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REVIEW PAPER

Barriers and Facilitators of Healthcare Access for Autistic Children in the UK: a Systematic Review

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Abstract

Background Individuals with autism are more likely to suffer from various physical and mental health problems and experience disparities in effectively accessing healthcare services. This review aims to identify studies that report on the experiences of autistic children, their parents/carers, and the healthcare professionals treating them; to develop an understanding of the facilitators and barriers to healthcare access in order to inform policies and practice to improve access to healthcare for autistic children in the UK.
Methods A total of 3069 records were screened, and 24 studies were included; six quantitative, four qualitative, and fourteen mixed-methodology studies.
Results Professional and parental knowledge about autism, sensory issues, challenging behaviour, system-level barriers, patient-provider-parent communication issues, lack of person-centred care, stigma, and culture emerged as significant barriers to accessing healthcare for autistic children.
Conclusions Families of autistic children experience several barriers to accessing healthcare. Recommendations for those planning services and clinicians are discussed.

Keywords Healthcare · Access · Review · Barriers · Facilitators · Children

Introduction

Autism spectrum disorder (ASD) (hereafter referred to as ‘autism’, Fletcher-Watson & Happé, 2019) is a neurodevelopmental condition characterised by difficulties in social communication and social interaction skills, repetitive behaviours, restricted interest, and stereotyped actions (American Psychiatric Association 2013; Kogan et al., 2009). The worldwide prevalence of autism has been reported to be between 1 and 2% of the population (Lai et al., 2017). Baron-Cohen et al. (2017) report that in the UK, the overall prevalence rate of autism is 1.57%. Autistic children will likely need more healthcare and intervention services than their peers due to co-occurring medical conditions (Barrett et al., 2014), as described below.

Different terminologies can be used when referring to autistic individuals, but they refer to the same profile. Some examples are autism or pervasive developmental disorder (Baron-Cohen et al., 2008; Barrett et al., 2014; Kogan et al., 2009). There are also different preferred ways autism can be described within the UK autism community. For example, most autistic people like being described as ‘on the autism spectrum’, professionals prefer the term ‘person with autism’, while adults prefer being described as ‘autistic’ (Kenny et al., 2015). As a mother of an autistic child, the first author has chosen to use the terms ‘children with autism’ and ‘autistic children’ interchangeably throughout this paper.

Autistic Children and Medical Conditions

Children with autism have an increased susceptibility to additional medical conditions. In fact, the risk of poor health in autistic individuals is estimated to be five times higher than their peers (Emerson & Baines, 2010). For example, neurological conditions such as epilepsy (Spence & Schneider, 2009), sleep disturbance (Bangerter et al., 2020; Cortesi et al., 2010), allergies (Lyall et al., 2015), feeding issues (Romero et al., 2016), and gastrointestinal problems

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(Chaidez et al., 2014; Isaksson et al., 2017) have all been reported. Autistic people are also more likely to experience mental health problems and psychiatric conditions such as anxiety or depression (Shephard et al., 2019).

Children and young people with autism are more likely to exhibit comorbid mental health disorders such as psychosis, sleep, anxiety and depressive disorders (Martini et al., 2022; Mahfouda et al. 2019; Gobrial, 2019; Rydzewska et al. Rydzewska et al., 2019), and are at higher risk of being hospitalised for psychiatric problems (Martini et al., 2022). Gobrial (2019)'s research on comorbid mental health disorders in children and young people with intellectual disabilities and autism found that 62.2% of children and young people with autism had high rates of having comorbid mental health disorders. According to Green et al. (2012), many autistic children experience mental health problems before age 5, which is associated with other co-occurring illnesses (American Psychiatric Association 2013). Hypo-reactivity, hyper-reactivity, and sensory seeking are prevalent in autistic individuals (Marco et al., 2011; Tavassoli et al., 2018), may be exacerbated in healthcare settings, and are associated with mental health problems such as anxiety (MacLennan et al., 2020), schizophrenia (Javitt, 2009; Yeap et al., 2008), depression, attention deficit hyperactivity disorder (ADHD), obsessive–compulsive disorder (OCD), and bipolar disorder (Bailliard & Whigham, 2017; Serafini et al., 2017).

Autistic children are 13 times more likely to access outpatient and inpatient healthcare services, including specialty care, medication use, psychiatric and non-psychiatric care, preventative care, and emergency department services (Gurney et al., 2006). Preventive healthcare services such as disease screenings, behavioural counselling and therapies, dental services, sexual reproductive health clinics, optician services, and immunisations are all essential in order to maintain good health (Turcotte et al., 2016). Decreased receipt of preventative services is related to poorer health outcomes, morbidity, under-addressed medical conditions, and use of emergency services (Cummings et al., 2016). Therefore, it is imperative to understand how individuals with autism can better access preventative services, as well as primary care, to improve their health outcomes.

The presence of these co-occurring medical conditions may be one of the reasons children and young people with autism are likely to access some healthcare services more than their peers. For example, a study done in Canada found that individuals with autism will use the services of their general practitioners or be hospitalised more than those without autism (Weiss et al., 2018). Several studies on both research and practice have drawn attention to the poorer health of people with autism (Nicolaidis et al., 2013), to unmet healthcare needs (Menezes et al., 2021), to lower health-related quality of life (Coales et al., 2019; Khanna et al., 2014), and to increased risk of mortality (Hirvikoski et al., 2016; Hwang et al., 2019; Mouridsen et al., 2008; Woolfenden et al., 2012) with some reporting twice the expected early death rate of the general population (Mouridsen et al., 2008) which could be linked to health inequalities. Together, these studies suggest there might be a disparity in accessing appropriate healthcare services for children with autism. Although there has been public health concern about people with developmental disabilities accessing high-quality healthcare since the move towards deinstitutionalisation in the 1970s (Lewis et al. 2002), it is concerning that individuals in this population still experience difficulties with accessing appropriate healthcare almost 50 years later (Nicolaidis et al., 2013).

Healthcare Access and Children with Autism

Levesque et al. (2013) defined healthcare access as the ability to seek services, identify healthcare needs and use, or be offered services appropriate to one's needs. The inability to access proper healthcare could lead to health inequalities (Hill et al., 2015), defined as avoidable and unjust differences in healthcare access, quality, and outcomes (Ouellette-Kuntz 2005). Although having autism is not a health disadvantage in itself, the associated co-occurring medical conditions may represent a disadvantage. Evidence suggests that autistic children, already disadvantaged by co-occurring conditions, might additionally experience adverse health outcomes due to the inability to access some health care. For example, autistic children are less likely to engage with some preventative healthcare services compared to other children with other special care needs (National Survey of Children's Health, 2008) largely because of sensory issues. These services might include regular dental check-ups (Kuhaneck et al. 2012; Alshihri et al., 2021; Cermak et al., 2015) or having injections.

Autistic adults will most likely need preventative services to manage and prevent things such as heart disease, diabetes, and hypertension (Turcotte et al., 2016). However, autistic children will have different preventative healthcare needs and might need services that offer early intervention, prevention, or treatment of co-occurring medical conditions, to ensure better long-term outcomes (Benachenhou et al., 2019). Unfortunately, there have been records of disparity in the receipt of preventative services for autistic people (Croen et al., 2015). This might be particularly problematic because most physical and mental health conditions that autistic people are prone to can be identified with routine screening that will allow them to be treated quickly (Croen et al., 2015).

Understanding the context of the barriers to access to healthcare can help tailor practice, policies, and research that could improve access to healthcare services for autistic children. Mazurek et al. (2020)'s study about how primary care providers' perceive barriers to treating autistic children found that the most important healthcare needs of autistic children are early diagnosis and treatment of co-occurring medical problems; however, these are often not managed well due to the lack of autism knowledge of the healthcare professionals and their confidence in treating behavioural and co-occurring conditions associated with autism (Soke et al., 2018; Mazurek et al., 2020). There are also reports of limited time and resources, access to care coordination, and shortages of autism specialists, which will likely lead to indirect healthcare inequalities for autistic children (Mazurek et al., 2020).

Although there is a considerable body of evidence on healthcare access for autistic individuals in the USA (Doherty et al., 2022; Mazurek et al., 2020; Walsh et al., 2021), disparities in access to healthcare services for autistic children in the UK have not been systematically examined in the literature. Thus, this review addresses that gap by examining what is known about the quality of the healthcare system concerning autistic children, and by reviewing articles that explore the experiences of autistic children when accessing healthcare services in the UK. Therefore, articles that specifically examine the experiences of autistic children, their parents and/or caregivers, and healthcare professionals treating them are reviewed to identify factors that act as facilitators or barriers to healthcare access for autistic children.

This review aims to synthesise the best available evidence exploring the experiences of autistic children in the healthcare system from the perspective of the healthcare practitioners, parents, and/or caregivers of autistic children. Specifically, the following research questions were explored:

- o Question 1: What methods have been used to investigate healthcare access for autistic children?
- o Question 2: What barriers and facilitators to healthcare access emerge from the evidence base?

Methods

Literature Search and Criteria

The PICO framework (Patient, Problem or Population, Context, Outcome framework; Butler et al., 2016) was used to inform the systematic review and define a focused question, vocabulary search strategies, and search filters to guide this research.

Three components of this framework (PCO) used were the following:

1. Patient, problem, or population (p): autistic children
2. Context (C): autistic children's experiences when accessing healthcare in the UK
3. Outcome (O): professionals, parents, and/or caregivers' perspectives

Sources of Information

The electronic databases searched are Embase (Ovid), Amed (Ovid), Health Management Consortium (Ovid), Ovid Emcare (Ovid), Medline (EBSCOhost), PsycINFO (EBSCOhost), CINAHL (EBSCOhost), Health Policy Reference Center (EBSCOhost), and Google Scholar. Also, grey literature such as conference proceedings, government publications, expert analyses, theses, and dissertations were also searched. Finally, a citation and reference tracking of the relevant studies was conducted and retrieved to identify additional studies.

Search Strategy

The search for articles was conducted from December, 2021, and ended in February, 2022.

The review was implemented using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis guidelines (PRISMA) (Moher et al., 2009) to provide a quality report and reliable, replicable conclusions.

Search Terms

The search terms relating to the strands of the systematic research, with Boolean operators and truncation, as seen in Table 1 below, were used to retrieve highly focused, high recall, and precision results. Full-text databases were searched individually to gather research studies using the keywords in Table 1.

Eligibility Criteria

The criteria in Table 2 were used to decide which studies were eligible for the systematic review.

Quality Assessment

The quality assessment used an adapted version of the Joanna Briggs Institute Appraisal Checklist (https://jbi.global/critical-appraisal-tools; accessed on 6 March 2022) to assess quantitative studies, while the CASP Qualitative Studies Checklist (https://casp-uk.net/casp-tools-checklists; accessed on 2 April 2022) was used for qualitative studies. JBI and CASP are chosen to assess the quality of the included studies because of the varied range of methodologies. According to Munn et al. (2020), JBI offers an approved method to assess the methodological quality of the reviewed studies, while CASP has demonstrated sound psychometric properties in Nadelson (2014).

Table 1 Search terms with Boolean operators and truncation

Search terms 1		Search terms 2		Search terms 3
EBSCOHOST Treatment Barriers" OR DE "Health Disparities" OR DE "Health Care Services" OR DE "Health Care Delivery" OR DE "Quality of Services" OR DE "Quality of Care" (health or "health care" or healthcare) N5 (inequalit* or disparit* or barrier* or facilitator* or challenge* or experience* or perspective*	AND	**EBSCOHOST** child* or infan* or adolescen* or teenage* or p#ediatric (children) AND (DE "Juvenile Delinquency" OR DE "Developmental Disabilities" OR DE "child Psychology" OR DE "Only children" OR DE "Disorders" OR DE "Autism Spectrum Disorders"	AND	**EBSCOHOST** autis* or ASD or autism spectrum disorder
OVID Quality of health care"/ OR "Delivery of health care"/ OR Health services accessibility/ OR health care disparities health OR "health care" OR healthcare) adj5 (inequalit* OR disparit* OR experience* OR barrier* OR facilitator*)		**OVID** Adolescent/ or child/ or children.mp (child* or infan* or adolescen* or teenage* or p?ediatric).ab		**OVID** (autism, or ASD or autis*or autism spectrum disorder)

JBI checklists have eight categories, while the CASP checklist has ten subcategories of analysis. Thus, in order to make the two checklists easily comparable, a percentage quality is also reported. The items are related to suitable methodology, aim of the research, data collection being appropriate and adequate, recruitment fitting, work ethics, consideration of the relationship between researcher and participants, and findings and the value of the research.

Reliability Method

An independent reliability checker (second author) checked the papers against the inclusion criteria and completed the quality rating for all 24 included articles.

There was an agreement on all paper inclusions checked except for one (Lawson, 2009). Lawson (2009) is a lived experience opinion piece, which was essential to include but could not be rated using the regular checklist. The inter-rater reliability was calculated using SPSS by comparing the independent checker's quality ratings and the first author's quality rating, giving an interclass correlation of 0.90 (95% confidence interval 0.78 to 0.96).

The data extracted from the papers are the aim of the study, sample size, age group, comparison group, the narratives the study focused on, study design, and data analysis.

Results

An initial literature search was conducted using the relevant terms in Table 1, with 'United Kingdom' as part of the search terms. However, this only returned 229 studies with only three relevant UK studies after duplicates were removed and the title, abstract, and full-text screening was done. This confirmed a need for a more wide-ranged search for the systematic review; therefore, the search terms were edited, and the word 'United Kingdom' was removed, as seen in Table 1. Note that the final dataset still only included studies conducted in the UK, but this screening was applied later in the process because using UK as a search term resulted in the search excluding appropriate papers. The new database search returned a total of 3069 potentially relevant studies. Manual searches of grey literature such as conference proceedings, government publications, expert analysis, thesis and dissertations, and citation and reference returned a further 59 records. The search returns were retrieved and imported to Endnote (https://www.endnote.com) and Covidence (https://www.covidence.org/) to organise and manage all relevant information of the studies. After that, the results were compared to identify duplicates picked up because similar specifiers are used in the databases. Identified copies were then removed, leaving a total of 2302 articles. Next, titles and abstracts were screened, after which identified papers were examined against the criteria for inclusion (see Table 2). The article itself was reviewed in full if the abstract was insufficiently clear. All studies that did not meet the inclusionary criteria were excluded, which resulted in 140 records. For papers where full text was unavailable online but where the study had passed the title and abstract screening, the full text was requested by emailing the first and last authors or contacting the relevant university. Finally, the full text was reviewed to determine if it met the inclusion criteria, leaving a total of 24 relevant articles (Table 3). Further details and the full process of the literature selection process can be found in the PRISMA flowchart in Fig. 1 below.

Table 3 gives extraction details of all the studies found during the systematic search. A mixture of qualitative, quantitative, and mixed-method studies was found. These comprised journal articles ($n = 22$), master's dissertations ($n = 1$), and online report ($n = 1$). Although the date range was kept open, all studies found were conducted between the years 1999 and 2020, were carried out in the UK, and included

Table 2 Inclusion criteria

Framework	Criteria	Rationale
Types of participants	**Studies about service users:** The participants must be 18 years and below. They must be diagnosed with autism. Further, studies in which at least 50% of the participants are 18 years and below were included **Studies about service providers:** The service providers must provide services to autistic children under the age of 18	The focus is on autistic children
Types of methods, outcome, processes, and measures	Methods that capture the perspectives and experiences of the children, their parents and/or caregivers, and service providers were included. Children's healthcare experiences should not be solely about autism diagnosis or autism interventions but should concern their primary health care	The review focus is on the experiences of autistic children and their parents and/or caregivers when accessing the primary healthcare system
Types of studies	All types of empirical research (quantitative, qualitative, or mixed) were included Systematic reviews were not included Studies had to be published in English and conducted in the UK to be included. Conference presentations and proceedings, website articles, government publications, expert analysis, thesis, and dissertations were also included. No restrictions on the publication date were set	The current study is focused on the UK healthcare system Grey literature was included to get the most out of the available evidence since not many studies are available on the subject

parents and/or carers of autistic children, autistic children, and professionals working with autistic children. The samples ranged from single case studies to very large groups ($n = 900$). Some articles were from the same research group and study (Transition Collaborative Group; $n = 4$).

A pattern emerged in the quality rating of the papers. All the articles rated high (Brammer, 2015; Fox et al., 2016; Jackson et al., 2019; Slade, 2014) were focused on parents' experiences of accessing healthcare for their autistic children. Although the low-quality articles included a mixture of parents and healthcare professionals, it was striking how none of the articles that focused on healthcare professionals' perspectives were rated as being of high quality.

Synthesis

Research question 1: What methods have been used to investigate healthcare access for autistic children?

In terms of the range of approaches to data collection in the literature review, there were five quantitative studies (Klein, Singh, Barry, Merrick, and Eades) and five qualitative studies (Lawson, Brammer, Fox, Jackson, and Slade), while 14 used mixed methods (Nesbitt, Singh, Pratt, Beresford, Brown, Christou, Kennedy, Unigwe, Thomas, Crane, Colver (a), Colver (b), Merrick, and Kirby). The qualitative studies were used to describe the lived experiences of autistic children and their parents and/or caregivers when accessing health care, while the quantitative studies measured the perceived impact of different barriers to healthcare access.

The papers focussed on different healthcare settings: Unigwe, Lawson, Christou, and Kirby discussed GP access; five studies discussed dental practice (Thomas, Eades, Klein, Barry, and Brown), and 11 examined mental health and the transition from child to adult services (Jackson, Crane, Singh, (Nesbitt and Singh (a and b)), Beresford, Merrick (a and b), and Colver (a and b)). Three studies focussed on hospital care (Pratt, Brammer, and Kennedy), and finally, two papers discussed all types of healthcare services (Slade and Fox).

Study samples included autistic children and young adults between the ages of 2 and 24 years. Few studies compared autistic children to neurotypical children (Fox, Barry, and Singh (a)). Most of the studies had large samples, with one study having a sample of $n = 1$ (Lawson). In more detail, eight studies had sample sizes between 2 and 50 (Klein, Brown, Brammer, Fox, Thomas, Nesbitt, Singh (a), and Jackson); three studies included a sample size between 50 and 100 (Pratt, Colver (a), and Colver (b)), and 13 studies included samples between $n = 100$ and $n = 900$ (Slade, Merrick (a and b), Eades, Colver (a and b), Crane, Unigwe, Christou, Beresford, Barry, Singh (a), and Kirby).

Klein and Pratt combined retrospective hospital data and the perspectives of patients, parents, and/or caregivers.

Table 3 Included studies, data extraction, and quality score

ID	Reference	Aim	Sample size	Age group	Comparison group	Narratives	Study design	Data analysis	Quality score
1	Klein et al. (1999)	To understand the experiences of people with autism in dental care settings	43 participants. Male = 39. Female = 4	4–26 years. (mean = 13.5 years)	None	Retrospective—charts review and patients, parents/caregivers' perspectives	Quantitative retrospective study. Charts review = gather epidemiological information. Questionnaire = obtain patient's satisfaction	Chi-square tests of independence = to investigate if the collected data were related. The null hypothesis of independence was tested for all categorical variables. Variables = behaviour category vs. bite block/papoose/sedation	7 out of 8 87.5%
Outcome: Papoose boards were used to manage those in the negative behaviour group. Knee-to-knee position was used to examine and treat children's mean age of 7.3 years. Thirty-seven percent were treated under OR under GA. Communicative management techniques (TSD, voice control) and immobilisation techniques were successful first-line methods to facilitate dental treatment for patients with AD. However, they failed in 37% of the patient									
2	Nesbitt, S. (2000)	To identify the current healthcare levels of provision available for autistic children	10 children	2–18 years	None	Professionals' and parents' narratives	Mixed method research. 1. Semi-structured interviews with key professionals. 2. Questionnaires for professionals to investigate current levels of satisfaction with services. 3. Questionnaires to parents to investigate levels of satisfaction with services. 4. Survey for parents	None provided	5 out of 8 62.5%
Outcome: There is a lack of information on how the services available can be accessed or how it's organised. Only 21% of professionals working with autistic children had received autism-specific training. Also no training in some autism-related issues such as behaviour management strategies and communication issues. Parental stress is increased by the inability to access services quickly									

Table 3 (continued)

ID	Reference	Aim	Sample size	Age group	Comparison group	Narratives	Study design	Data analysis	Quality score
3	Kirby et al. (2005)	Investigates teachers' and GPs' knowledge about learning difficulties	105 teachers. 105 GPs	Not provided	None	GPs' and teachers' perspectives	Quantitative- questionnaires to collect teachers' and GPs' knowledge of six common learning difficulties. Qualitative data collected from open responses to the labels	DSM-IV criteria were used to score the response	7 out of 8 87.5%
Outcome: Knowledge from both professional groups was limited. They both have only cursory awareness. However, teachers gave more correct definitions than GPs									
4	Singh et al. (2008)	To explore organisational, clinical, policy and protocols involved in children's transition to mental health services. Identify factors that facilitate or impede effective transition from CAHMS to AMHS	42 teams	Not provided	None	Professionals' narratives	Quantitative study. Literature review of the transition from child to adult mental health. Questionnaire survey—to collect data and identify transition protocols	Key transition-related themes were derived from the literature search, transition protocols and TRACK study participants. Themes identified (e.g. transition boundary) were allocated to pertinent procedural concepts (e.g. transition criteria and service boundaries) to generate protocols containing specific themes per procedural concept	7 out of 8 87.5%
Outcome: Not all protocols meet all requirements set by government policy. There is discontinuity of care provision for some patients who "graduate" from CAMHS services but are not accepted by adult services. Discontinuity of mental health and poor transition of care result from complex service structures, service boundaries, different protocols, and possible policy-practice gaps									
5	Lawson, R. (2009)	A mother's experience about her autistic child's visit to the doctor's	1 parent. 1 child	A 13-year-old girl	None	Personal narrative	Opinion, qualitative. A mother narrates her experience with her autistic child's visit to the doctor's	None provided	NA

Table 3 (continued)

ID	Reference	Aim	Sample size	Age group	Comparison group	Narratives	Study design	Data analysis	Quality score
Outcome: A private waiting area was provided, and the GP is quite knowledgeable about autism and its implications. The visit to the doctor was a good one, but not all visits are									
6	Singh et al. (2010)	To explore children's experiences of transitioning to adult mental health services	154 teenagers. Mean age 18.12 years	78 males, 76 females	Pathways are categorised as optimal or sub-optimal	Service users, carers, and professionals' narratives	Mixed-method research. Data collection from the case-note survey. Qualitative semi-structured interviews to understand the views of service users, carers and professionals and to identify organisational factors that are facilitators or barriers to transition and continuity of care	Stata Version 9 for Windows was used for logistic regression to determine predictors of optimal transition	7 out of 8 87.5%
Outcome: Most transitions from CAMHS to AMHS are poorly planned, executed, and experienced									
7	Pratt et al. (2011)	To improve the process of admission for young people with learning disabilities and autism	52 children. 20 staff and 4 families	Not provided	None	Carers' and staff's narratives	Mixed-method research. Data collection from the children's inpatient service audit with a large paediatric intensive care unit. Demographic and numeric data from ward staff about any child with behavioural problems. Informal interview with 20 staff and 4 families	None provided	4 out of 8 50%
Outcome: Parents feel the problems encountered during admission could have been avoided with planned admissions and increased awareness of the process and individual needs. Staff feels de-skilled, are uncertain about ASD, and lack knowledge beyond the basic training. Preplanning that involves the family and informed staff can reduce distress and improve the patient and staff's experience									

Table 3 (continued)

ID	Reference	Aim	Sample size	Age group	Comparison group	Narratives	Study design	Data analysis	Quality score
8	Barry et al. (2013)	It examined the problems autistic children encounter while accessing dental care services	56 parents/ carers, 112 children. 11 children—mildly affected by autism. 13 children—moderately affected, 26 children—severely affected	Age 3–16 Male—43 in each group. Female—13 in each group	Control group—56 parents/carers of age-matched healthy, neuro-typical children	Parents/carers' personal narratives	Quantitative study. A cross-sectional, case–control questionnaire study. Focus group of parents/ carers of autistic children and literature review to identify barriers to dental care experienced by autistic children. Questionnaire to identify the main barriers to dental care experienced by autistic children	Cases and controls were compared using chi-square and Fisher's exact test	8 out of 8 100%
Outcome: Autistic children encounter difficulties in accessing dental care and travelling to dental surgery and are more prone to negative behaviours									
9	Beresford et al. (2013)	To investigate young people's and their parents' experiences of transition from children's to adult services	112 children	16–24 years	None	Parents/carers' personal narratives	Mixed-method design—interviews and survey. Survey autistic young people and their parents to understand their support needs. Interviews with professionals and parents/carers of young adults with autism to gather their experiences of mental health transfer	Not provided	5 out of 8 62.5%
Outcome: Some sites are well equipped to support autistic young people while some are not									
10	Slade (2014)	To understand the needs and experiences of autistic children and their families and carers and the effect of ethnicity	13 focus groups. 130 participants in total	Not Provided	None	Parents' perspective	Qualitative study. Structured discussion to gather the challenges encountered when accessing help	Not provided	10 out of 10 100%

Table 3 (continued)

ID	Reference	Aim	Sample size	Age group	Comparison group	Narratives	Study design	Data analysis	Quality score
Outcome: Most participants claimed that the challenges faced were based on autism, not ethnicity									
11	Brown et al. (2014)	To understand parents' perception of barriers and facilitators of good practice when caring for autistic children in dental care settings	19 children. 13 males. 6 females	5 children—5–7 years. 7 Children—12–15 years. 1 young person—17–21 years	None	Parents/carers' personal narratives	Mixed-method online questionnaire survey with open and closed questions to gather participants' information. In-depth semi-structured interviews based on responses from the questionnaires	Answers to the open questions were analysed thematically. SPSS statistics are used to analyse responses to the closed question. Interviews were recorded and transcribed verbatim and then analysed with the thematic framework. Finally, the three authors independently analysed the data to test the credibility of the findings	7 out of 8 87.5%
Outcome: More than half of the participants experienced difficulties related to autism. Evidence suggests that some dental practices lack knowledge about autism, how it affects behaviour and responses, and how to communicate or adapt their practice to cater for individual needs									
12	Brammer, A. (2015)	To understand the experience of parents of autistic children attending a Radiology department	5 families	8–19 years	None	Parents' perspective	Qualitative study. Parents were interviewed to gather their perceptions of the use of person-centred needs assessment (PCNA) before attending a magnetic resonance (MR) scan at the hospital	Colaizzi's seven-step approach and thematic coding were used to analyse the semi-structured interview to explore the relationship between the themes identified and the context of the social environment	10 out of 10 100%
Outcome: All participants except one were happy with their experience in the radiology department. The participant claimed the major problem experienced was the busy waiting areas									

Table 3 (continued)

ID	Reference	Aim	Sample size	Age group	Comparison group	Narratives	Study design	Data analysis	Quality score
13	Merrick et. al. (2015)	To report the characteristics of 3 groups of people transferring from paediatric to adult health services	374	14–18 years	Two cohorts of young people with ASD without a significant learning disability	Young people and parents' perspectives	Quantitative study. Young persons and a parent completed the "Mind the Gap' Scale—about their experience of service, the Rotterdam Transition Profile-a 9 domain questionnaire about their involvement in life situations, and the Warwick and Edinburg mental well-being scale- a 14-item questionnaire to capture their well-being	Chi-squared tests—for comparisons of GMFCS for the cerebral palsy group. T-tests—for comparisons of SRS total scores, a parent-reported and young person reported SDQ for the ASD group, and age of diagnosis and HbA1c levels for the diabetes group. Wilcoxon sign rank tests-to measure the difference in satisfaction scores between young people and their parents	8 out of 8 100%
Outcome: Parents' satisfaction with the service received is lower than the children's									
14	Fox et al. (2016)	To understand attitudes toward help-seeking for autistic children in UK Somali Migrant Community	17 children. Girls—5. Boys—12. 15 Parents. Male—3. Female—2. Average age—36 years	4–13 years	None	Parent's perspective	Qualitative study. In-depth interviews to explore parents' experiences of having a child with autism	Inductive thematic analysis to analyse the interview data	10 out of 10 100%
Outcome: Help-seeking attitudes for autistic children might be affected by cultural-specific issues									

Table 3 (continued)

ID	Reference	Aim	Sample size	Age group	Comparison group	Narratives	Study design	Data analysis	Quality score
15	Christou. E (2016)	To ensure autistic people can access healthcare services successfully	900	Not provided	None	Parents/advocates and professionals' perspectives	Mixed-method research. Oral and written evidence from autistic individuals, Telephone interviews with individuals and parents/advocates. Survey candidates were recruited through convenience sampling methods and the internet Snowballing methods through social media	None provided	5 out of 8 62.5%
Outcome: Autistic individuals face several challenges when accessing healthcare									
16	Kennedy et al. (2016)	To develop integrated pathways for patient care improvement. To raise awareness and redesign hospital care provision	Not provided	0–25 years	None	Parents/advocates and professionals' perspectives	Mixed-method research. Data collection from questionnaires, audits and evaluative feedback from parents, carers and staff and stakeholder conference	None provided	2 out of 8 25%
Outcome: Lack of staff awareness, patient/staff experience, rights, safety, and behaviour when providing care were highlighted as some of the barriers to accessing appropriate healthcare for autistic children in hospital settings. The development of integrated pathways improved patient care outcomes									

Table 3 (continued)

ID	Reference	Aim	Sample size	Age group	Comparison group	Narratives	Study design	Data analysis	Quality score
17	Unigwe et al. (2017)	To investigate GPs' ability to manage autistic patients and factors affecting it	304 GPs	27–70 years	None	GP's perspectives	Mixed-method research. Online, self-report survey on background, training, and experience as a GP and regarding autism. Fourteen-item self-efficacy scale questionnaire about their knowledge of autism. Open questions about their experiences of working with autistic patients	Correlational analysis to assess the relationships between knowledge of autism, training, perceived self-efficacy and other variables. Regression analysis—to analyse potential predictors of GPs' perceived self-efficacy	7 out of 8 87.5%
Outcome: More than 39% of the GPs have never had formal training in autism. Limited abilities to manage autistic patients. There are failings across the healthcare system. There is an urgent need for specialist service provision									
18	Thomas et al. (2018)	To gather parents' experiences with autistic children and understand how they think dental services can be improved	17 parents	4–13 years	None	Parents' perspectives	Mixed-method research. Snowballing sampling technique. Face-to-face, semi-structured interviews to gather dental experiences, difficulties they may have had, and what they think the dental team could have done to prevent the challenges. Discussions were audio-recorded and then transcribed verbatim	The data were analysed with thematic framework to identify the issues described	7 out of 8 87.5%

Table 3 (continued)

ID	Reference	Aim	Sample size	Age group	Comparison group	Narratives	Study design	Data analysis	Quality score
Outcome: There must be a strong relationship between the parents and the dental team for a successful care experience. Parents should be seen as experts and advocates for their children because they might have answers to issues that arise during dental visits									
19	Crane et al. (2018)	To understand obstacles faced when accessing mental health services	130 young adults. Online survey—109. Detailed interview—21	16 to 25 years	None	Young autistic adults' perspectives	Mixed-method research. Community-based participatory research (researchers + young autistic adults) Online survey and semi-structured interview to gather information on the background and health care experiences	Face validity was used to measure the mental health problems of the young autistic adults	7 out of 8 87.5%
Outcome: Autistic young adults sometimes face difficulties accessing their own mental health and other challenges accessing mental health care. It is essential to listen to and learn from young autistic people to ensure that their health care is met									
20	Colver et al., (2018a, 2018b)	To explore the features associated with better outcomes for young people with long-term conditions	374 longitudinal mixed methods study. 118 autistic individuals	14–18.9 years	None	Young autistic adults' perspectives	Longitudinal, mixed methods, qualitative sub-study. Home visit to collect baseline data, then three more visits, 3 years apart. Questionnaires about the features of services experienced. Interviews with family members and health professionals to gather more information about their experiences	Linear or logistic regression analysis to measure satisfaction with mental health services and mental health well-being	7 out of 8 87.5%

Table 3 (continued)

ID	Reference	Aim	Sample size	Age group	Comparison group	Narratives	Study design	Data analysis	Quality score
Outcome: Parents' involvement, health self-efficacy, and adult team involvement are associated with better outcomes for young people									
21	Colver et al., 2018a, 2018b	To describe the extent to which service providers offer nine proposed beneficial features of transition services	374 longitudinal studies. 13 sampled from the longitudinal cohort for the sub-study. 34 parents or health professionals	14–18.9 years	Young people attending diabetes services might experience beneficial features compared to young people with autism	Young autistic adults' perspectives	Longitudinal, mixed methods, qualitative substudy. Home visit to collect baseline data, then three more visits, 3 years apart. Questionnaires about the features of services experienced. Interviews with family members and health professionals to gather more information about their experiences	Chi-squared or T-tests as appropriate was used to analyse characteristics of the participants and assess potential bias	8 out of 8 100%
Outcome: The nine proposed beneficial features of transition services were poorly provided. Less than half of the services provided age-banded clinic, written transition plan, transition manager for the clinical team, a protocol for promoting health self-efficacy, or holistic life-skills training									
22	Eades et al. (2019)	To investigate UK dental professionals' knowledge of autism and perceived confidence in treating autistic patients	482 UK dental professionals	22–70 years. Male—94. Female—259	Difference between knowledge and self-efficacy levels between those with and without personal experience of autism, and those trained in autism versus those without training	Dental professionals perspective	Quantitative study. Online, self-report survey to gather participants' background information, autism knowledge, self-perceived efficacy	Correlation analyses to assess the relationships between knowledge of autism, self-efficacy and other variables. Mann–Whitney U or T-tests were used to compare self-efficacy levels and knowledge against those with personal experience of autism, trained and untrained. Thematic analysis was used to analyse all qualitative responses	8 out of 8 100%

Table 3 (continued)

ID	Reference	Aim	Sample size	Age group	Comparison group	Narratives	Study design	Data analysis	Quality score
Outcome: Over half of the participants had no formal training in autism. Their confidence in treating an autistic patient is moderate. They also complained about the lack of resources to implement support strategies									
23	Jackson et al. (2019)	To understand experiences of raising an autistic child and their access to mental health services	7 mothers. 34–47 years	11–15 years	None	Parents' perspective	Qualitative study. Semi-structured interviews to gather information about socio-demographic background and experiences of mental health services	Interpretative Phenomenological Analysis (IPA) was used to explore the lived experience of the participants	10 out of 10 100%
Outcome: All the participants complained about negative experiences accessing mental health. Inconsistencies were found in the process of gaining access to mental health services									
24	Merrick et al. (2020)	To understand autistic children and adolescents' experiences of transition from childhood to adult mental health services	118 young people. 113 parents/carers	14–21 years	None	Young people and parents' perspectives	Mixed-method research. Longitudinal study. Socio-demographic, mental health, and mental well-being data and experiences of health-care services data were collected from clinical case notes, questionnaires, and interviews	Data were analysed by SPSS version 23. Variables compared with ANOVA or χ2-tests. Regression to identify predictors of successful transfer from CSMHS to AMHS. Framework analysis was used to organise the data	7 out of 8 87.5%
Outcome: Some of the participants transitioned successfully, while others reported negative experiences of transition and unmet care needs									

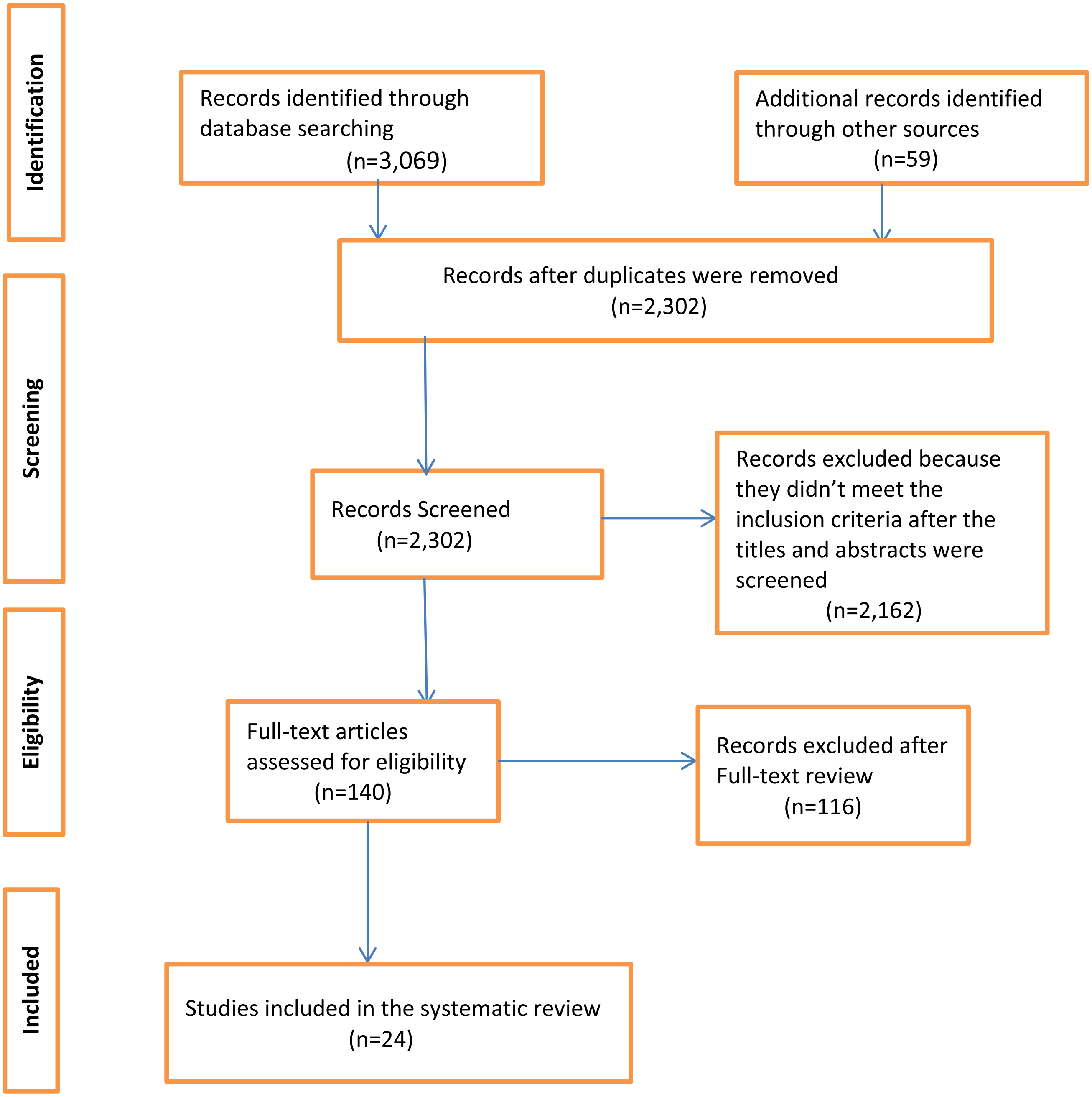

Fig. 1 The PRISMA flowchart. Adapted from Moher et al. (2009). This diagram documents the search strategies used to collect studies exploring autistic children and adolescents' experiences when accessing healthcare services in the UK

Five studies obtained the views of a mixed sample including professionals, service users, and their parents (Kennedy, Christou, Pratt, Singh (b), and Nesbitt), while four studies focused more directly on the professionals' perspectives (Kirby, Singh (b), Unigwe, and Eades). Conversely, 14 studies reported the parents' and service users' personal experiences (Slade, Merrick, Jackson, Colver (a and b), Crane, Thomas, Fox, Merrick, Brammer, Brown, Beresford, Barry, and Lawson). Only a few papers included autistic individuals themselves: two studies included autism advocates (Christou and Kennedy), and three studies included young autistic adults (Crane and Colver (a and b).

In addition, diverse data collection approaches were used in the included studies. Two studies used focus groups (Barry and Slade); seven studies utilised retrospective hospital data from case notes or charts (Klein, Singh (a and b), Merrick, Barry, and Pratt); nine studies used surveys (Eades, Berresford, Brown, Christou, Unigwe, Crane, Nesbitt, and Singh (a and b)), 12 studies made use of questionnaires (Klein, Unigwe, Colver (a and b), Nesbitt, Singh (a), Merrick (a and b), Brown, Kennedy, Kirby, and Barry); while interview methods were used by 14 studies (Berresford, Brown, Brammer, Fox, Christou, Thomas, Crane, Nesbitt, Singh (a), Colver (a and b), Merrick (a), Pratt, and Jackson). The various analysis methods utilised in the included studies are illustrated in Table 3.

oooResearch question 2: What barriers and facilitators to healthcare access emerge from the evidence base?

Despite the varied methodology described above, a consistent set of seven barriers emerged across the studies reviewed.

1) A total of 19 studies addressed autism knowledge. Measurement of autism knowledge was grouped into two domains: #1) Healthcare professionals' knowledge and training and #2) service user and carer knowledge about specialist services and knowledge about navigating the healthcare system. Twelve studies assessed professional knowledge about autism and autism training (Lawson, Brammer, Christou, Jackson, Kennedy, Unigwe, Thomas, Eades, Merrick (a), and Slade), and seven studies accessed parental and patient knowledge about specialist services and knowledge about navigating the system (Slade, Crane, Thomas, Christou, Fox, Brammer, and Nesbitt).
2) Christou, Brown, Lawson, Pratt, Slade, Fox, Brammer, Barry, and Klein reported sensory issues and resulting behaviour.
3) System-level barriers, which include access to services, lack of coordinated information, and collaboration between services and limited resources, were discussed in Nesbit, Unigwe, Thomas, Eades, Jackson, and Barry.
4) The transition from CAMHS to AMHS was discussed in Singh, Beresford, Brammer, Merrick (a), Kennedy, Unigwe, Colver (a), Merrick (b), and Colver (b).
5) Person-centred care, including the pre-admission and admission process, reasonable adjustment of the environment, and services, was discussed by Brown, Thomas, Kennedy, Merrick (a and b), Brown, Brammer, Barry, Lawson, Colver (a), Crane, Kennedy, Barry, and Pratt.
6) Communication issues between parents, children, and professionals as well as language barriers and professional-client relationships were discussed by Brown, Brammer, Thomas, Colver (a and b), Jackson, Slade, Lawson, and Beresford.
7) Fox, Crane, and Slade discussed stigma and cultural attitudes towards mental illness.

The synthesis describes these seven barriers in more detail in the following sections.

Professional Knowledge and Training

Professional Training

The healthcare needs of autistic children can sometimes be complex and require the attention of knowledgeable and trained professionals. However, there seems to be a gap in autism-specific training, for example, the omission of the following important topics: the organisation of services, behaviour management strategies, and communication issues (Eades, Unigwe, Slade, and Christou). Participants reported encounters with health professionals who themselves identified a lack of experience, training, or understanding of autism (Slade, Christou, Nesbitt, Eades, and Unigwe) although training appeared higher for dental professionals (Eades).

Two studies explored the effect of healthcare culture on access to healthcare for autistic children (Slade and Brammer). For example, cultural practice among the hospital staff that does not recognise the need to carry out pre-admission assessments for autistic children. This could be linked to the fact that the government legislations appear to place more emphasis on the training of staff working with autistic adults (Autism Act 2009), while little guidance is available about the staff working with autistic children (Brammer).

Professionals' Knowledge

Eades and Unigwe reported high awareness and knowledge of autism among professionals. However, their focus of knowledge seems to be centred on autistic children's sensory needs and ability to feel empathy (Eades), while they lack knowledge about autistic people's co-occurring mental health issues (Eades, Unigwe, Kennedy, and Nesbitt). Despite high levels of overall knowledge of autism being reported by the professionals, they still reported low self-efficacy in consulting with and managing autistic patients, felt that autistic children were difficult to treat, and were unaware of resources to facilitate treating this group (Unigwe, Eades, and Pratt). In addition, staff indicated particular uncertainty about autism compared to other disorders (Pratt), and were unaware of the best way to behave when providing care for autistic children in hospital settings (Kennedy and Nesbitt), especially where professionals were not specialists in their area. Greater confidence and self-efficacy was reported by trained professionals and those who have treated or are currently treating autistic patients, or had personal experience of autism (Eades and Unigwe) than those who have not received any autism-specific training or treated autistic patients. This reliance on personal connections to autism might result in a narrow understanding of autism (Unigwe), delays in diagnosis or diagnostic overshadowing where patients' concerns about co-occurring medical conditions are dismissed as 'part of their autism' (Christou). Overall, the literature reveals low levels of professional knowledge and confidence when treating autistic children and this could be a barrier to healthcare access.

Service User and Carer Knowledge

Parents' Knowledge

Three studies (Brammer, Fox, and Beresford) discussed parental knowledge and its effect on access to healthcare for autistic children. Some parents report being overwhelmed by a lack of understanding of autism and its terminologies (Fox), healthcare pathways (Beresford), or available personal adjustments that could be made for their children (Brammer). This hinders their ability to seek or access appropriate physical or mental healthcare required to treat their autistic child's co-occurring medical conditions. In addition, Fox reported that parents whose first language is not English or those unfamiliar with the UK healthcare system might encounter more significant problems than those whose first language is English. At the same time, Brammer highlighted the need for interpreters to bridge the language barrier.

Young Person's Knowledge

One study (Crane) discussed the impact a young person's knowledge about autism could have on their ability to seek help. Autistic individuals' ability to differentiate between autism and mental health problems was reported as essential to distinguish between being sick or not. However, some autistic children suffer from alexithymia, a co-occurring symptom of autism, which makes it difficult for them to know if their feelings or thoughts are part of their autism or a sign of mental health problems and whether it is time to seek help (Crane).

Environmental Factors

The hospital or healthcare environment is related to the background factors that could hinder accessing optimal health care for autistic children (Brammer). Some aspects of the healthcare environment, such as car parks, ambient design of the hospital (Brown), or highly populated areas, could impact the experiences of parents and their autistic child's access to healthcare and lead to behavioural issues. When not properly designed and managed, the environment could lead to failed medical interventions and even cancellation of appointments (Kennedy, Brown, and Thomas). For many autistic children, the most significant barrier to accessing optimal healthcare service is a sensory overload of the environment (Christou, Barry, and Brown). For example, more than half of the participants in the studies reviewed reported experiencing difficulties in the waiting room. Some of the most common triggers are enclosed places, bright lights, strange tastes, and strange smells (Barry, Brown, and Barry). The environment is especially challenging for autistic children where it is busy and noisy (Barry, Thomas, and Kennedy), or where children have to sit next to strangers (Thomas), all of which contribute to heightened anxiety of the children and the parents (Thomas, Brown, Barry, and Kennedy). In addition, some parents reported that their child showed behavioural challenges (such as screaming or hitting) in the waiting area (Barry, Thomas, and Kennedy), while some parents feel the need to wait away from people in empty corridors (Brammer).

Similarly, some children become distressed due to hypersensitivity to touch by the healthcare practitioners, specifically head touching. The intense sensory experience of an autistic child can lead to challenging behaviour such as spitting, crying, lying on the floor, head butting, biting or hitting the staff, or self-harming, especially when distressed (Barry, Brown, Christou, Eades, and Klein). In addition, sensory overload could also lead to physical reactions and symptoms (Christou) like anxiety-induced irritable bowel, sickness, seizures (Thomas), or vomiting (Barry).

When behavioural issues occur in healthcare settings, there is usually a need to reduce the stressor or exert management techniques (Eades). Managing challenging behaviour in autistic children can reportedly involve communication techniques (Barry and Klein), or pharmacological management (Klein) or behaviour modification (Eades and Klein). These management methods for treating autistic children in hospital or dental practices often fail patients, and sometimes treatment is carried out with general anaesthesia, especially if there is a need to carry out comprehensive treatments (Klein).

System-Level Barriers to Healthcare Access

Lack of Information and Clear Pathways

Lack of joined-up services (Unigwe) and coordinated information (Thomas, Nesbitt, and Unigwe) is a significant concern in healthcare services, especially in mental health services, dental services, and transition from child to adult care. For example, there is no coordinated information on the number of autistic children known to any given London borough (Nesbitt), and this is also true for some other parts of the UK (Thomas and Unigwe). Likewise, Nesbitt revealed that individual professionals provided information about the children from memory because there was no children's database maintained on autistic children. Furthermore, there was no system for reporting autism-specific classifications available.

There is a resounding negative narrative from mothers and/or caregivers about accessing services for their autistic children (Thomas, Crane, Jackson, Slade, and Nesbitt). Participants reported not receiving complete information about available services or being discouraged from pursuing support (Slade and Thomas). Many reported experiencing a delay in accessing appropriate dental care because of confusion over specialist dental services available for autistic children and the referral process, which many described as bureaucratic and complicated (Slade). Many parents of autistic children could not find information about the services available to them (Thomas, Crane, Jackson, and Slade), some had to research the pathways themselves, then inform the professionals about their child's needs (Slade and Thomas), while some GPs found it difficult to access resources (Unigwe and Nesbitt). Further, the scarce information and resources attained were thought to contain too much jargon (Slade). Nesbitt and Unigwe also reported that some professionals are unclear about the appropriate referral pathways for autistic children, even though they believed it was the role of a GP to have all the information about the local services and to be able to provide parents and carers with such details (Unigwe).

Limited Resources

Many mothers complained about waiting too long for their child to be seen by mental health services, most times without support or advice (Eades and Jackson). Once attained, the professional support on offer is usually too short for a complex condition (Eades, Unigwe, and Jackson). Some professionals commented on the extra time needed for treating autistic children because of how complex their needs are, which usually takes more time than allocated. This was especially highlighted with regard to the high workload caused partially by the closure of specialist services due to a lack of funding (Eades, Unigwe, and Slade). Professionals sometimes reported working hard to make adjustments when treating autistic children because they felt the need to provide best levels of care, despite the time constraints, lack of funding (Eades), and the fact that such adjustments are not recognised by NHS systems (Eades and Slade).

Some parents are concerned about their child's safety in the hospital and the lack of enough staff to keep them safe (Brammer). In addition, some parents expressed concerns about the lack of professionals from a more diverse workforce with different cultural backgrounds who they believed would be able to provide more effective support (Slade). However, some caregivers believe that professionals with the same cultural background might make false assumptions based on their shared cultural backgrounds (Slade). Some professionals claim that primary health care professionals should not take on specialist roles because they do not have the resources or are not equipped to care for autistic patients (Unigwe and Eades).

Transition

Parents' experience of service transfer from CAMHS to AMHS was predominantly negative (Beresford, Singh, Brammer, Merrick, Kennedy, and Colver). Only 4 of the 90 participants in Singh experienced optimal transition, Young people with autism, or those with a borderline learning disability might not be prioritised for care and might fall through the care net, and there is a lack of care plan for those refused by AMHS (Singh (a)). Loss of continuity and lack of information sharing between CAMHS and AMHS also often caused a significant barrier to accessing appropriate healthcare for autistic young people who have a chronic or lifelong co-occurring mental health condition (Beresford, Singh, Merrick (a), Kennedy, and Colver). The loss of relationship developed with the therapist in CAMHS reportedly had a negative impact on some children's mental health (Beresford and Kennedy). In addition, the interruption of reasonable adjustments, individualised services, and intense support offered in CAMHS but not available in AMHS can also have a severe impact on mental health service support (Merrick (a), Kennedy, and Colver (a)). Interactions between the services pre-transfer, meeting the adult team before the transfer, appropriate parent involvement, and promotion of health self-efficacy were related to better outcomes for those transferred (Merrick (a) and Colver (b)).

Person-Centred Care, Pre-admission, and Admission Process

Many parents also believed that the problems encountered by their autistic children and themselves could have been avoided with personal adjustment tailored to their child's particular needs, family circumstances, and planned pre-admission since each autistic child's needs are unique (Pratt, Barry, Slade, and Eades).

Individualised assessment before the appointment date and increased awareness of the individual's needs are believed to ensure that the children encounter minimal surprises, make the day more manageable, and receive treatment successfully (Pratt and Eades). Participants felt that phoning the dental surgery prior to arrival (Barry), provision of pagers to parents (Thomas), and providing immediate access upon arrival would be helpful (Barry, Thomas, and Lawson). Having quiet zones (Kennedy and Lawson) or an agreed maximum waiting time (Kennedy) has also been reported to be a reasonable environmental adjustment for autistic children (Thomas).

Collaboration with parents by hospital staff to gather information about their child's needs and potential triggers (Crane and Kennedy) would also be useful, so that an effort can be made to adapt to the child's nuances and individual needs (Thomas). An example of a person-centred approach is a special session created for the child to visit the hospital before the appointment to familiarise themself with the equipment, what it does, the environment, or the professionals responsible for their care (Kennedy and Brown). However, some parts of healthcare services might not have pre-admission assessments due to issues such as lack of knowledge or available healthcare practitioners (Brammer). This could lead to an inability to access optimal healthcare services (Barry, Thomas, and Kennedy) or complete withdrawal from seeking healthcare services, especially if the parents or caregivers feel services are not tailored to their child's autism (Crane).

Most of the participants whose individual needs assessment was completed were happy about the short waiting times, reasonable adjustments made, and the compassion of the professionals (Brammer). However, Thomas reported that the stress and anxiety experienced by the family before, during, or after unsuccessful visits could lead to violence at home, self-harming, or withdrawal from healthcare services.

Communication

One focal point of all discussions in the articles was unambiguous communication, which allows parents to act as an advocate for their children confidently and is involved enough for parents to feel that they are in a collaborative partnership with professionals (Eades, Jackson, Brown, Beresford, and Thomas). Parents of autistic children should be seen as experts on their child's specific needs because they have first-hand knowledge of their children's problems and are in the best position to articulate how best to deal with their child (Thomas, Brown, and Eades). However, some parents felt they had to fight to be heard (Jackson), while some reported that the professionals minimised their concerns about their child's co-occurring issues and dismissed it as just another typical symptom of autism that they could do nothing about (Thomas, Brown, and Eades).

There are two distinct themes being addressed here: language proficiency and communication issues more broadly. Almost all of the studies reviewed except for two (Beresford and Lawson) reported significant negative experiences of communication with healthcare professionals. Some participants complained about not being informed about their child's transition (Singh, Beresford, Brammer, Merrick (a), Kennedy, Unigwe, Colver (a), Merrick (b), and Colver (b)), lack of clarity or proactive contact (Eades, Jackson, Brown, Beresford, and Thomas). Parents reported that some professionals make assumptions based on appearance or ethnicity, especially if the families have strong accents (Slade). They reported not being listened to (Slade and Jackson), and language barriers (Slade). This forced some participants to rely on their family members to translate even though they could only partially understand the information themselves (Slade). In addition, parents commented on the need for support either by providing a professional that speaks their language or support in the form of information and resources available in different languages or providing formal interpreters (Eades, Jackson, Brown, Beresford, and Thomas). However, some participants claimed that the interpreters sometimes misunderstand them because of their own cultural assumptions, thereby missing the meaning behind the information communicated (Slade).

There are few instances of good communication outcomes where the parents felt listened to (Lawson, Beresford, Brown, and Jackson). However, one parent felt she was listened to because of her background in nursing, so she could research what she wanted and express it to the healthcare professionals (Jackson), which links back to parent knowledge.

Stigma and Culture

The stigma associated with autism makes some parents hide away their children, which might prevent them from getting the necessary healthcare (Slade, Fox, and Crane). Some parents are badly spoken about by the community, feel ashamed, and are blamed for doing something wrong during pregnancy to make their child autistic (Slade) which extends into healthcare settings and families' willingness to seek treatment. Some parents also avoid seeking help because they feel judged by professionals (Brown, Thomas, and Jackson). For example, participants described how their dentists put pressure on them without considering the sensory issues associated with autistic individuals and brushing (Thomas and Brown), while some felt blamed for their child's distress (Jackson).

Discussion

The present paper aimed to identify what is known about disparities and facilitators of healthcare access for autistic children in the UK. In total, 24 studies that met the inclusion criteria for the systematic review were identified. The studies discussed different aspects of healthcare access, such as GP access (Unigwe et al., 2017; Lawson, 2009; Christou 2016; Kirby et al., 2005), mental health (Jackson et al., 2019; Crane et al., 2018; Singh et al. Singh et al., 2010), dental practice (Thomas et al., 2018; Eades et al., 2019; Klein et al. 1999; Barry et al., 2013; Brown et al., 2014), transition (Beresford et al., 2013; Colver et al., 2018a, 2018b; Colver et al., 2018a, 2018b; Merrick et al., 2015; Merrick et al., 2015; Nesbitt, 2000; Singh et al., 2008, 2010), and hospital services (Brammer, 2015; Kennedy et al., 2016; Pratt et al., 2011).

Various methods were used to investigate healthcare access for autistic children and the included studies gathered data from varied sources. For example, some data were collected specifically from the service users' and parents' perspectives; some studies explored the professionals' perspectives alone; some combined the parents, service users, and professionals' experiences for their data; some included autism advocates in their research; while some explored the perspectives of young autistic adults.

In general, all articles identified barriers that resulted in poorer access to healthcare or poor quality of care for autistic children and autistic young adults, while only a subset of the studies provided evidence on facilitators. Despite the limited literature and differing methodologies, similar facilitators and barriers were reported across the 24 studies. The barriers and facilitators found were professional and parental knowledge about autism, sensory issues, challenging behaviour, system-level barriers, patient-provider-parent communication issues, lack of person-centred care, stigma, and culture. Some aspects of these will be discussed in detail below.

Difficulties in verbal or non-verbal communication were reported to affect access to healthcare negatively (Brammer, 2015; Eades et al., 2019; Klein et al. 1999) or impact an individual's ability to report medical conditions (Slade, 2014). One autism-related factor affecting healthcare access is the atypical nature of the social or communication skills of individuals with autism, which is always unique to each person (Eades et al., 2019; Klein et al. 1999). For example, an autistic person might find it challenging to process the three streams of information: visual (ability to look at the health care practitioner), verbal (listening to information), and processing (thinking about the information given) (Hurlbutt & Chalmers, 2002).

Another aspect that should be considered is parental autism. Sandin et al. (2014)'s study of the familial risk of autism found that the heritability of autism and autistic disorder was estimated to be 50%. Healthcare professionals should be aware that there is a notable proportion of autistic children whose parents are also autistic. This is because being an autistic parent might make communication with healthcare professionals about an autistic child's healthcare needs challenging. Some parents are particularly anxious about being misunderstood about their autistic children if they are autistic themselves (Pohl et al., 2020). They often feel misunderstood by healthcare professionals and have difficulties in deciding which information to share, which could lead to feelings of anxiety (Pohl et al., 2020). These difficulties could be alleviated by checking beforehand the best way to communicate with the patients and what support is necessary during healthcare appointments. Thus, autism sometimes affects how an autistic individual sees the world, which could be different to that of a non-autistic individual, subsequently affecting the interaction between them (Milton et al., 2022). This review has highlighted the importance of communication as both a barrier and a facilitator to healthcare access. Understanding the best way to communicate with patients during appointments will improve healthcare delivery and, consequently, the autistic child's health. However, research into the best ways in which to achieve this is still needed.

The findings from this review also suggest that there is a need for personalised care tailored to the autistic child's needs which is similar to the findings of Prato et al. (Prato et al., 2019)'s research about the factors that determine the quality of a hospital experience. Prato et al. (2018) found that creating activities to promote empowerment, valuing the person, and creating a suitable environment will allow healthcare practitioners to pay better attention to their patient's individual needs instead of taking the one-size-fits-all approach. Personalised care also applies to autistic children experiencing adverse effects like sensory overload. A notable finding that emerged from the data synthesis is the effect of sensory sensitivities on autistic children. Individuals with autism often suffer from elevated sensory processing, which affects one or more sensory modalities such as touch, sound, smell, sight, or taste (Miller et al., 2007). This over-sensitivity usually affects their everyday lives (Tyler et al., 2014; Danesh et al. 2021; Miller et al., 2007), which could also affect their ability to access appropriate healthcare. These environmental factors could lead to autistic children exhibiting challenging behaviours, ultimately making parents and/or caregivers less inclined to seek medical help for their children. However, simple, reasonable adjustments such as the provision of a quiet room (Lawson, 2009) or headphones (Pfeiffer et al. 2019) could improve the experiences of an autistic child in a healthcare setting.

There is also a wealth of literature about the effect of sounds on autistic children (Danesh et al. 2021; Williams et al., 2021; Sansosti et al., 2004), which sometimes prevents treatment from being carried out in traditional dental settings (Klein et al. 1999). Most times, children need to be physically restricted in order to carry out assessments or treatment due to the effect of sound (Eades et al., 2019). It could cause anxiety for the parents, staff, and the child involved (Pratt et al., 2011), and also make the professionals feel de-skilled. Therefore, there is a need to exert caution in using tools with loud noises and offering alternative taste preferences or apparatus to reduce the stressor (Eades et al., 2019). These findings reinforce the need for healthcare settings to arrange personalised care plans to ensure the visit goes well. This review found that reasonable adjustments that would benefit autistic children in reducing sensory sensitivities are reduced waiting times (Barry et al., 2013; Kennedy et al., 2016; Lawson, 2009; Thomas et al., 2018), giving a pager that would call in patients at the exact time they are needed (Thomas et al., 2018), or allowing parents to leave a mobile phone number while on site (Lawson, 2009).

An example of a framework that could improve personalised care, healthcare access, the quality of life, and life expectancy of autistic individuals (if implemented effectively) is outlined in the NHS Long Term Plan (National Health Service, 2019). In chapter 3, the Plan outlines objectives for progress in care quality and outcomes, with a subsection specifically relevant to learning disability and autism. Section 3.31 outlines plans to tackle the causes of morbidity and preventable deaths in people with a learning disability and for autistic people, including a commitment to pilot the introduction of a specific health check for people with autism. Section 3.32 outlines plans to improve its understanding of the needs of people with learning disabilities and autism, including providing healthcare staff with information and training on supporting people with autism and ensuring all healthcare providers make reasonable adjustments to support people with autism. This section also includes plans to implement a ‘digital flag’ in the patient record to alert staff that a patient has autism.

UK healthcare systems are configured in such a way that GPs often have a crucial role of ‘gatekeeping’ and referral to other healthcare services, including mental health. Therefore, exploring GP training and knowledge is vital to understand how they manage autistic children’s healthcare. Unigwe et al. (2017)’s study of autism knowledge among healthcare practitioners found that some professionals’ sources of knowledge about autism are non-expert. For example, some healthcare practitioners’ knowledge is from their personal connections or information obtained from the media, which could shape their views about autistic patients’ needs (Jones & Harwood, 2009). Jones and Harwood (2009)’s study of the media representations of autism in Australia found that autistic people are labelled as dangerous or uncontrollable which affects how they are treated. Although personal relationships might be somewhat effective in providing some invaluable sight into autistic patients’ issues, each person’s autism is usually unique; therefore, lack of knowledge and understanding of autism could lead to making common assumptions about autistic people’s cognitive ability and developmental or emotional features (Unigwe et al., 2017). Lack of expert autism training or sources of information for GPs is concerning given that they are often the first contact for healthcare needs and are often responsible for making decisions about autistic children’s health and the referral process. These findings suggest a critical need for healthcare professionals’ training (Department of Health and Social Care 2016). A framework was launched after the publication of the Long-Term Plan (2019), which outlines the capabilities relating to autism that NHS healthcare staff are expected to have. The capabilities are grouped into five domains which are one, understanding autism, two, personalised support, three, physical and mental health, four, risk, legislation and safeguarding, and five, leadership and management and education and research (Skills for Health 2019). This training can be provided through short online educational programmes (McCormack et al. McCormack et al., 2020), which have been found to be effective in tackling stigma in other populations (Gillespie-Lynch et al., 2015).

This literature review also highlights the dearth of evidence about system-level barriers to accessing healthcare services for autistic children. A prominent finding of this review was an immense need for, but an inability to access, healthcare services. This is similar to Nicolaidis et al. (2015)’s findings of system-level barriers affecting access to healthcare. Healthcare professionals have a limited understanding of the resources available to them (Unigwe et al., 2017) or are often unwilling to make the referral for autistic individuals (Slade, 2014) while some parents believed they would only be able to access support once they reached a crisis point (Slade, 2014). Taken together, the inequity and inability to access appropriate healthcare services for autistic children could increase the stress of caring for an autistic child (Nesbitt, 2000). Furthermore, navigating the complex administrative healthcare system and the lack of clear referral pathways and information is also reported as system-level barriers (Nicolaidis et al., 2015). This is supported by Vogan et al. (2017)’s research which found that more than half of the study participants experienced problems getting information about accessing healthcare services. Therefore, the provision of concise and precise information, accurate signposting to available services, and coordinated information between services might improve access to healthcare. These have been reported to improve other services such as transport and education (Southby & Robinson, 2018). Better access to healthcare services designed for parents of autistic children is needed to reduce the disparities in accessing healthcare (Beresford et al., 2013) and, consequently, increase the service users’ overall well-being. It might also reduce the burden or stress parents encounter when navigating the system, which could prevent or discourage them from seeking help.

Even though the included studies span over 21 years (1999 to 2020), it is surprising how the results and the themes within the studies did not vary across time, setting, and location (Walsh et al., 2021; Doherty et al., 2022; Soke et al. 2018; Mazurek et al., 2020; Heslop et al., 2021; Boshoff et al., 2021; Mencap, 2012). Although policies and legislatures keep changing and upgrading over time, the barriers encountered by autistic children and their parents when accessing healthcare services remain constant, which reinforces the need for the current study.

Strengths and Limitations

This systematic review has several strengths. Overall, the quality of the 24 included studies was assessed to be high, with most scoring between 80 and 100% on the quality checklists and only two studies (Kennedy et al., 2016; Pratt et al., 2011) scoring 50% or less.. This adds weight to the reliability and validity of the findings to practice, policy, and care. Also, although JBI and CASP are the critical appraisal tools used to assess the quality of the included studies because of the varied range of methodologies, there might be other tools that would allow better comparison between the different methodologies; therefore, future research should consider this.

Another significant strength of this review is that the studies included the perspectives of parents, autistic children, and healthcare professionals about healthcare access for autistic children, allowing for more varied data collection. Further, the samples of the studies vary from small to large ($n = 1$ to 900). Finally, the search strategies were well refined, and there was high agreement between the author and the quality checker, suggesting that the screening and selection process were robust and the papers were reliably evaluated.

Nevertheless, some methodological limitations should be considered. First, although the fact that grey literature was included in this review could be seen as a strength, it should also be noted that this means that peer review has not been undertaken for all studies. Two papers (Brammer, 2015; Slade, 2014) have yet to be peer reviewed in academic journals. These papers are important to include because they contain much relevant information and since not many studies are available on the subject in the UK. Secondly, this review focuses on the experiences of autistic children in accessing healthcare services, which means young adults over 18 were excluded. Further research is needed to synthesise similar information for autistic young adults. Thirdly, most of the data used were based on parents' or self-report metrics of access to healthcare experiences; therefore, findings might be biased by self-report (Rosenman et al. 2011). Also, some pieces of literature are from the same group of studies, which confirms that not enough studies are being carried out on this topic.

Conclusion

The primary healthcare system varies worldwide, meaning people's experiences differ depending on the healthcare system. This is why it is essential to conduct this systematic review focused on studies done in the UK to understand the challenges faced explicitly by UK patients. This can then provide a context for other national healthcare systems. Healthcare services are especially vital for autistic children, as they experience more healthcare issues. However, the barriers identified here sometimes deter or discourage some parents from seeking healthcare services for their autistic children.

Seven overarching barriers emerged from this review, even though the studies used different methodologies. The ongoing aim of this research is to use this synthesised evidence base to explore how to best provide resources needed by the professionals and also to develop a framework for the disparities in healthcare access that can be personalised to the service users.

This review confirms disparities in healthcare access and utilisation for autistic children and their parents and/or caregivers. However, several gaps in the literature were identified including that, surprisingly, only a few studies examined the facilitators extensively. Although there is evidence of efforts to create interventions and ways to evaluate their effectiveness (Kennedy et al., 2016; Brammer, 2015; Christou 2016), it is striking how few studies explored these topics explicitly.

Further research is needed to investigate healthcare experiences from the perspective of professionals, parents, and young people themselves, in order to improve equality of access to core services.

Declarations

Conflict of Interest The authors declare no competing interests.

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