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**Improving Health and Social Care Access for Children with Autism in the
United Kingdom**

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Table of Contents

1. Prevalence of the Problem	3
2. Introduction Including Literature-Based Background	4
2.1 Context of the Study	4
2.2 Literature on Access to Health and Social Care	4
2.3 Theoretical Framework	5
2.4 Literature Gap	6
3. Rationale & Research Question/Aims/Hypothesis	6
3.1 Rationale	6
3.2 Research Question	7
3.3 Research Aim and Objectives	7
3.4 Hypothesis	7
4. Research Methodology	8
4.1 Research Design	8
4.2 Recruitment, Sampling & Study Participants	9
4.3 Materials/Data Collection Method/Procedure	9
4.3 Proposed Data Analysis Technique	9
4.4 Ethical Considerations	10
5.0 Implications of Research	10
6.0 Research Timeline (Gantt Chart)	11
7.0 References	12

1. Prevalence of the Problem

Autism is a significant health and social-care problem affecting children in the UK and is becoming a more visible issue, however, the prevalence recorded should not be considered as a rise in cases. Increased awareness, better identification and changes in diagnostic practice may also play a part in higher prevalence recorded (Kirby and Payne, 2023). Additionally, the UK has variations in terms of identification and assessment which can lead to variations in prevalence of the condition, so that administrative prevalence should be treated with caution. This distinction is key, as prevalence statistics provide information on the size of the potential need but do not provide any information on whether there is a need that is being met by the health and social-care systems (Drakeford and Majeji, 2024).

Considered with limited access to services, the significance of this problem becomes more apparent. There has been evidence of ongoing issues with the delay in diagnosis, waiting time, lack of continuity of referral, and specialist support is not available on a consistent basis (Roman-Urrestarazu et al., 2021). Such challenges may also occur during the assessment of autism and in relation to other health and social care services such as mental health services, community paediatric services, speech and language therapy, occupational therapy and social care. It is not always a problem of lack of services, but rather the provision of timely, coordinated and appropriate services (Walsh et al., 2023).

Such disadvantage can be explained as arising from institutional and environmental barriers and not as a direct result of autism itself through the Social Model of Disability. Likewise, Levesque's Patient-Centred Access Framework proposes a framework of interrelated areas of access, such as approachability, availability, accommodation and appropriateness (Doherty et al., 2021). Thus, while nominal service availability may result in delays, complex pathways and family navigation burdens, this can turn into poor access and exacerbate unmet needs and inequalities. This gives a good justification for exploring the complex interplay between structural, organisational and professional conditions and the health and social-care access of autistic children in the UK (Babalola et al., 2025).

2. Introduction Including Literature-Based Background

2.1 Context of the Study

Children on the autism spectrum have a variety of communication, sensory, behavioural and support needs and may need a range of health, mental-health, social-care, educational and community supports (Boshoff et al., 2021). This complexity is explicitly acknowledged in the UK policy context. NICE states that autistic children should also receive health and social care regardless of their intellectual developmental level or any other condition they may have and suggests an integrated multidisciplinary approach, including health, mental health, education and social care provision (Mendez et al., 2025). The presence of this type of policy expectations is not evidence that access is realised in practice. The analytical central issue then is the difference between formal entitlement and substantive accessibility. The Social Model of Disability is relevant because it focuses on looking beyond the disability and towards barriers in the environment and institutions (Coughlan et al., 2020). Ethics of communication, inflexible appointments, sensory unfriendly environments, professional assumptions and fragmented referral systems can therefore then become individual differences into unequal access. This view is echoed in evidence from the UK which has shown that communication challenges, lack of autism knowledge and lack of reasonable adjustments and system-wide barriers are linked barriers to accessing healthcare (Babalola et al., 2025).

2.2 Literature on Access to Health and Social Care.

Parr et al (2024) said that there is a basic conflict between availability and meaningful access in the literature. Services may be formally available but may be long and complex, with unclear eligibility and pathway requirements, making it difficult for families to access the services that are needed. A systematic review of 24 studies in the United Kingdom revealed that key factors influencing access to healthcare are professional and parental knowledge, sensory needs, communication, stigma, person-centred care and system-level barriers. Qualitative research in South Wales also showed that professionals felt that pathways were fairly well defined, whilst parents and other education professionals felt pathways were confusing and parents needed to coordinate health and education services. This comparison questions the idea that a structured pathway equates to easy to access care.

O'Nions et al (2023) demonstrated that a second issue that is debated is whether to explain individual or structural. Parental knowledge/expertise/advocacy issues can have a negative unintentional effect on the individualisation of inequality, suggesting families are required to learn how to 'operate services' to get them to work for them. New evidence in the UK, though, suggests that despite being willing, professionals' ability to deliver responsive care can be limited due to a variety of factors including systemic workload, resource constraints, waiting times and inconsistent adjustments. Therefore, access is seen not as a lack in the family or in institutions, but as a joint occurrence of family resources and institutional conditions.

Keville et al (2025) identified that there is a third debate to be had about fragmentation. Support for autism is spread across NHS services, local authorities, education and voluntary services, with failure at any stage blocking the way. This is a systems view: An effort to enhance one service does not necessarily enhance access to the system if there is another service that is a bottleneck. This can be dealt to the organisation and result in a reliance on parental advocacy as a means to compensate for the fragmentation of the system rather than a true family involvement.

2.3 Theoretical Framework

The study will be organised in two complementary frameworks. The Social Model of Disability will start by exploring how disadvantage is created by organisational practices and environmental factors. Though its downside is that an exclusive structural interpretation can minimize the needs of individual patients, it's supported by a Patient-Centred Access to Healthcare Framework developed by Levesque, Harris and Russell (Loizou et al., 2024). Levesque et al. define access as a process that occurs when an individual's capacity to perceive, seek, reach, pay for and engage in care is matched by approachability, acceptability, availability/accommodation and affordability. This structure enables the analysis to identify the failure points for access and not assume they are all equal. Some information is unclear, such as approachability; some information concerns availability/accommodation, and some information concerns appropriateness, such as inappropriate professional responses. It also has multilevel orientation which facilitates interhousehold, organisation and health system interaction (Hey et al., 2023).

2.4 Literature Gap

While there is some evidence of significant barriers to health services access, the findings are not consistent throughout the health service, in different points along the care pathway and in different perspectives (Bundy et al., 2022). The gaps noted in the existing systematic review were the lack of breadth of evidence and lack of certain specialisms in the health care system. In more recent studies, the differences between parent and professional views of an access barrier are also identified, that is, access cannot be understood solely from a single stakeholder's point of view (Calleja et al., 2020). The resulting gap is, therefore, not a lack of research, but rather, fragmentation of the existing research. This work seeks to fill that gap, by collating and combining the existing UK qualitative evidence in health and social-care settings, and by analysing common and conflicting themes in a framework inspired by the Social Model of Disability and Levesque's access framework. The study then transcends identification of single barriers and attempts to understand how the structural, organisational and family level factors can interact in reproducing unequal access (Pemovska et al., 2024).

3. Rationale & Research Question/Aims/Hypothesis

3.1 Rationale

Despite the policy commitment across the UK to 'coordinated and person-centred and equitable' access to health and social care, persistent inequalities are still a concern for autistic children (Sultan, 2025). The issues of service available are not sufficient to explain the problem, because the timing of service availability, eligibility requirements, lack of linkages in referrals, knowledge and capacity of professionals and families to access services can all interact and help determine whether formal provision becomes a meaningful access. The Social Model of Disability suggests that institutional and environmental factors can be barriers to disability, and the Levesque et al.'s Patient-Centred Access Framework shows that access comes from multiple factors that are interconnected, such as approachability, availability, accommodation and appropriateness. Therefore, it is important to consider how inequalities are reproduced throughout the broader care pathway when analysing isolated barriers (Brice et al., 2021).

Existing UK evidence is also fragmented and exists in multiple services, populations and stakeholder views. This fragmentation also provides a justification for secondary, qualitative research which can systematically draw together existing qualitative accounts without repeating primary research. Manual thematic analysis is especially suitable to be used because it allows for the identification of recurring, divergent and interconnected meanings across studies but still allows for the interpretation of the contextual meaning (Oakley et al., 2021). The study aims to explain, however, not only barriers, but also the intersection of barriers at structural, organisational, professional and family levels. A focus on children with autism is justified as childhood access can have a significant impact on developmental support, education, wellbeing and longer-term service pathways; the UK offers unique multi-agency context where responsibilities for health, social care and education are interdependent (Wigham et al., 2023).

3.2 Research Question

What barriers affect early diagnosis and access to support services for children with **autism spectrum disorder** in the United Kingdom?

3.3 Research Aim and Objectives

Aim:

To explore barriers influencing early diagnosis and access to support services for children with autism spectrum disorder in the UK.

Objectives:

- To identify factors contributing to delayed autism spectrum disorder diagnosis.
- To examine challenges families face when accessing health, educational and social support services.
- Evaluate the impact of delayed diagnosis on children and families.
- Recommend strategies to improve service accessibility and early intervention pathways.

3.4 Hypothesis

There is no need to develop a formal hypothesis for the proposed study as it is exploratory and qualitative in nature. It aims to explain and confirm meaning,

experience and pattern from the current qualitative evidence and does not try to statistically test a pre-defined causal relationship. Proposing a hypothesis, however, would bring a deductive, variable-based logic to the study which is contrary to its interpretivist approach and manual thematic analysis.

4. Research Methodology

This study will be a secondary qualitative research study looking at the existing qualitative evidence of access to health and social care services for children with autism in the UK. No primary participants will be recruited, and no interviews or questionnaires or observation will be carried out. Evidence will be cited from mainly qualitative, peer-reviewed studies, supported where methodologically suitable by qualitative evidence syntheses and qualitative findings from service or policy reports from the UK. Only where the methods used, data provenance and relevance can be established, will government, NHS or local-authority/credible third-sector sources be included (Chatfield, 2020).

A qualitative approach is appropriate since the research question focuses on how and why access barriers are experienced and constructed as opposed to measuring their frequency. Quantitative data can provide some evidence of the extent of the waiting times and/or the service use but may not be sufficient to give a full account of families' experiences of fragmented pathways, professional communication, eligibility processes or the burden of coordinating services (Beck, 2023). These meanings and contextual mechanisms can be made more apparent with qualitative evidence. Secondary qualitative research is not the unmediated encounter with the participant experience, however, interpretations must be dependent on those of the original researchers and the way they collected, selected and reported their data. This will be clearly identified during evidence quality assessment and theme development. The method stresses interpretation and critical sensitivity to the constraints of secondary evidence (Cheong et al., 2023).

4.1 Research Design

The study will use an interpretivist secondary qualitative study design that will involve qualitative evidence synthesis and manual reflexive thematic analysis. Interpretivism is suitable as access is socially and contextually experienced and is not necessarily the same (Ozuem et al., 2025). The Social Model of Disability will highlight the

disabling barriers created by institutional practices, and Levesque's Patient-Centred Access Framework will identify the various types of failures by approachability, availability, accommodation and appropriateness. But secondary analysis involves interpretive distance as participants for the original study cannot be interrogated. Thus, findings will be based on the reported experiences and methodological variation and reporting quality will be seriously taken into account (Wilson, 2025).

4.2 Recruitment, Sampling & Study Participants

No human subjects will be directly recruited as this study will be analysing existing evidence. Instead, purposive sampling will seek UK qualitative research on the health or social-care access, experiences, barriers or facilitators of autistic children. Each source needs to include enough methodological detail and/or qualitative results – only quantitative and/or UK studies of adults will be accepted. Evidence can be of autistic children, parents, carers and professionals. But analytic consideration of unequal representation is very important, as parental and/or professional perspectives may marginalise children's perspectives and hence normalize the concept of access inequalities.

4.3 Materials/Data Collection Method/Procedure

Data collection will be by systematic searching, screening and manual extraction and not through primary participation with data collection participants. The following databases will be searched: PubMed/MEDLINE, CINAHL, Scopus, Web of Science, PsycINFO and supplementary Google Scholar, policy evidence NHS, NICE and government sources. Autism will be used alongside a concept of healthcare/social care and access/barrier. Manual data entry of eligible studies will take place by author, setting, participants, method, findings, barriers and theoretical relevance. Distinguishing original findings from the processing of interpretation by the researchers will enhance transparency and provide an analytical trackable path.

4.3 Proposed Data Analysis Technique

It will employ manual reflexive thematic analysis (Braun and Clarke) to identify patterns in the sections of evidence they extract. There will be familiarisation, manual coding of barriers (waiting, referrals, communication), construction of candidate themes and a critical review of the barriers. Inconsistencies will be kept as they could be signs of

variation which may indicate contextual differences not signs of analytical error. These themes will then be explained using the Social Model and Levesque. The analysis will not only start describing barriers but also the mechanisms of how the organisational fragmentation can result in transfer of the coordination responsibilities to the family and thus perpetuate unequal access (Cheong et al., 2023).

4.4 Ethical Considerations

While no one is being recruited, ethical responsibility still plays a crucial role in understanding children's experiences and their disability. Secondary research ethics will be adhered to as specified in the institutions. Analysis will not use a deficit model to represent children with autism and focus on questioning whether children with autism are being silenced by parents or professionals (Taherdoost, 2021). Original findings will be cited with a degree of accuracy, with no selective omission, distortion or inappropriate generalisation. Published accounts will not be used to identify individuals. A reflexive log will record coding decisions, interpretive assumptions and theme development, increase transparency and giving recognition to the reality of the interpretation of the researcher as a process rather than an objective discovery of theme (Panayiotou et al., 2026).

5.0 Implications of Research

The study might shed light on the interaction between fragmented pathways, communication problems and service discontinuity, and how these factors limit meaningful access to services, with implications for more integrated practice, and for family navigation (Radev et al., 2024). Cross-service synthesis at policy level could identify the impact of variation in commissioning, capacity and geography on inequality. But implications will not be prescriptive but depend on evidence. The study could also reveal gaps in knowledge, especially the lack of representation of the views of autistic children, intersectional inequalities, geographical differences between the UK nations and transition to adult services. These gaps create opportunities for future primary and comparative and longitudinal studies that could prioritize the studies (McBain et al., 2020).

6.0 Research Timeline (Gantt Chart)

Research Timeline (Gantt Chart)

Activity	W1-2	W3-4	W5-6	W7-8	W9-10	W11-12	W13-14	W15-16
Refine research question & proposal								
Literature review								
Database searching								
Screening & selection of studies								
Manual data extraction								
Manual coding								
Development of themes								
Critical thematic synthesis								
Apply theoretical frameworks								
Dissertation/report writing								
Critical editing & referencing								
Final review & submission								

Figure 1:Gantt Chart

Source: Self-Created

7.0 References

- Babalola, T. T., Dipper, L., and Botting, N. (2025). Barriers and facilitators of healthcare access for autistic children in the UK: a survey of parents and healthcare professionals. *International Journal of Developmental Disabilities*, 1-11.
- Beck, C. T. (2023). The value of secondary analysis for qualitative inquiry. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 52(6), 421-424.
- Boshoff, K., Bowen-Salter, H., Gibbs, D., Phillips, R. L., Porter, L., and Wiles, L. (2021). A meta-synthesis of how parents of children with autism describe their experience of accessing and using routine healthcare services for their children. *Health and Social Care in the Community*, 29(6), 1668-1682.
- Brice, S., Rodgers, J., Ingham, B., Mason, D., Wilson, C., Freeston, M., ... and Parr, J. R. (2021). The importance and availability of adjustments to improve access for autistic adults who need mental and physical healthcare: Findings from UK surveys. *BMJ open*, 11(3), e043336.
- Bundy, R., Mandy, W., Crane, L., Belcher, H., Bourne, L., Brede, J., ... and Cook, J. (2022). The impact of early stages of COVID-19 on the mental health of autistic adults in the United Kingdom: A longitudinal mixed-methods study. *Autism*, 26(7), 1765-1782.
- Calleja, S., Islam, F. M. A., Kingsley, J., and McDonald, R. (2020). Healthcare access for autistic adults: A systematic review. *Medicine*, 99(29), e20899.
- Chatfield, S. L. (2020). Recommendations for secondary analysis of qualitative data. *The Qualitative Report*, 25(3), 833-842.
- Cheong, H. I., Lyons, A., Houghton, R., and Majumdar, A. (2023). Secondary qualitative research methodology using online data within the context of social sciences. *International Journal of Qualitative Methods*, 22, 16094069231180160.
- Coughlan, B., Duschinsky, R., O'Connor, M. E., and Woolgar, M. (2020). Identifying and managing care for children with autism spectrum disorders in general practice: A systematic review and narrative synthesis. *Health and Social Care in the Community*, 28(6), 1928-1941.

Doherty, A. J., Atherton, H., Boland, P., Hastings, R., Hives, L., Hood, K., ... and Chauhan, U. (2020). Barriers and facilitators to primary health care for people with intellectual disabilities and/or autism: an integrative review. *BJGP open*, 4(3), bjgpopen20X101030.

Drakeford, O. M., and Majebe, N. L. (2024). Transforming autism care in the US: Conceptualizing a data-driven, social work-based framework for early diagnosis and intervention. *International Journal of Frontiers in Medicine and Surgery Research*, 6(2), 117-125.

Heyl, J., Hardy, F., Tucker, K., Hopper, A., Marcha, M. J., Liew, A., ... and Gray, W. K. (2023). Data quality and autism: issues and potential impacts. *International Journal of Medical Informatics*, 170, 104938.

Keville, S., Mills, M., and Ludlow, A. K. (2025). Exploring mothers' experiences of accessing an Education Health and Care Plan (EHCP) for an autistic child attending mainstream school in the United Kingdom. *International Journal of Developmental Disabilities*, 71(7), 1061-1072.

Kirby, L., and Payne, K. L. (2023). Knowledge of autism gained by learning from people through a local UK Autism Champion Network: A health and social care professional perspective. *Autism*, 27(8), 2507-2517.

Loizou, S., Pemovska, T., Stefanidou, T., Foye, U., Cooper, R., Kular, A., ... and Johnson, S. (2024). Approaches to improving mental healthcare for autistic people: systematic review. *BJPsych open*, 10(4), e128.

McBain, R. K., Kareddy, V., Cantor, J. H., Stein, B. D., and Yu, H. (2020). Systematic review: United States workforce for autism-related child healthcare services. *Journal of the American Academy of Child and Adolescent Psychiatry*, 59(1), 113-139.

Mendez, M. A., Oakley, B., Canitano, R., San José-Cáceres, A., Tinelli, M., Knapp, M., ... and Arango, C. (2023). Autism care pathway in Europe. *European Psychiatry*, 66(1), e81.

Oakley, B., Tillmann, J., Ruigrok, A., Baranger, A., Takow, C., Charman, T., ... and Murphy, D. G. (2021). COVID-19 health and social care access for autistic people: European policy review. *Bmj Open*, 11(6), e045341.

O'Nions, E., Petersen, I., Buckman, J. E., Charlton, R., Cooper, C., Corbett, A., ... and Stott, J. (2023). Autism in England: assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data. *The Lancet Regional Health–Europe*, 29.

Ozuem, W., Willis, M., Ranfagni, S., and Omeish, F. (2025). Thematic analysis in an artificial intelligence-driven context: a stage-by-stage process. *International journal of qualitative methods*, 24, 16094069251362982.

Panayiotou, E., Dimitriadou, M., Charalambous, A., and Tsitsi, T. (2026). A Thematic Analysis of Ethical Issues Faced by Nursing Students in Clinical Practice. *Sage Open Nursing*, 12, 23779608261436765.

Parr, J., Wigham, S., Farr, W., Male, I., Isard, L., Lees, R., ... and Grahame, V. (2024). A national research survey of childhood autism assessment services in the UK: empirical evidence of diagnostic practice, challenges and improvement opportunities. *BMJ Paediatrics Open*, 8(1), e002496.

Pemovska, T., Loizou, S., Appleton, R., Spain, D., Stefanidou, T., Kular, A., ... and Johnson, S. (2024). Approaches to improving mental health care for autistic children and young people: a systematic review and meta-analysis. *Psychological medicine*, 54(10), 2313-2343.

Radev, S., Freeth, M., and Thompson, A. R. (2024). How healthcare systems are experienced by autistic adults in the United Kingdom: A meta-ethnography. *Autism*, 28(9), 2166-2178.

Roman-Urrestarazu, A., Van Kessel, R., Allison, C., Matthews, F. E., Brayne, C., and Baron-Cohen, S. (2021). Association of race/ethnicity and social disadvantage with autism prevalence in 7 million school children in England. *JAMA pediatrics*, 175(6), e210054.

Sultan, M. A. (2025). Equitable access to sustainable healthcare services for children with autism. *BJPsych International*, 22(1), 11-14.

Taherdoost, H. (2021). Data collection methods and tools for research; a step-by-step guide to choose data collection technique for academic and business research

projects. *International journal of academic research in management (IJARM)*, 10(1), 10-38.

Walsh, C., O'Connor, P., Walsh, E., and Lydon, S. (2023). A systematic review of interventions to improve healthcare experiences and access in autism. *Review Journal of Autism and Developmental Disorders*, 10(2), 185-202.

Wigham, S., Ingham, B., Le Couteur, A., Wilson, C., Ensum, I., and Parr, J. R. (2023). Consensus statements on optimal adult post-autism diagnosis support and services: Delphi process following a UK survey of autistic adults, relatives and clinicians. *Autism*, 27(2), 344-355.

Wilson, J. (2025). Interpretive description and reflexive thematic analysis: Exploring conceptual coherence and methodological integrity. *Qualitative health research*, 10497323251378303.