

## How can the UK healthcare system adapt to the increase of patients with autism spectrum disorder?

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### Abbreviations

*AASPIRE – Academic Autism Spectrum Partnership in Research and Education<sup>7</sup>*

*ASD – Autism Spectrum Disorder*

*GP – General Practitioner*

*NIH – National Institute of Mental Health*

### Abstract

As the number of people in the UK with an autistic spectrum disorder (ASD) diagnosis increases, there has become a more obvious gap in the healthcare system for how the service is set up to support these individuals. This article looks at statistics of autism diagnosis and the regularity of attendance to healthcare services with the view to providing coping strategies for the future. Whilst also looking at the effectiveness of the current studies and how they could be adapted to get better quality data in order to address this problem that is growing larger and potentially causing huge problems for patients. Results found that there can be more ways to improve the experience of healthcare for patients with ASD, including both in environmental factors and education/awareness from practitioners and the public.

### Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder affecting children and adults. Its common characteristics include challenges in social interaction and communication, and the inability

to alter routine or interests, which is often linked to repetitive behaviours.<sup>1</sup> There has been an increase in ASD prevalence worldwide over the past 20 years<sup>2</sup> and approximately 1 in 100 children are diagnosed with the condition globally.<sup>3</sup> Most notably in England, there is an increase in people with an open referral for suspected autism diagnosis. This has risen to 125,109 people in July 2022, an increase of 34% since October 2021.<sup>4</sup> This review article covers some research conducted in Western medical practice surrounding how patients with autism struggle to access healthcare services and investigates what can be done to combat these problems.

Escalation in autism diagnoses has led to an increase in the number of people with ASD using healthcare services. Due to this, limitations and barriers that prevent people with ASD from receiving the correct or best care have been brought to light.<sup>5</sup> The World Health Organization highlights the importance of equal healthcare access for the entire population. However, currently there are more unmet healthcare needs amongst those with autism.<sup>6</sup> Identifying barriers preventing people with ASD from having the same opportunities as those without should help the healthcare service adapt for autism.

### Methodology

To find the papers used in this article, PubMed was used for the initial search. The focus of the research stemmed from the key words: 'healthcare,' 'autism spectrum disorder' and 'barriers/inequalities'. Once the overarching systematic reviews were identified using these key words, the primary data from within these reviews was used to ensure the data was interpreted from the primary source article and

not as secondary data. Another specific filter was that only data from the last 20 years was used to provide the most relevant data where possible. This was achieved with the eldest paper originating from 2006 and most of the data used from 2020 or more recent. Lastly, the identification of the website by The Academic Autism Spectrum Partnership in Research and Education<sup>7</sup> and its links to the National Institute of Mental Health (NIH)<sup>8</sup> provided a bank of resources to search through, using the same specifics as within the PubMed application.

## Results

People with ASD are commonly using healthcare services for the comorbidities they have alongside their ASD.<sup>9</sup> Some of these comorbidities include epilepsy, gastrointestinal problems and type 1 diabetes. Individuals diagnosed with epilepsy or are an offspring/sibling of someone with epilepsy are more at risk of being diagnosed with ASD, especially if diagnosed in childhood.<sup>10</sup> Gastrointestinal problems include recurrent diarrhoea, constipation and food sensitivities, and a common presentation is increased challenging behaviour in children with ASD.<sup>11</sup> Type 1 diabetes and ASD have risen in prevalence. Due to the invasive way diabetes must be treated, it is more likely for those with ASD to have an adult manage their diabetes into adolescence.<sup>12</sup> If there are circumstances preventing ASD patients from effective treatment, their comorbidities might not be treated correctly, increasing the risk of poor health in their lifetime.

A study conducted in Canada investigated the type of healthcare service adults with ASD use and their satisfaction with the service.<sup>13</sup> Results identified that after family doctors (general practitioners, GPs), the next most used service was the dentists, followed by counsellors and psychiatrists. However, it was a small study of 40 adults and is therefore not representative of the general population. There was also bias towards mental health services, possibly due to the health of participants involved. Looking at both this study<sup>13</sup> and the analysis of physical health conditions<sup>9</sup> it can be derived that there is a need for the same range of services to be available to all patients regardless of an ASD diagnosis.

With these frequently visited clinical services in mind, two studies in the US investigated the barriers faced by adults with ASD compared to non-autistic adults and adults with other disabilities. The first study devised both long and short-form online surveys. It compiled 41 questions about barriers faced into nine overriding categories.<sup>14</sup> The category with the biggest difference between the three groups was sensory barriers. 26.7% of participants with ASD stated that sensory distractions, such as light, sounds and smells, disrupted communication, made examinations difficult or caused general discomfort compared to just 6.3% and 1% for other disabilities and no disability respectively.<sup>14</sup> This was also identified in an interview-style survey, as sensory triggers such as harsh lighting and reflective surfaces were flagged as an issue causing overstimulation and reduced ability to engage with the service.<sup>15</sup> A Swedish online study looked specifically into the sensory stimulation affecting adults with autism compared to those without.<sup>16</sup> Interestingly, the biggest issue were auditory stimulants such as echoes, TVs and ticking clocks. A lot of emphasis was put on these sounds causing stress or overwhelming feelings, something not addressed by non-autistic adults. Another major difference between the two groups of participants was that movements, odours or verbal output from other patients caused the feeling of unpredictability and stress for patients with ASD.<sup>16</sup>

Another issue discovered in the surveys was that participants felt like their clinician had no understanding of what autism was or how to treat them, which often made them feel like they did not want to disclose their autism for fear it would affect their care.<sup>15</sup> An online self-report study has been conducted and 304 GPs from across the UK took part.<sup>17</sup> Of the 91.4% of the GPs who stated that they had at least one patient with autism, 10.1% had more than 30, and 65.8% said that this number had increased since their career had started. Almost the same number of GPs had not received any autism training

in their primary degree or GP specialisation as those who had not received any further training since initial qualifications, which are 63.5% and 65.8%, respectively. 39.5% had not received any training about autism at all. The second part of the survey was 14 questions on self-efficacy. The average score was 4.8 out of a possible 10, and the prescription of medication was identified as the least confident aspect of care.<sup>17</sup> If the growing number of ASD patients in GP surgeries are affected by the lack of confidence from their GPs on aspects of treatment and management for their comorbidities, then there is a risk of a reduced likelihood that GPs will refer their patients to diagnostic assessments that recognise autism diagnoses.<sup>17</sup> In the future, the volume of GPs with the inability to recognise or refer patients could raise the number of individuals who have underlying autistic symptoms and do not disclose them to clinicians.

A contrasting study comparing experiences between adult with and without autism demonstrates that not all experiences of clinical services among the two groups are significantly different.<sup>18</sup> This online survey asked participants from both groups questions about their healthcare experience, use of healthcare, unmet medical needs and self-efficacy. Results showed no significant difference between their satisfaction on healthcare as the total score, using a 4-point Likert scale (for example, never, sometimes, usually or always), is only slightly lower for participants with ASD. Although they only produce ordinal data and are more at risk of bias, they are easier to be created for online use, which can maximise responses.<sup>19</sup> Despite the overall survey not producing huge discrepancies between the two groups' responses, one area of the questionnaire that did demonstrate a difference in participants with autism was the recorded lower self-efficacy in healthcare that these individuals have.<sup>18</sup> This could be what causes them to also identify a higher number of unmet healthcare needs within the ASD population in this study.<sup>18</sup>

To address these issues that result in reduced care and lack of confidence in healthcare, a 'toolkit' has been created in the US to try and overcome some of the barriers adults with autism face.<sup>20</sup> This was created as part of research conducted by a US association called AASPIRE (the Academic Autism Spectrum Partnership in Research and Education<sup>7</sup>). It is described as a collection of information to aid the quality and availability of healthcare for adults with autism and is accessible online. The study conducted to evaluate the content of the 'toolkit' concluded that it was easy to use, as 92.1% would recommend it to a friend and 94.9% would recommend to a healthcare practitioner. Having used the 'toolkit' alongside a clinical scenario, the number of barriers experienced almost halved compared to before, and both self-efficacy and patient-provider communication went up.<sup>20</sup> Despite the improvements that the 'toolkit' makes to the accessibility of healthcare services, the adults using it still must rely on technology, as the study was only conducted on those who are able to access the internet and it does not help to eliminate the physical experiences, such as sensory issues, when attending the service.

## Discussion

The surveys used to conduct these studies were conducted on small cohorts that do not necessarily represent the entire population of people with ASD. Most of the data used has come from studies in the US. Looking at studies since 2000, the median prevalence of autism in the US is 21.6/100,000 people, slightly higher than the median in Europe using studies since 1999 which is 18.8/100,000.<sup>3</sup> However, for all disabilities, the US, Europe and Western Pacific are all very similar statistically.<sup>3</sup> Even though the US has a higher median rate of ASD, the UK rate of ASD diagnosis is similar and the ASD population is increasing. This means that the UK can learn from the US studies to make better improvements.

What has demonstrated the elevated level of expertise the US studies in the ASD research field is the use of the AASPIRE 'toolkit' and website<sup>7</sup> in many of the studies. It is a revolutionary source of information for patients, carers and healthcare providers for research-based information on autism and the challenges it might cause for

patients and those in their network all in one place. The connection to the NIH and their research<sup>8</sup> could allow the UK to do something similar with their research to create our own version of the American ASD 'toolkit' in the future. However, with the limited studies on the subject currently in the UK this is still a futuristic idea rather than a realistic suggestion to come out of the research.

The other main limitation of the studies used in this article was that the minimum age of participants in the sources was 18, and the fact that children with autism also use healthcare is not considered. Data from US showed children diagnosed with autism have almost six times as many outpatient visits annually compared to non-autistic children, and when compared to children with other developmental disabilities, nearly twice as many.<sup>21</sup> Therefore, there is uncertainty as to whether the experiences and barriers identified by the participants in the studies would be relevant to children and young adults. Surveys, possibly using the Likert-style scale due to their ease of use, could be given to young adults and children with autism. Outcomes should be compared to the findings from adults to see if the changes that need to be made to the healthcare system are applicable to all ages. Differences in the data could also be used to ensure that there is equality in the availability of healthcare across age groups as well as disabilities.

The strengths of the article are that it has culminated data from around westernised medical services and has made a clear analysis of what need to change within healthcare for the treatment of patients with ASD to be more equal and comparable to those without the condition. What researchers can do next in the future is to look more specifically into each area of the issues outlined to make more specific suggestions. Therefore, secondary research could be carried out and followed up to allow for a less holistic comparison of the adaptability of healthcare for patients with ASD and those without, focusing on each identifiable limitation more acutely. Secondly, despite the applicability and relevance of the research in this article to the UK, there could be more emphasis on UK research to ensure that the data used is as relevant to the research question as possible.

The healthcare system is currently not well adapted to cope with the increased number of patients with ASD, especially when there is a huge variation in the diagnosis and presentation of ASD.<sup>22</sup> These studies have outlined that there is inequality in the delivery of healthcare to individuals with ASD and as a result, there is a risk that this could leave patients with unmet healthcare needs. Adaptations to education, environments and accessibility should be made to prevent people with ASD not attending healthcare services for their comorbidities, dental health and mental health. In the long term, this will hopefully prevent patients with ASD from living with undiagnosed comorbidities. If there is a continuation of unmet healthcare needs, there could be a risk to patients with ASD having longer stays in hospital, more emergency appointments and a decreased quality or length of life. More guidance and awareness of how variations of ASD present and the common characteristics that can cause people with autism difficulty engaging with healthcare should be made available to clinicians and the public. Simple measures such as being able to adopt non-verbal communication skills to come across as less patronising, or describing procedures slowly should be integrated into training to prevent clinicians coming across as judgemental.<sup>16</sup> Not only should this improve the confidence of individuals with ASD in healthcare, but it could allow clinicians the ability to gain more confidence in recognising ASD in their patients and making appropriate referrals.

Improvements to the environment around the growing proportion of patients with ASD will hopefully allow them to have a better experience with healthcare. Firstly, to help improve the education of the clinicians that will be in contact with patients with ASD, programmes should be made to promote the skills needed and to allow clinicians to understand the specific healthcare needs of individuals with ASD.<sup>23</sup> Alongside practitioner awareness, public awareness needs to be promoted. This will not only mediate the cause

of some ASD patients stress in healthcare environments but might also maximise the opportunity for early screening and therefore earlier access to healthcare.<sup>23</sup> Other physical barriers could be overcome by simple changes such as having individual chairs in waiting rooms so no one sits too close, additional time in consultations, or removing the risk of loud echoes or reflective surfaces.<sup>16</sup>

## Conclusion

The adaptability of healthcare is essential to providing people with ASD the confidence to use services and trust in clinicians. Reducing the barriers to accessing healthcare for patients with ASD imminently to cope with the rising number of autism diagnoses will help make healthcare better suited to the diverse patient population.

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### Rosie-Jane Widdowson

Hello! I am a third-year medical student at Plymouth University. This piece started life as an SSU on the topic of 'healthy variation, what is normal?' and 'the healthcare environment', but has developed into a review article on the topic of autism and healthcare, which is a topic close to my heart and never fails to spark new interest in me. I have enjoyed the writing and editing process and hope to continue writing in the future to support my interests which are currently paediatrics, plastic surgery, and neurology.

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