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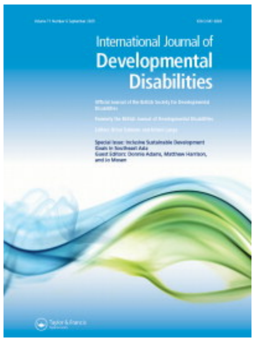

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Barriers and facilitators of healthcare access for autistic children in the UK: a survey of parents and healthcare professionals

Tonia T. Babalola, Lucy Dipper and Nicola Botting

Ringgold Standard Institution - School of Health and Medical Sciences, City St George's University of London, London, United Kingdom of Great Britain and Northern Ireland

ABSTRACT

Objectives: Access to healthcare services for autistic children remains a significant challenge with barriers affecting autistic children, parents and healthcare practitioners. This study investigates the difficulties by examining the perspectives of parents and Healthcare Professionals (HCPs) on healthcare access for autistic children in the UK. It builds on a previously published systematic review and uses the Theoretical Domains Framework to identify key barriers, facilitators and potential solutions in primary care settings, specifically General Practitioner (GP), dental and accident and emergency Departments of hospitals.

Methods: Two online surveys were conducted targeting healthcare practitioners and parents of autistic children, exploring facilitators, interventions and strategies to improve healthcare access. In total, 43 parents and 41 HCPs participated. Descriptive statistics, chi-square tests, independent t-tests and correlation analyses were used to compare responses and identify key patterns.

Results: Findings indicated that autistic children faced many healthcare access barriers related to limited autism-specific knowledge among HCPs, reasonable adjustments, sensory sensitivities, communication challenges, and system level barriers. HCPs acknowledged systemic limitations, including high workloads and insufficient resources. Discrepancies were observed between parental and HCP perspectives.

Conclusions: The study highlights the urgent need for systemic improvement to healthcare access for autistic children. Improved autism training for healthcare professionals, structured pre-appointment communication, and sensory friendly environments are crucial steps to equity of care. Given the complexity and diversity of autistic children's needs, a flexible and individualised approach is needed to address healthcare inequality in this group.

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Healthcare; access; review; barriers; facilitators; children

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental condition, as defined in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; American Psychiatric Association 2013) and in UK guidelines (National Institute for Health and Care Excellence (NICE) 2012). It may involve differences in social interaction, social communication, and patterns of behaviour, though these characteristics are not present in all autistic children. Although international prevalence rates vary, in the United Kingdom it is estimated that between 30 and 160 per 10,000 children have a diagnosis of autism (Baron-Cohen et al. 2009). Autism is currently thought to be more common in males than females, with some studies suggesting that the male to female ratio may be as high as 4:1 (Levy, Mandell, and Schultz 2011). The fact that such a high number of children have an autism diagnosis confirms how critical this research area is. Many autistic children in the UK remain undiagnosed or face long waiting times for assessment, with some waiting years for a formal diagnosis (NHS England 2021). Delays and missed diagnoses are particularly common among females, who may present differently and be more likely to mask or camouflage their difficulties (Hull, Petrides, and Mandy 2020).

The importance of reducing health inequalities has been one of the aims of international health policies (World Health Organization Commission on Social Determinants of Health 2009; Marmot 2010), which

CONTACT Tonia T. Babalola Tonia.Babalola@citystgeorges.ac.uk City St George's University of London Ringgold Standard Institution - School of Health and Medical Sciences, London EC1V 0HB, United Kingdom of Great Britain and Northern Ireland.

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emphasise how important early childhood experience and the developmental health of children are. NICE (2016) incorporated into their guidance the six policy objectives by Sir Michael Marmot (2010) and The Equality Act 2010 (UK Government 2010), to ensure that factors affecting vulnerable groups of people are addressed in order to reduce health inequalities. Although these policies have in part informed nationwide training, such as the Oliver McGowan training, to increase healthcare practitioners' autism awareness knowledge (Department of Health and Social Care 2022), there are still autistic individuals experiencing health inequalities in the UK (Tregnago and Cheak-Zamora 2012; Casagrande and Ingersoll 2017).

Our previously published systematic review (Babalola et al. 2024) identified key gaps in knowledge on healthcare access for autistic children in the UK, including the lack of studies capturing both parent and healthcare professional perspectives, which the present study attempts to address. While some research has examined these issues in *other countries*, UK-specific evidence remains limited. Although interventions to improve access have been developed and evaluated (e.g. Kennedy et al. 2016), few studies have explored these topics in depth within the UK context.

Findings from our earlier review suggest that there is no 'one size fits all' solution to remove the disadvantages autistic children encounter when accessing healthcare services, partly because the children have a heterogeneous set of skills and needs. Therefore, it is essential to learn directly from healthcare practitioners, parents and caregivers of autistic children to understand the barriers and their possible solutions (Pellicano, Dinsmore, and Charman 2014). The exact nature of many barriers is unclear and few studies addressed a broad range of health service specialisms (Babalola et al. 2024). It is critical to generate new knowledge about interventions targeting autism-specific barriers in order to continue to improve healthcare access for autistic children in the UK.

To address these gaps, two surveys were conducted. The first survey was developed for the parents and/or caregivers of autistic children. This focused on barriers faced when accessing healthcare for autistic children in the UK and possible interventions. The second survey was designed for healthcare professionals and focused on facilitators, interventions and preventions that could improve access to healthcare for autistic children. In addition to building on our earlier review (Babalola et al. 2024) the survey was informed by the Theoretical Domains Framework (TDF) (Michie et al. 2005), which is designed to explore behavioural determinants and has been applied successfully in healthcare research.

This article will use the term 'autistic children' as a terminology to describe groups of autistic children. This is to align with the preferences of many in the community (Kenny et al. 2016), including the first author, who is a mother of an autistic child, and to maintain consistency throughout the document. Using 'autistic children' recognises autism as part of the identity of those described, rather than something they have. This approach honours the voices of those in the autism community and is in line with current thinking on identity and disability.

Aims and objectives

Aim

To explore the barriers to healthcare access for autistic children in the UK by surveying both parents and healthcare professionals, building on common issues identified in a previous systematic review.

Objectives

1. Identify the key barriers experienced by parents and healthcare professionals in accessing GP, dental, and accident and emergency (A&E) services.
2. Compare whether parents' and healthcare professionals' perceptions of these barriers differ.
3. Explore facilitators and recommendations that may improve access to care.

Method

This was primarily a quantitative cross-sectional survey study, incorporating descriptive and inferential statistical analyses. Free-text responses were also included to provide contextual examples, but were not analysed using formal qualitative methods.

Recruitment and participants

Advertisements to recruit two groups of people were posted online from February 2023 to July 2023 *via* social media platforms such as Facebook, Twitter, LinkedIn, and Google using personal and university handles. The groups of people targeted were parents of autistic children and healthcare professionals.

Convenience sampling was used to recruit participants. A self-selection (volunteer) sampling method allowed the participants to voluntarily agree to be part of the research. In total, 43 parents of autistic children and 41 healthcare practitioners completed sufficient sections of the surveys (details presented in results). Participants were included in the analysis if they completed more than 40% of their respective surveys. This threshold ensured sufficient core items were completed to allow meaningful analysis while retaining as many partially completed surveys as possible to maximise the sample size. While certain questions differed between the parent and healthcare professional surveys to reflect group-specific contexts, both versions contained a core set of comparable items, detailed in Supplementary File 1.

Survey development

The surveys were created using the Qualtrics platform, a secure online tool for building, distributing, and analysing surveys. They primarily consisted of close-ended questions, including multiple-choice, checkbox, and 5-point Likert scale items, with a small number of optional free-text boxes to allow participants to elaborate on their answers. Survey questions were developed by mapping the key areas identified in our previous systematic review onto relevant domains from the Theoretical Domains Framework (TDF) (Michie et al. 2005) to ensure comprehensive coverage of behavioural determinants. They included knowledge and training, reasonable adjustments, sensory sensitivities, communication, and system-level barriers, and were applied to healthcare generally and specifically to the three health services that are a focus of this article (GP, Dentist, A&E).

The TDF includes twelve domains covering factors such as knowledge, skills, professional role, beliefs, motivation, decision processes, environmental context, social influences, and behavioural regulation. It is designed to explore determinants of current and desired behaviours, based on a synthesis of 83 behaviour change theories (Atkins et al. 2017), and is well suited to identifying both barriers and facilitators to practice change. The TDF has previously been successfully applied in different healthcare settings and clinical behaviours (Barry et al. 2023; Lienhart et al. 2023).

Building on the TDF, the Capability, Opportunity, Motivation – Behaviour (COM-B) model was then used to categorise these key areas into domains (Capability, Opportunity, and Motivation), which are thought to interact to determine whether a behaviour will occur. This process ensured that the questions addressed not only *what* barriers exist but also *why* they persist and *how* they might be changed. This dual framework informed both the structure and the language of the survey, especially when designing questions for healthcare professionals on their confidence, preparedness, and perceived limitations in treating autistic children. Although the TDF did not map precisely onto the key areas arising from the literature, it informed the structure and wording of the questions. Survey questions falling under 'usual source of care', for example, did not easily fit under any TDF domains. However, the systematic review (Babalola et al. 2024) informed the inclusion of these items.

The survey was developed through an iterative process informed by insights from an initial Patient and Public Involvement and Engagement (PPIE) group as well as the evidence base. The aim was to ensure the survey explored key barriers to healthcare access for autistic children, while being both theoretically grounded and reflective of user experiences. The structure of the surveys was designed to allow for some direct comparison across a) participant groups and b) healthcare services. However, some questions included in the HCP survey were removed or worded differently in the parents' survey to maximise relevance. For the parent survey, all questions were the same across sections for the questions about GP and Dentist, but were slightly different for A&E. For example, questions about autism knowledge and how long parents wait for non-emergency appointments were the same for both GP and Dentist, but different for A&E because A&E does not deal with non-emergencies. Further, some questions in each service provider section were the same, so these could more easily be compared. The complete survey questionnaires for both parents and healthcare professionals are provided in Supplementary File 1.

Procedure

Pilot testing

Early drafts of the survey were piloted with three parents and two healthcare professionals (a GP and a senior nurse). Their feedback led to several changes. Some questions, especially in the HCP version, were rephrased after feedback suggested they might be perceived as too direct. For example, early wording around healthcare professionals' willingness to accommodate autistic children was revised to adopt a more neutral, reflective tone. This helped ensure that the survey was inclusive and non-judgmental, and would encourage honest and open responses. In addition to tone, the PPIE group also highlighted issues around emotional nuance and lived experience. This led to the inclusion of new questions about the emotional impact of healthcare visits, reasons for avoiding care, and the level of support parents felt. Some questions were also reordered to improve flow and reduce cognitive load, and typographical issues were corrected.

The final version of the survey was therefore designed to be both theoretically robust (based on literature and behaviour change theory) while also maintaining sensitivity to participants' perspectives. Questions were written in plain, accessible language, ensuring they reflected the lived experiences of families and practitioners.

Survey implementation

Ethical approval was granted in December 2022 by the proportionate review committee of the Centre for Language and Communication Science Research at City ST. Georges University of London, ethics number ETH2223-0211.

The survey was launched in February 2023 and was open for six months. The survey responses included no identifying details (including no recording of IP addresses); therefore, the responses were completely anonymous unless respondents chose to share their emails (for future contact). Informed consent was obtained from participants through an information and consent document attached to the top of the survey, which included a series of questions to confirm consent. Only those who consented were routed to the survey.

Data analysis

Because this survey was designed to scope perspectives, the main presentation of results involves descriptive quantitative data. Free-text responses were reviewed to provide illustrative quotes for context, but were not analysed thematically using formal qualitative methods. For key comparison questions across groups, independent t-tests and chi-square analyses were used. For within-group comparisons across different services, related t-tests were employed. In practice, these within-group analyses were only conducted for parent responses, since there were limited numbers of HCP respondents from each healthcare service, making statistical comparison invalid.

Results

Participants

Out of 148 parents who clicked the survey link, 43 (29.05%) completed more than 40% of the survey. Most were mothers, White, and educated to an undergraduate level. Child characteristics varied: 65.1% ($n = 28$) were male, and ages ranged from under 10 ($n = 17$; 39.53%) to 10–18 years ($n = 23$; 53.48%) (Mean = 10.45 years, SD = 4.6). Children attended a range of educational settings, most commonly mainstream primary ($n = 16$; 37.20%) and specialist provision ($n = 13$; 30.23%).

Additionally, of the 98 HCPs who clicked the survey link, 41 (41.83%) completed over 40%. Ages ranged from under 40 to 68 years (Mean = 41.45, SD = 11.55). All reported direct experience with autistic children.

Barriers to accessing healthcare

Perceived barriers. Most parents ($n = 31$; 75.61%) identified 'no appointment soon enough' as the main barrier to accessing healthcare, followed closely by 'sensory issues' ($n = 29$; 74.36%) and 'appointment flexibility' ($n = 29$; 72.50%). As one parent explained:

> *'The wait, especially with a child that has insight and wants support. The delays mean that at times, issues have started to develop because no health professional is available to offer support' (P 20).*

In contrast, healthcare professionals most frequently highlighted 'healthcare environment' ($n = 33$; 84.62%), 'sensory difficulties' ($n = 35$; 89.74%), and 'challenging behaviour' ($n = 36$; 92.31%) as key barriers—two of which parents rated much lower. For example, only 25% of parents ($n = 10$) selected 'healthcare environment', compared to 84.62% ($n = 33$) of HCPs.

Although over 50% agreement between both groups existed for some factors (e.g. waiting room issues, lack of appointment flexibility, staff knowledge), these associations were statistically non-significant (Fisher's Exact $p > 0.058$). Other factors, such as travel time, stigma, and communication issues, revealed divergence: fewer parents saw these as barriers, while more than half of HCPs considered them significant.

Knowledge gaps. Parents rated GPs ($n = 8$; 20.51%), dentists ($n = 3$; 8.33%), and A&E staff ($n = 9$; 20.93%) as having limited autism knowledge. One parent described their frustration:

> *'There's a one-dimensional view of autism, and a child who can speak and sit still is viewed as fine' (P 24).*

In contrast, HCPs self-rated their knowledge highly ($M = 73.91/100$) and 85.37% ($n = 35$) reported having received autism training. While 97.5% ($n = 39$) of

HCPs believed they understood communication and sensory needs, parents reported frequent incorrect assumptions by HCPs. Only 29.3% ($n = 12$) of healthcare settings reported training non-clinical staff.

Sensory sensitivities. Sensory sensitivities were widely reported by parents, particularly in crowded or noisy environments and during physical examination. One parent shared:

> *'My son is unable to sit still and there is a stigma attached to that, especially in somewhere like a doctor's surgery' (P 31).*

Another noted;

> *'He wants to touch everything, so it's constant reminders to keep his hands to himself and listen' (P 19).*

Touch sensitivity was common at the GP ($n = 36$; 87.80%), dentist ($n = 30$; 85.71%), and A&E ($n = 20$; 80%). Significant differences were noted in smell and taste discomfort across settings, with this being more noticeable at the GP (Cochran's Q X^2 (2) =12.20, $p = 0.002$).

Most parents said no reasonable adjustments were made: 86.05% ($n = 37$) at GPs, 44.74% ($n = 17$) at dentists, and 73.08% ($n = 19$) at A&E. The reported presence of reasonable adjustments was significantly more likely in dental settings than GPs (Cochran's Q X^2 (2) =7.00, $p = 0.030$). When made, adjustments were usually appropriate.

The HCPs largely agreed with parents on common sensory sensitivities. However, only 39.02% ($n = 16$) confirmed that adjustments were being made for these, and most ($n = 25$; 65.85%) were unsure whether these adjustments were appropriate. Systemic constraints, including time and funding, were the most common explanations in free-text responses.

Communication. Overall, 82.93% ($n = 34$) of parents reported their child's inability to express pain as a major communication barrier. In total, half ($n = 21$) said they were not given enough time to express concerns, and nearly 70% ($n = 30$) felt their concerns were not acknowledged. A parent commented:

> *'They make you feel like you should be able to control your child' (P 35).*

Another noted their experience with frontline staff:

> *'Sometimes they don't seem aware of the challenges that might exist for a child with ASD and can be quite impatient' (P 20).*

HCPs reported adapting communication, but discrepancies emerged. While 51.2% ($n = 21$) said they 'always' adapted, only a minority of parents agreed. A significant association was found between respondent type and perception of communication adaptation (Fisher's Exact $p = 0.004$). Parents ($n = 37$; 86%) were more likely than HCPs ($n = 27$; 65%) to rate communication as a barrier ($p = 0.041$).

Both groups generally agreed on shared communication challenges (e.g. attention difficulties, extra processing time). However, HCPs were more likely than parents to identify parental misunderstanding of autism terminology as a barrier to healthcare access (54.55% ($n = 18$) vs. 15.38% ($n = 6$), $p = 0.003$). This finding reflects HCPs' perceptions rather than an objective assessment of parental knowledge.

System-level barriers. Parents reported long wait times for GP and dental appointments, with some waiting over six months. One parent shared: 'We have been waiting 19 months to see a paediatrician' (p 20). While travel times were not a major issue, 90.91% ($n = 30$) cited waiting as a core concern. HCPs acknowledged these delays; 24.4% ($n = 10$) reported wait times exceeding six months, but also noted that most children were seen within 30 min of arrival.

Facilitators and recommendations

Only 13.95% ($n = 6$) of parents reported healthcare access as effortless. When asked what worked well, nearly half (47.05%) could not identify anything. Issues highlighted in free text responses included delays, misunderstanding of autism, and failure to adapt to invisible needs.

Both parents and HCPs suggested several facilitators to improve access, however HCPs noted that current National Health Service (NHS) conditions limit feasibility. Only 9.76% ($n = 3$) of HCPs felt that the resources to implement changes were available. Table 1 presents the most endorsed solutions (>65% in both groups).

Discussion

Summary of the key findings

This survey explored the perspectives of parents and healthcare professionals (HCPs) on barriers and facilitators to healthcare access for autistic children in the UK. Across GP, dental, and A&E settings, families reported multiple and intersecting barriers, including long wait times, sensory difficulties, poor communication, and a lack of reasonable adjustments.

Table 1. Most endorsed solutions.

Question	Group	No	Yes	Fisher's exact *p* value
Additional time for assessment and treatment				1.000
	Parents	15/43 (34.9%)	28/43 (65.1%)	
	HCPs	14/41 (34.1%)	27/41 (65.9%)	
A calm and patient receptionist				0.631
	Parents	11/43 (25.6%)	32/43 (74.4%)	
	HCPs	13/41 (31.7%)	28/41 (68.3%)	
A quieter waiting room or available quiet room				1.000
	Parents	15/43 (34.9%)	28/43 (65.1%)	
	HCPs	14/41 (34.1%)	27/41 (65.9%)	
Adequate information sharing/communication				0.639
	Parents	12/43 (27.9%)	31/43 (72.1%)	
	HCPs	14/41 (34.1%)	27/41 (65.9%)	
Better HCPs' knowledge, training and understanding of Autism				0.476
	Parents	11/43 (25.6%)	32/43 (74.4%)	
	HCPs	14/41 (34.1%)	27/41 (65.9%)	
Flexibility of appointment- Last/First appointment/specific day and time				0.644
	Parents	15/43 (34.9%)	28/43 (65.1%)	
	HCPs	12/41 (29.3%)	29/41 (70.7%)	
Reduced/ No waiting time				1.000
	Parents	12/43 (27.9%)	31/43 (72.1%)	
	HCPs	12/41 (29.3%)	29/41 (70.7%)	
Specific needs of the patients recorded				0.631
	Parents	11/43 (25.6%)	32/43 (74.4%)	
	HCPs	13/41 (31.7%)	28/41 (68.3%)	
Timely/Easy to book appointments				1.000
	Parents	13/43 (30.2%)	30/43 (69.8%)	
	HCPs	13/41 (31.7%)	28/41 (68.3%)	

A key finding was the mismatch in how each group perceived these barriers. Parents emphasised practical and environmental challenges, such as appointment delays and inadequate adjustments, while HCPs more often attributed difficulties to family-related or behavioural factors. Even when HCPs reported autism awareness or training, this did not consistently translate into care that parents perceived as autism-informed. This suggests that well-intentioned efforts may be misaligned with families' priorities, leading to ineffective or misplaced solutions. Systemic constraints, which include high workloads, resource shortages, and structural inflexibility, were identified by both groups as limiting the delivery of tailored care. These findings reinforce the need for co-designed, context-specific interventions that reflect lived experience, as well as structural reforms to embed flexibility and accountability into routine practice.

Parents frequently identified long wait times, sensory sensitivities, lack of reasonable adjustments, and challenges with communication as the most critical barriers to healthcare access. In contrast, healthcare professionals were more likely to attribute delays to family-related issues such as parental stress, the child's challenging behaviour, or communication difficulties. While both groups acknowledged the presence of barriers, the emphasis placed on different aspects suggests a disconnect between lived experience and professional assumptions. For instance, while over 75% of parents highlighted 'no appointment soon enough' as a reason for avoiding care, this was rated far less prominently by HCPs. In contrast, HCPs strongly emphasised environmental factors like waiting room noise or seating arrangements—barriers that were less frequently raised by parents. This mismatch has important implications. It suggests that healthcare services may be focusing their efforts on solving problems they perceive as important, rather than those prioritised by families themselves. Previous studies have similarly highlighted this gap, noting that professionals often overestimate their ability to accommodate autistic individuals while underestimating the practical challenges faced by families (Pellicano, Dinsmore, and Charman 2014; Crane et al. 2018). If healthcare providers rely primarily on internal assumptions or generic training, they may overlook critical issues such as inflexible scheduling or a lack of pre-visit preparation. These misalignments can divert attention from potentially resolvable issues and negatively impact engagement with services over time. Aligning perspectives between service users and providers is therefore essential, not only for improving individual care experiences but also for designing effective, sustainable interventions. This finding supports calls for participatory approaches that prioritise the voices of autistic people and their families in shaping services (Pellicano, Dinsmore, and Charman 2014).

Despite longstanding legal and policy requirements—such as The Equality Act 2010 and the Autism Act 2009—this study found that reasonable adjustments are rarely offered consistently across healthcare settings. The majority of parents reported that no adjustments were made for their child's needs, particularly in GP and A&E environments. When adjustments were provided, the majority of the parents felt they were appropriate and helpful. This suggests that the problem is not a lack of clarity about what works, but a failure to implement it routinely. Healthcare professionals who participated in the survey often reported making adjustments. However, many admitted uncertainty about whether these were effective, and cited systemic constraints such as limited authority, building design, staffing pressures, and resource limitations as barriers to wider implementation. This inconsistency reflects a broader issue of structural inflexibility in healthcare delivery. Even simple, low-cost adjustments such as pre-appointment calls, sensory-friendly waiting spaces, or visuals outlining what to expect were absent in many cases, as reported by the parents in the survey. These findings align with prior research suggesting that although policies exist to mandate autism-friendly care, they are rarely operationalised at the service level (Muskat et al. 2015; Nicolaidis et al. 2015). The gap between policy and practice may also reflect a broader issue in health systems, where adjustments are often seen as 'extras' rather than essential to equitable care. It is concerning that the feasibility of making adjustments is often constrained not by knowledge, but by systemic barriers. Addressing this requires not only improved training, but also leadership accountability, funding, and strategic redesign of care pathways to embed flexibility as a standard instead of an exception. This study adds weight to calls for the NHS to go beyond awareness and commit to operational change that ensures adjustments are universally available and tailored to individual need (Pellicano, Dinsmore, and Charman 2014; Nicolaidis et al. 2015; NICE 2021).

The survey revealed that structural issues, such as long waiting times, fragmented care pathways, and under-resourced services, remain some of the most pressing barriers to healthcare access for autistic children. Both parents and healthcare professionals acknowledged that delays in securing appointments, particularly for non-emergency concerns, were common and often prolonged. Some parents reported waiting months for access to paediatric or mental health services, with worsening symptoms during the interim. This aligns with broader critiques of the NHS system, where overstretched services and staff shortages limit timely access to care (NHS Confederation 2022; British Medical Association 2023). Importantly, the burden of managing this delay often fell on parents, who described having to 'chase' services or make multiple calls to secure appointments, which added emotional and logistical strain to families already managing complex needs. Healthcare professionals themselves recognised these systemic limitations but also expressed a sense of powerlessness to enact change. Several cited high workloads, staffing shortages, or rigid institutional procedures as reasons they could not deliver the care they believed was necessary. These findings resonate with previous studies that highlight how system inefficiencies, rather than individual attitudes, are often the root cause of poor care experiences for autistic individuals (Mason et al. 2019). Notably, the level of care required did not significantly influence whether families experienced delays or frustration, which suggests that these are widespread structural issues rather than isolated to certain 'complex' cases. Without targeted investment in resources, clearer triaging protocols, and improved coordination between services, even the best-trained practitioners may struggle to offer inclusive and timely care. This emphasises the importance of systemic reform alongside workforce development, which could ensure that healthcare structures are equipped to meet the needs of neurodiverse populations and reduce inequality, rather than exacerbate it.

Implications for research and practice

The findings from this study point to a clear and urgent need for structural and practice-level changes to improve healthcare access for autistic children. A key implication is the importance of embedding flexibility into healthcare systems as standard practice. Adjustments such as quiet waiting spaces, visual aids, first or last appointment slots, and pre-appointment communication are not new ideas. They are well-established recommendations under the Autism Act 2009 and the NHS Long Term Plan. However, this study shows that implementation remains inconsistent, often dependent on the personal motivation of individual practitioners rather than embedded policy. Addressing this gap requires a shift from treating these supports as optional extras to considering them as baseline components of equitable care.

Routine practices should include a short pre-appointment call to identify adjustments (Nicolaidis et al. 2013), the use of hospital passports (Kennedy et al. 2016), and staff training in sensory processing and communication needs (Walsh et al. 2023). Within dentistry, targeted work is underway to support autistic children's the oral health. Chauhan et al. (2025) highlighted key challenges and informed the toothPASTE support package, which offers practical strategies for families and dental teams (https://www.autismtoothcare.com/). These actions are low-cost and potentially high-impact. For example, providing photos of the clinic and practitioner ahead of the visit or allowing brief familiarisation visits could significantly reduce distress for some children (NICE 2016). Training should not only focus on healthcare professionals, but also include non-clinical staff such as receptionists, who are often the first point of contact and whose attitudes and communication styles significantly shape parents' experiences (Walsh et al. 2023).

Participatory co-design should underpin service development. Involving autistic individuals and their families in shaping services ensures that interventions are grounded in real need rather than professional assumptions. Co-design approaches have shown success in other healthcare fields and are increasingly being advocated in autism research (Fletcher-Watson et al. 2019). Future implementation efforts should include continuous feedback loops, such as focus groups, family advisory boards, or patient surveys, to ensure accountability and allow real-time adjustments (Pellicano, Dinsmore, and Charman 2014).

There is also a need for future research to move beyond the identification of barriers and towards intervention testing. Studies should evaluate how specific adjustments, such as visual supports, sensory-friendly modifications, or triage changes, influence access and outcomes (Nicolaidis et al. 2015). Implementation science frameworks, including the TDF and COM-B models, are particularly useful in designing and evaluating these interventions in context (Michie, van Stralen, and West 2011). Longitudinal research could also track whether improved access leads to better health outcomes or reduced reliance on emergency care.

Finally, commissioners and policy makers must recognise that improving access is not only a matter of training or good intentions; it requires investment and accountability. System-level reforms should include targeted funding to support environmental adaptations, protected time for staff training, and integrated care pathways that reduce duplication and delay. Without such action, families will continue to shoulder the burden of navigating a system that was not built with their needs in mind. This study makes clear that while the knowledge of what works is growing, meaningful change depends on translating that knowledge into practice at scale.

Limitations

The sample size, while adequate for exploratory purposes, was relatively small and recruited *via* convenience sampling. Participants were recruited solely through online methods, which may have excluded individuals without internet access or those less active on social media. This approach may also have biased the sample towards participants who are more engaged or motivated to contribute to autism-related research. As a result, the findings may not be representative of the broader population of parents and professionals. Most parent respondents were White, and fathers were underrepresented, limiting the diversity of perspectives captured. In addition, the study did not classify participants by level of support need, which may influence healthcare experiences (Taylor and Henninger 2015). Similarly, most HCP respondents appeared to be those already motivated or engaged in autism-related care, which may have biased results towards more favourable views of practice.

While some barriers identified may also affect children with other intellectual and developmental disabilities, this study focused on autistic children to explore autism-specific challenges, building on our previous systematic review (Babalola et al. 2024). Future research could compare these findings with those from other IDD groups to identify shared and condition-specific barriers.

The surveys also relied on self-report data, which are subject to recall bias and social desirability effects, particularly among healthcare professionals reporting on their own practices. Moreover, while the survey allowed comparisons across healthcare services (GP, dental, and A&E), small sub-sample sizes prevented a full breakdown of HCP responses by service type and comparisons across services, which could have provided more service-specific insights.

Another limitation is potential nonresponse bias. Comparison of full and partial responses suggests that those who dropped out may have experienced higher levels of stress or time pressure, meaning their perspectives, perhaps more negative, were not fully captured. Finally, although TDF and COM-B were used to frame questions and guide analysis, not all survey items mapped cleanly onto the framework. This reflects both the real-world complexity of measuring behaviour and access within overstretched health systems, and the fact that some important issues, such as the availability of a usual source of care or systemic service constraints, fall outside the direct scope of behavioural determinant frameworks. In these cases, items were retained because they were identified as key barriers in the systematic review and PPIE process, highlighting the need for flexibility when applying theoretical models to complex, multifaceted healthcare challenges.

Despite these limitations, the study's combination of theoretical rigour, lived-experience input, and dual-perspective design makes it a valuable foundation for future work. The findings offer actionable insights while pointing to the need for larger, more representative studies to confirm and build upon these results.

Conclusion

This study highlights the complex and multi-layered barriers that autistic children and their families face when accessing healthcare in the UK. Drawing on the perspectives of both parents and healthcare professionals, the findings reveal clear mismatches in perceptions, particularly around what constitutes a barrier and how adjustments are delivered in practice. While healthcare professionals often felt confident in their autism knowledge and the support they provide, parents frequently reported a lack of meaningful adjustments, poor communication, and difficulty navigating overstretched services. This disconnect suggests that well-intentioned efforts may miss the mark when not grounded in the lived realities of autistic families. Crucially, the study shows that even when healthcare professionals are motivated to help, systemic constraints, such as high workloads, long wait times, and inadequate resources, undermine their ability to deliver accessible care. Reasonable adjustments, while often straightforward and cost-effective, are inconsistently applied, with families describing a 'pot of luck' approach to quality and responsiveness. This inconsistency not only erodes trust in the system but also perpetuates health inequalities. To address these issues, healthcare must shift from reactive to proactive models of care that centre autistic children's needs. This includes routine pre-appointment planning, training for all staff (including non-clinical teams), and meaningful co-design with families. Broader structural reforms, supported by policy, funding, and accountability, are essential to enable sustainable improvements. While challenges remain, this study highlights that many of the solutions are already known. The task now is to prioritise implementation, ensuring that autism-inclusive care becomes the norm, not the exception.

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ORCID

Tonia T. Babalola http://orcid.org/0009-0009-9512-7162
Lucy Dipper http://orcid.org/0000-0002-5918-3898
Nicola Botting http://orcid.org/0000-0003-1082-9501

Data availability statement

The data that support the findings of this study are available upon reasonable request from the corresponding author. They are not publicly available due to privacy considerations.

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