	Eldest recently verbal; younger two non-speaking; one uses an iPad for communication	Nine-year-old had cystic fibrosis and epilepsy; substantial sensory and communication support needs across children
P06	Mother	Girl, 15 years	Verbal with familiar people; may not speak with unfamiliar people	Dyspraxia, dyslexia, social anxiety, pica and sensory sensitivities
P07	Mother	Girl, 15 years	Verbal	Lactose intolerance; sensory and social-communication needs discussed
P08	Father	Boy, 16 years	Non-speaking	High daily-living support needs; IBS, epilepsy, medical phobia and depression reported
P09	Mother	Boy, 4 years	PECS use and echolalia described	Restricted eating, sensory difficulties and substantial communication support needs
P10	Mother	Two boys, aged 10 and 9 years	Both minimally speaking	Eldest had ADHD, high anxiety and medical phobia
P11	Mother	Girl, 13 years	Verbal	Anxiety and sensory difficulties; possible eating disorder discussed but not formally diagnosed
P12	Mother	Boy, 12 years	Non-speaking; uses Proloquo2Go AAC and has some emerging spoken words	Sensory needs and anxiety related to unfamiliarity/change

Table 2. Healthcare professional participants

ID	Professional role	Clinical experience	Healthcare setting
HCP01	General practitioner	26 years as a GP; previous paediatric experience	NHS general practice/primary care
HCP02	General practitioner	25 years as a GP	General practice/primary care
HCP03	Learning disability nurse	4 years as a disability nurse	Learning disability/community services
HCP04	Nurse	25 years in day surgery	Hospital day surgery, including paediatric patients
HCP05	Children's nurse	4.5 years in paediatric settings	General paediatric hospital ward
HCP06	Nurse/emergency department manager	23 years in paediatric acute healthcare	Emergency department/acute medicine
HCP07	Speech and language therapist	17 years as an SLT	Complex-needs/AAC services; substantial special-school experience
HCP08	Speech and language therapist	16 years as an SLT	Paediatric early-years community services, primarily children under 5