Healthcare service use patterns among autistic adults: A systematic review with narrative synthesis

Thesis

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By

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Abstract

Objective: Autistic adults often have complex healthcare needs and therefore have a high need for healthcare services, from primary care to inpatient hospital services. This population experiences unique barriers to healthcare that impact the health services that they use. We sought to conduct a systematic review on the service utilization patterns of autistic adults relative to populations of non-autistic adults to inform the healthcare system about how this population interacts with the healthcare system.

Methods: We systematically searched six research databases (Pubmed, Embase, CINAHL, Psyc INFO, Web of Science, and Scopus) to identify articles examining autistic adults' healthcare utilization patterns relative to non-autistic adult populations. Inclusion criteria included: 1) discrete sample of autistic adults, 2) quantitative design, 3) reports use (e.g., odds) of specified healthcare service(s) among autistic adults, 4) compares use to that of non-autistic adults, and 5) uses US healthcare data. Health services of interest included: 1) emergency department (ED) use, 2) hospitalizations, 3) primary care use, 4) preventive services, and 5) outpatient visits for mental health conditions.

Results: Our search strategy identified N = 2,964 unique articles. Data were ultimately extracted from N=16 articles. ED utilization was examined in 12 studies, hospitalization

in 8 studies, outpatient mental health visits in 5 studies, preventive services in 3 studies, and primary care visits in 2 studies. Among included studies, autistic adults' service use patterns were compared to those of non-autistic population controls, adults with intellectual disability, and adults with attention-deficit/hyperactivity disorder. Autistic adults most commonly had a higher frequency or odds of utilization of healthcare services relative to these comparison groups.

Conclusions: Autistic adults may utilize healthcare services to a greater degree than many other adult populations. Frequent use of tertiary healthcare services may reflect that lower levels of care are not meeting autistic adults' needs. Future research should further examine primary and secondary healthcare services received by autistic adults and identify targets for improvement, as well as emphasize training healthcare providers to care for autistic adults which may ultimately reduce autistic adults' high utilization of the ED and inpatient services.

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Publications

1. **Gilmore, D**., Harris, L., Longo, A., Hand, B.N. (2020). Health status of Medicare-enrolled autistic older adults with and without intellectual disability: An analysis of inpatient and institutional outpatient medical claims. Autism, https://doi.org/10.1177%2F1362361320955109
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Fields of Study

Major Field: Health and Rehabilitation Sciences

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Chapter 1: Introduction

Background:

Autism spectrum disorders (hereafter termed ASD or autism) are a group of neurodevelopmental disorders that are highly prevalent globally (Chiarotti & Venerosi, 2020). According to the Centers for Disease Control, autism diagnoses among children in the United States have increased from one in 68 in 2010, to one in 54 in 2016 (CDC, 2020). Prevalence is estimated to be approximately 1.7% among children in the United States (Christensen, 2018). Autism is characterized chiefly by core symptomology associated with repetitive behaviors and difficulty with communication and social interaction (American Psychiatric Association, 2013). Primary care providers commonly diagnose autism in children in healthcare settings (Monteiro et al., 2019), however autism is also frequently diagnosed in children in educational settings (Pettygrove et al., 2013). There are no established pharmacological treatments for the core symptoms of autism, and behavioral interventions are characteristically modestly effective (Zwaigenbaum et al., 2015).

Autism can reliably be diagnosed by age two (Johnson & Myers, 2007), however the median age of diagnosis is after age four (Christensen, 2018). Many children, especially racial and ethnic minorities, may not be diagnosed until later (Daniels & Mandell, 2014), or experience disparities in screening (Bishop-Fitzpatrick & Kind, 2017;

Zuckerman et al., 2013). Later diagnosis is undesirable as it may reduce the efficacy of interventions and hamper development in important domains like social and communication skills (MacDonald et al., 2014) and cognitive functioning (Smith et al., 2015).

Importantly, people may be diagnosed with autism in adulthood (Leedham et al., 2020), and those individuals who were first diagnosed with autism as children are now aging into adulthood. In fact, 50,000 autistic individuals turn 18 years old each year (Interagency Autism Coordinating Committee (IACC), 2017). Like other populations, aging into adulthood has implications for myriad aspects of autistic people's lives, such as independence and employment (*2017 National Autism Indicators Report*, 2020). However, reaching adulthood has particular implications for autistic adults' healthcare, as the current healthcare system in the United States is largely unprepared to meet their unique healthcare needs.

Knowledge Discrepancy:

That the U.S. healthcare system is not prepared to provide tailored, quality healthcare for autistic adults is concerning, as this population is rapidly growing (Interagency Autism Coordinating Committee (IACC), 2017). The system's lack of preparation is not chiefly a matter of difficulty implementing interventions or accommodations to care, as is known to be a challenge among autistic children (Brookman-Frazee et al., 2018; Lord et al., 2005; Wilson & Landa, 2019). Rather, it is largely a product of the stark discrepancy in the volume of research on the healthcare needs of autistic children versus those of autistic adults (Gotham et al., 2015; Jang et al., 2014; Mandell, 2013; Murphy et al., 2016). There is indeed a wealth of literature

examining healthcare related questions among autistic children, such as questions pertaining screening and diagnosis (Carbone et al., 2020; Randall et al., 2018), co-occurring conditions (Cohen et al., 2018; Rubenstein et al., 2018), and interventions (Srinivasan et al., 2016; Woo et al., 2015). The research emphasis on autistic children is driven largely by established evidence that early identification and treatment improve outcomes (Zwaigenbaum et al., 2015). However, many of these healthcare-related questions have not been examined with the same rigor among autistic adults, resulting in knowledge gaps in crucial domains like autistic adults' physical health (Cashin A. et al., 2018).

Contributing factors to this discrepancy are many, such as improvement of core autism symptoms with age (Bal et al., 2019), and frequent grouping of autistic adults with other populations with disabilities in research studies (Dunn et al., 2019; Lewis et al., 2002; Lunsky et al., 2019). Hence, there is a relative paucity of knowledge about the healthcare and health status of autistic adults compared to autistic children. This knowledge gap is an important one to close, as it has implications for autistic adults' physical and mental health even from a transition age, as early as 16 years old (Roux et al., 2015).The immediate need for a greater research emphasis on topics relevant to autistic adults' healthcare has been voiced nationally by the Interagency Autism Coordination Committee (IACC), a federal advisory group comprised of policy makers, healthcare providers, autistic adults, and other key stakeholders (Interagency Autism Coordinating Committee (IACC), 2017).

State of the Knowledge:

In the past decade there has been a modest growth in the body of literature surrounding autistic adults and their healthcare. Although many questions remain to be answered in this arena, we are slowly beginning to gain a picture of key facets of autistic adults' healthcare; some evidence is available pertaining to autistic adults' physical and mental health (Bishop-Fitzpatrick & Rubenstein, 2019; Croen et al., 2015; Hand, Angell, et al., 2020; Lai et al., 2019; Lever & Geurts, 2016), healthcare needs (Nicolaidis et al., 2015), barriers to care (Dern & Sappok, 2016; Raymaker et al., 2017), effectiveness of delivery models (B.N. Hand, Coury, White, et al., 2020), and utilization patterns (Benevides et al., 2020; Vohra et al., 2016a). Emerging facets, too, such as autistic adults' healthcare experiences (Camm-Crosbie et al., 2019a; Hand, Coury, Darragh, et al., 2020; Nicolaidis et al., 2013a), are increasingly being explored.

Physical Health and Mortality Outcomes:

The available literature has consistently found autistic adults to face a high number of co-occurring physical health conditions (Bishop-Fitzpatrick & Rubenstein, 2019; Croen et al., 2015; Hand, Angell, et al., 2020). Indeed, autism does not exist in a vacuum; autistic individuals have distinct physical health needs that impact their health and quality of life, and autistic adults desire a greater emphasis on research addressing these conditions (Interagency Autism Coordinating Committee (IACC), 2017). Co-occurring physical health conditions such as gastrointestinal disorders (Fröhlich et al., 2019) and obesity (Broder-Fingert et al., 2014) are well documented among autistic children, and many of these conditions appear to persist into adulthood. For example, autistic adults have been found to be at higher risk of many common physical health

conditions like diabetes, obesity, and hypertension, and even of rare conditions like Parkinson's disease than the general population (Croen et al., 2015). Although some of these studies have limited generalizability due to sampling from specific health systems (Croen et al., 2015) or geographic regions (Bishop-Fitzpatrick & Rubenstein, 2019), new nationally representative evidence indicates that autistic adults' high prevalence of co-occurring conditions persists into older adulthood as well (Hand, Angell, et al., 2020). As such, a high prevalence of co-occurring physical health conditions among autistic adults is being established as a characteristic feature of this population's health status, substantiating the need for further health services research.

Evidence also indicates that autistic adults face a greater likelihood of early all-cause mortality (Hirvikoski et al., 2016), inpatient mortality (Akobirshoev et al., 2020), and mortality from injury (Guan & Li, 2017) than various comparison groups. Autistic women may be at particularly high risk for inpatient mortality (Akobirshoev et al., 2020). Factors that explain autistic adults' heightened risk for mortality in these contexts remain to be elucidated. Nevertheless, this evidence too underscores the need to close the knowledge gap pertaining to autistic adults' healthcare and health status, as factors such as co-occurring conditions and healthcare access may plausibly be linked to mortality outcomes.

Mental Health Conditions:

The mental health status of autistic adults, although not wholly elucidated, has been more closely examined in the literature than other health-related domains. Autistic adults appear to have a high prevalence of myriad mental health conditions (Lai et al., 2019). Anxiety (Buck et al., 2014; Croen et al., 2015; Lever & Geurts, 2016) and

depression (Cage et al., 2018; Lever & Geurts, 2016) are two of the most frequent co-occurring mental health conditions experienced by autistic adults. Others, such as schizophrenia spectrum disorders and bipolar disorder, have also been shown to be highly prevalent among autistic adults when compared to the general population (Croen et al., 2015). Like physical health conditions, research on mental health conditions is highly prioritized by autistic adults (Interagency Autism Coordinating Committee (IACC), 2017).

However, research on autistic adults' mental health conditions is complicated substantially by a factor known as diagnostic overshadowing (Rosen et al., 2018), whereby symptoms of autism may be attributed to a co-occurring psychiatric disorder, when in fact these symptoms are characteristic of ASD itself. Conversely, emotional symptoms, for example, may be attributed to ASD, but really be manifestations of a co-occurring psychiatric disorder. Indeed, autistic adults were found in a recent study to be more likely to receive a mental health diagnosis compared to non-autistic participants but were less likely than non-autistic participants to agree with their mental health diagnosis (Au-Yeung et al., 2019). Although not specifically termed, diagnostic overshadowing was identified as a primary factor among the participants contributing to misdiagnosis of mental health conditions. As such, the prevalence of co-occurring mental health conditions among autistic adults may not be wholly understood, and additional research is warranted in this domain of autistic adults' healthcare.

Healthcare Experiences and Barriers to Tailored Services:

The body of literature pertaining to autistic adults' healthcare experiences is largely consistent, finding that autistic adults frequently have suboptimal healthcare

experiences (Nicolaidis et al., 2013a; Vohra et al., 2016a). Their healthcare experiences are influenced by multiple barriers to healthcare, of which they experience more than the general population. Barriers may exist at the individual, provider, and healthcare system level (Raymaker et al., 2017). Barriers at the individual level may be related to autism itself, such as autistic adults' verbal communication skills, sensory sensitivities, and challenges with processing information quickly. At the provider level, autistic adults may experience barriers related to providers not being willing to provide needed accommodations to care, or inability to effectively involve supporters in patients' healthcare. Finally, at the systems level, autistic adults may have difficulty navigating the healthcare system, or accessing healthcare facilities.

Although the combination of barriers experienced by each autistic individual is variable, their ubiquitous presence to some degree among all autistic adults contributes to healthcare experiences within this population that are characteristically suboptimal. In recent studies, specific aspects of suboptimal healthcare experiences have been characterized, such as a higher odds of unmet healthcare needs, and lower healthcare self-efficacy, likely contributing to autistic adults' low satisfaction with their healthcare (Nicolaidis et al., 2013a). However, emerging evidence indicates that specific healthcare delivery models, like the patient centered medical home, may be effective at reducing autistic adults' barriers to healthcare and improving their healthcare experiences (Hand, Coury, Darragh, et al., 2020). Healthcare services that consistently meet the needs of autistic adults are far from established, requiring further investigation in future work.

Access to Providers and Services:

Few healthcare providers are trained to provide care for autistic adults (Zerbo et al., 2015). As such, autistic adults may have access to healthcare, but not to healthcare that meets their unique needs. The shortage of providers trained in autism contributes to the challenging transition from pediatric to adult healthcare for transition-age autistic individuals (Cidav et al., 2013; Roux et al., 2015). Most healthcare providers are not prepared to provide accommodations to care that autistic adults might need like alternative methods of communication (Nicolaidis et al., 2015), therefore contributing to the barriers to healthcare experienced by autistic adults. Encouragingly, some providers desire more training in providing care for autistic adults (Maddox et al., 2020), even in specific domains such as communication (Urbanowicz et al., 2020). An increase in trained providers is necessary to mitigate autistic adults' barriers to healthcare, as well as to correct misconceptions that providers may have about autistic people, such as that they uniformly exhibit challenging behaviors (Maddox et al., 2020).

As autistic individuals age into adulthood, they may experience what has been termed in prior work a "service cliff" (Turcotte et al., 2016), whereby healthcare service utilization decreases among transition-age autistic individuals after high school (Havlicek et al., 2016; Nathenson & Zablotsky, 2017; Shattuck et al., 2011). Service needs change among autistic people as they age (Cidav et al., 2013), and leaving their pediatrician may explain autistic adults' infrequent use of many types of services compared to autistic children and adolescents (Turcotte et al., 2016). Reduction in service use in adulthood is likely reflective of a shortage of trained healthcare professionals rather than a reduction in need, as autistic adults experience a high

burden of physical and mental health conditions (Croen et al., 2015; Hand, Angell, et al., 2020; Lai et al., 2019).

Healthcare Service Utilization:

Research on barriers to healthcare services among autistic adults is crucial. However, so too is research on the extent to which autistic adults utilize various healthcare services. Like other facets of healthcare-related research, research pertaining to service utilization is growing; autistic adults' utilization of primary, secondary, and tertiary healthcare services is steadily being elucidated. However, studies have employed myriad sampling techniques and study designs, while specifying different services of interest. As such, definitive statements about this population's healthcare utilization are not yet established.

Among national samples, utilization patterns have been variable. A recent study found autistic adults' all-cause utilization of services like outpatient visits, inpatient visits, and the emergency department to be influenced markedly by demographic factors, such as urban versus rural residence. Utilization of these services may be highest among young, male autistic adults (Jariwala-Parikh et al., 2019). Another national study found autistic adults to have low utilization of primary care and therapy services (e.g. occupational therapy), while having a high utilization of the emergency department (Benevides et al., 2017).

Smaller studies have found that autistic adults utilize some services, like counseling and primary care, more often than others like case management or occupational therapy (Vogan et al., 2017). Evidence regarding ED use has perhaps been the most consistent. Autistic adults appear to utilize the emergency department at

high (Benevides et al., 2017, 2020) and even increasing rates (Vohra et al., 2016a), resulting in ED utilization that is more frequent than is characteristic of non-autistic adults (Nicolaidis et al., 2013a). Autistic adults may be more frequently hospitalized than other populations for conditions like self-injurious behavior (Shields et al., 2019) or conditions that are sensitive to ambulatory care (Zerbo et al., 2018). With regard to preventive services, available evidence is fairly consistent, indicating that autistic adults typically utilize preventive care services, like vaccinations (Nicolaidis et al., 2013a) or screenings (Zerbo et al., 2018) more frequently than the general population.

Chapter 2: Rationale for Review

The literature pertaining to various facets of autistic adults' healthcare and health status is growing steadily. Some questions, pertaining to topics such as mental health (Hollocks et al., 2019), quality of life (Ayres et al., 2018), and suicidality (Zahid & Upthegrove, 2017) have been examined recently with systematic reviews. However, upon a preliminary review of the literature and the PROSPERO registry for systematic reviews, I determined that other important topic areas, such as that of healthcare utilization, have not been examined with a systematic review methodology. It is important that the healthcare utilization patterns of autistic adults be examined with a systematic review, as an aggregation of available evidence will offer a clear picture to researchers, clinicians, and other stakeholders of how this growing population currently interacts with the healthcare system.

The healthcare utilization patterns of autistic adults are certainly influenced by myriad factors such as barriers to healthcare (Raymaker et al., 2017), less access to services (Turcotte et al., 2016), few providers trained in autism (Unigwe et al., 2017), and a high prevalence of co-occurring physical and mental health conditions (Croen et al., 2015). Most autistic adults experience a combination of these factors. Although variable at the individual level, the interplay of these factors contributes to healthcare utilization patterns among autistic adults that are unique from other populations. It is important that autistic adults' healthcare utilization patterns be elucidated so that

healthcare systems, policy makers, and providers can be readied and capable of meeting the needs of this growing population (Shattuck et al., 2014).

As such, I proposed to conduct a systematic review to describe the available evidence regarding autistic adults' healthcare utilization patterns. Systematic reviews are critical to inform healthcare decision making, change, and identify new avenues for research. As opposed to a narrative review that gathers the available literature on a general topic of interest, a systematic review provides a concise description and analysis of available data pertaining to a specific research question. Systematic reviews are considered a high level of evidence and are characterized by eight well-defined steps to ensure a focused identification, interpretation, and dissemination of available evidence. These steps include: 1) formulation of a review question, 2) definition of inclusion and exclusion criteria, 3) development of a search strategy, 4) selection of relevant studies, 5) data extraction, 6) quality assessment, 7) analysis of results, and 8) dissemination of findings (Uman, 2011).

Specifically, I aimed to describe the frequency with which autistic adults utilize key healthcare services in comparison to other groups such as the general population, non-autistic adults, or adults with other disabilities. This information is important because it will inform needed changes to the healthcare system both now and in the future for the provision of thorough and individualized health care for autistic adults. For example, if evidence consistently finds frequent use of the emergency department among autistic adults, this might inform the immediate need for providers trained to provide care for autistic individuals in these settings. Concurrently, this evidence would emphasize the need for investigating causative factors behind less frequent use of other

services like preventive or primary care. We need a clear picture of autistic adults' healthcare utilization to provide direction for health services change that promotes autistic adults' utilization of the healthcare services that best meet their needs.

A plethora of healthcare services could plausibly be included in this systematic review as services of interest. My preliminary review of the literature indicated that among autistic adults, utilization of some services had been examined with greater frequency than others. As such, I proposed to include the following health services as those of interest in this review: 1) emergency department use, 2) hospitalizations, 3) primary care use, 4) preventive services, and 5) outpatient visits for mental health conditions. While not a comprehensive list of health services, these services intersect primary through tertiary levels of healthcare, and are those that have been examined in research studies. My review of the literature did not identify studies that examined utilization of other services among autistic adults, like specialist visits (e.g., gastroenterology). As such, I proposed not to include them as services of interest in this review.

With an emphasis on healthcare utilization services that have been characterized to some extent in research studies, this review offers a valuable contribution to the literature. It contributes to the body of knowledge about autistic adults' healthcare, examining the important topic of this population's healthcare utilization patterns compared to those of other groups of non-autistic adults. This review aligns with nationally recognized priority research areas (Interagency Autism Coordinating Committee (IACC), 2017), and therefore responds to the research preferences of the autism community. The question that I proposed to answer in this systematic review is:

“How do key healthcare service use patterns among autistic adults differ from other populations?”

Chapter 3: Methods

I conducted a systematic review of the literature on the healthcare utilization patterns of autistic adults in the United States. This review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009). The study protocol for this systematic review has been registered with PROSPERO, the International Prospective Register of Systematic Reviews (registration # CRD42020213499).

Inclusion and Exclusion Criteria:

Studies were included in this review if they met the following inclusion criteria: 1) included a discrete sample of autistic adults or sample consisting primarily of autistic adults, 2) had a quantitative design, 3) reported frequency of utilization of specified service area(s) among autistic adults, 4) compared utilization in service area(s) to a comparison group, and 5) described utilization patterns in the United States. Studies were excluded if they did not include any autistic individuals who were at least 18 years of age, or if the sample was comprised primarily of non-autistic adults (e.g., the sample was comprised of adults who had different kinds of developmental disabilities of which autism was not the majority). Qualitative studies, unpublished research, reviews, non-human studies, books, case studies, and presentations were excluded. Studies not utilizing US healthcare data, and those that did not compare autistic adults' healthcare utilization to a comparison group were also excluded. These inclusion and exclusion

criteria were chosen strategically, as they provided an appropriate level of specificity to identify articles most relevant to the research question.

Healthcare Services of Interest:

In this review, healthcare services of interest included: 1) emergency department use, 2) hospitalizations, 3) primary care use, 4) preventive services, and 5) outpatient visits for mental health conditions. These services were selected after a preliminary review of the literature and consultation with a health sciences librarian. While other healthcare services could theoretically be included in this review, these were chosen intentionally, as they are services that have been described in the available literature as identified by a preliminary search.

Search Strategy:

The search strategy for this review was developed with the assistance of a health sciences librarian. Searches were conducted within six distinct research databases to promote a comprehensive search of the available literature. Databases included PubMed, Embase, Web of Science, Scopus, CINAHL, and Psyc Info. The search strategy was modified slightly for two databases (Pubmed and Embase) due to their unique indexing terms and search refinement capabilities. All searches contained phrases and keywords pertaining to autism, adulthood, and the specified healthcare services. I also reviewed the reference lists of included articles to identify any additional relevant studies. To gather the most recent evidence pertaining to autistic adults' healthcare utilization, I searched the specified databases from the years 2010-2020. An example search strategy (for Pubmed) is provided below:

(autism spectrum disorder[mesh] OR autism[tw] OR autistic[tw] OR asd[tw]) AND (adult[mesh] OR adult[tw] OR adults[tw] OR adulthood[tw]) AND (hospitalization[mesh] OR emergency service, hospital[mesh] OR emergency medical services[mesh] OR emergency medicine[mesh] OR emergency treatment[mesh] OR emergency[tw] OR emergencies[tw] OR primary healthcare[mesh] OR primary care[tw] OR primary healthcare[tw] OR primary health care[tw] OR preventive health services[mesh] OR preventive[tw] OR preventative[tw] OR mental health services[mesh] OR mental health services[tw] OR mental healthcare[tw] OR mental health care[tw] OR mental health[mesh] OR patient acceptance of healthcare[mesh] OR utilization[tw] OR utilisation[tw] OR health services for persons with disabilities[mesh]) NOT “adult spinal deformity”

Study Screening:

One rater (DG) built a platform within Covidence systematic review software so that retrieved articles could be screened in an organized and efficient fashion. DG then independently conducted the searches in the specified databases and imported batches of retrieved articles into Covidence systematic review software, which automatically removes duplicate articles. DG and one other rater (MK) independently reviewed article titles and abstracts to determine inclusion vs exclusion using a checklist developed specifically for this study (Table 1 below).

Inclusion:	Yes	No	Cannot Tell
Does the study describe a discrete sample of autistic adults of which the majority are ≥18 years old?			
Does the study compare autistic adults' healthcare utilization to that of a comparison group?			
Was the study conducted in the United States using US healthcare data?			
Exclusion	**Yes**	**No**	**Cannot Tell**
Does the study describe a sample that is not comprised of autistic adults or of which less than half are autistic adults?			
Does the study report healthcare utilization outcome(s) among autistic adults without reference to a comparison group?			
Is the source a qualitative study, unpublished research, a review, non-human study, book, case study, or presentation?			
Was the study conducted outside of the United States using healthcare data from another country?			
Full text article available in English?			

Table 1: Decision matrix of key questions for title and abstract screening

Items within the checklist are divided into an inclusion and an exclusion section. Items can be marked as "Yes" "No" or "Cannot Tell." If any items were marked as "Yes" in the exclusion section of the table, the rater marked the article for exclusion within Covidence. If none of the items in the exclusion section were marked as "Yes", and all those in the inclusion section were marked as "Yes", the rater included the article within Covidence. Articles for which items were marked as "Yes" or "Cannot Tell" in the inclusion section, or for which items in the exclusion section were marked "Cannot Tell" but none were marked "Yes" received a vote of "Maybe" within Covidence. This process is depicted in Figure 1.

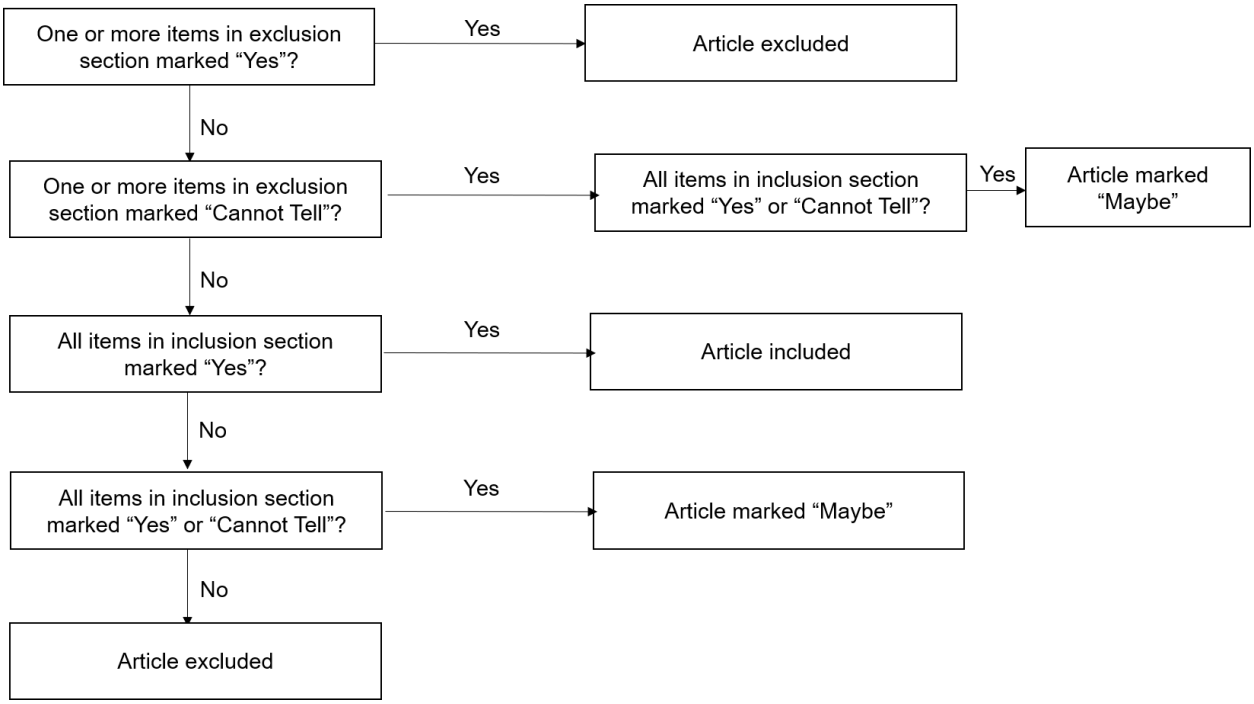

Figure 1: Title and abstract screening process

Articles that were marked for inclusion by two raters, marked as “maybe” by two raters, or were marked for inclusion by one rater and “maybe” by the other rater proceeded to the full text review stage. Conflicts were defined as one rater marking an article for inclusion or “Maybe” and the other marking the article for exclusion within Covidence. Conflicts were resolved via discussion. If no consensus was reached through discussion, a third team member (BH) used the checklist and provided a third vote to determine if the article would proceed to full text review. At the full text review stage, the raters utilized a similar inclusion vs exclusion checklist (Table 2 below) to decide which articles would proceed to the data extraction stage.

Inclusion:	Yes	No
Does the study describe a discrete sample of autistic adults of which the majority are ≥18 years old?		
Does the study employ quantitative research methods?		
Does the study report autistic adults' frequency of utilization of one of the specified outcome areas?		
Does the study compare autistic adults' healthcare utilization to that of a comparison group?		
Was the study conducted in the United States using US healthcare data?		
Exclusion	**Yes**	**No**
Does the study describe a sample that is not comprised of autistic adults or of which less than half are autistic adults?		
Does the study report healthcare utilization outcome(s) of interest among autistic adults without reference to a comparison group?		
Is the source a qualitative study, unpublished research, a review, non-human study, book, case study, or presentation?		
Was the study conducted outside of the United States using healthcare data from another country?		
Full text article available in English?		

Table 2: Decision matrix of key questions for full text review

To proceed to data extraction, all items in the inclusion section of the checklist had to be marked as "Yes", and none of the items in the exclusion section could be marked as "Yes". This process is depicted in Figure 2.

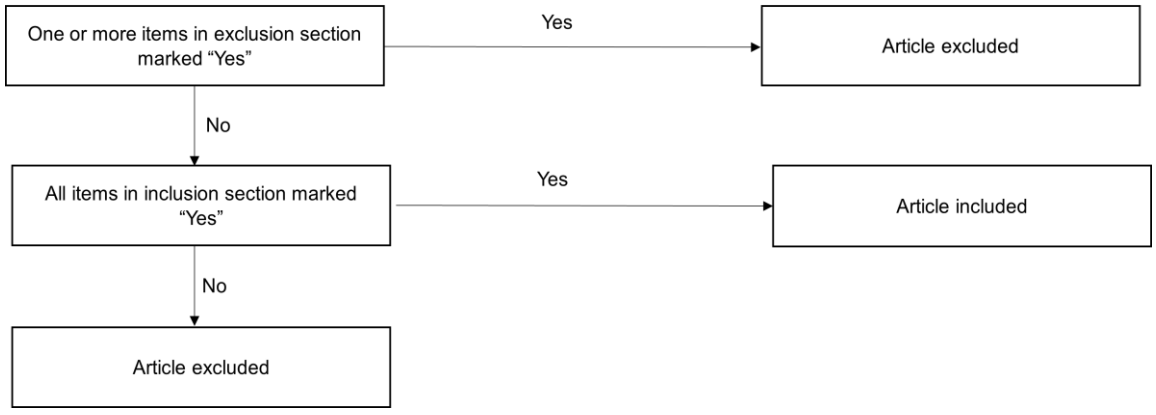

Figure 2: Full text review process

Conflicts were resolved via discussion. If no consensus was reached through discussion, a third team member (BH) used the checklist and provided a third vote to determine if the article would proceed to data extraction.

Data Extraction and Quality Assessment:

The following relevant study characteristics and data were extracted from included studies: 1) study purpose, 2) data source, 3) study sample, 4) sample demographic characteristics, 5) service(s) examined, and 6) key findings. These data were organized into an evidence table. In addition to the data elements described above, included studies were assessed for quality using the LEGEND (Let Evidence Guide Every New Decision) evidence appraisal forms specific to the study design from Cincinnati Children's Hospital. These tools are linked here: https://www.cincinnatichildrens.org/research/divisions/j/anderson-center/evidence-based-care/legend. The LEGEND system provides a thorough assessment of quality by evaluating critical components such as validity, statistical significance, clinical significance, and conflict of interest. Results from the evidence appraisals for included studies were used to inform interpretation of results. According to the LEGEND system, levels of research evidence can range from 1a (e.g., high quality systematic reviews or meta-analyses) to 5b (e.g., lesser quality expert opinion or case reports). In this evidence appraisal system, smaller numbers indicate more rigorous study designs and each article is evaluated and determined to be either "good quality" (denoted with an "a") or "lesser quality" (denoted with a "b").

Strategy for Data Synthesis:

I conducted a systematic review with narrative synthesis for this project rather than a systematic review with a meta-analysis, as a meta-analysis would likely not be possible due to characteristically heterogeneous study designs within the health services literature. Quantitative findings were grouped by the service(s) examined in the study. The narrative synthesis of findings was complemented with an evidence table. The narrative synthesis provided necessary discussion of identified patterns among the various service areas and their interpretation. Results obtained from quality assessments were used to inform the discussion of findings and their interpretation.

Chapter 4: Results

The results of our search strategy at each stage of the review are shown in Figure 3. Our search strategy identified 2,964 unique articles, and we ultimately included 16 articles in this systematic review.

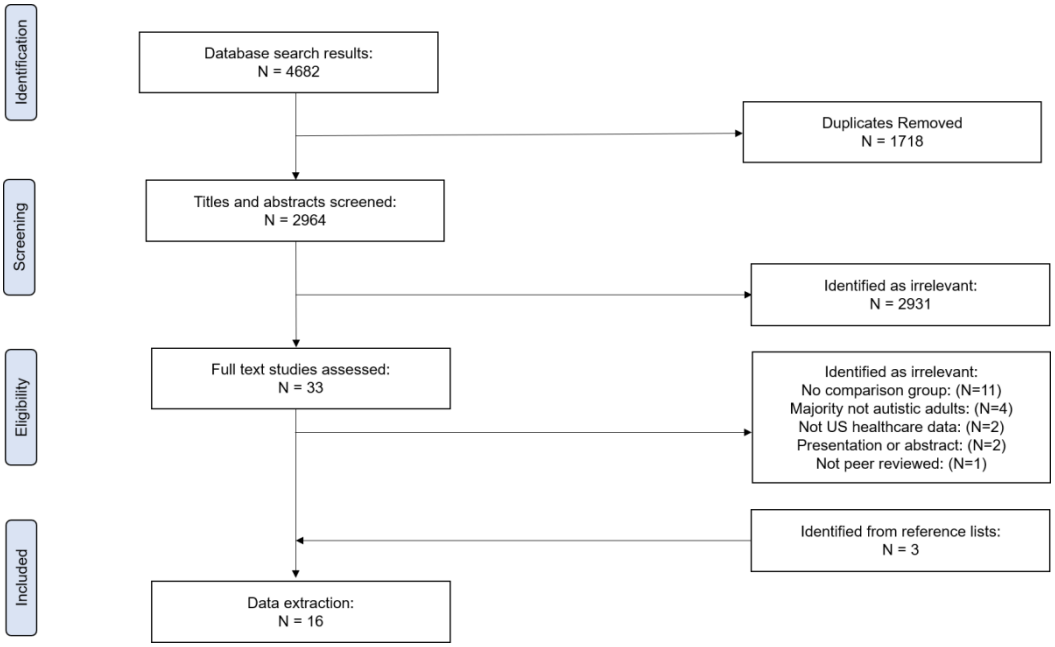

Figure 3: PRISMA flow diagram

Description of Included Studies:

Important features of included studies can be found in Table 3. All studies employed cross-sectional designs. Data sources were predominantly at the state or national level (e.g., Medicaid claims), with two studies collecting data via interview or

survey. ED utilization was examined in 12 studies, hospitalization in 8 studies, mental health visits in 5 studies, preventive services in 3 studies, and primary care visits in 2 studies. Across all studies, >248,000 autistic adults were included (one study did not report a specific sample size). Eleven studies compared health service use between only an autism and non-autism population comparison group (PC), and three studies (Ames et al., 2020; Benevides et al., 2020; Zerbo et al., 2018) included an autism group with more than one comparison group (e.g., attention-deficit/hyperactivity disorder (ADHD) and PC). Two studies reported only descriptive statistics as indicators of service utilization between autistic and non-autistic groups (Iannuzzi et al., 2015; Shea et al., 2018). Studies varied in their report of participant demographic characteristics, with 10 studies not reporting the mean age of autistic or non-autistic adults. Among the studies that reported the mean age of autistic adults, mean age ranged from 14-37. Proportions of males in the samples of autistic adults were between 41-85%.

ED Utilization					
Reference (Author, year)	**Study Purpose**	**Data Source**	**Sample Characteristics**	**Key Findings**	**Quality Score**
Benevides et al., 2020	To identify rates of ED utilization among transition-age adults with ASD, ASD + ID, and ID only	Medicare data (2010)	N=3,499 ASD individuals (78% male; mean age=23) N=2,048 ASD individuals with co-occurring ID (74% male; mean age=23) N=13,178 individuals with ID (55% male; mean age=24)	Adults with ASD or ASD + ID had fewer annual ED visits than adults with ID-only (p < 0.001)	3b
Nakao et al., 2014	To compare the rates and associated costs of NTDC-related ED visits among individuals with and without ASD	NEDS (2010)	N= ASD individuals reported as <0.1% of adult sample of 103,450,324 (% male not reported; mean age not reported) N= Non-ASD individuals reported as <0.4% of adult sample of 103,450,324 (% male not reported mean age: not reported)	ASD adults had reduced odds of a NTDC-related ED visit compared to the PC (p <0.001).	3a
Liu et al., 2017	To examine rates of ED utilization in ASD individuals compared to individuals without ASD	MarketScan claims data (2005-2013)	N= 87,683 ASD individuals (80% male; mean age=14) N= 56,178,622 Non-ASD individuals (51% male; mean age=16)	ASD adults 18-21 y.o. used the ED at increasing rates over the study period (as high as >30% in a given year) where adults of the same age in PC group had static utilization over the study period (3-4% per year) (p < 0.0001)	3a
Deavenport-Saman et al., 2016	To examine factors associated with ED utilization among individuals with and without ASD	2006–2009 administrative ED discharge data	N= 2,426 ASD individuals (84% male; mean age not reported) N= 155,476 Non-ASD individuals (54% male; mean age not reported)	ASD adults did not statistically differ from PC adults on rates of ED visits per year	3a
Iannuzzi et al., 2015	To identify the most common problems for which ASD and non-ASD individuals present in the ED	NEDS (2010)	N= 109,021 ASD individuals (79% male; mean age not reported) N= 128,849,332 Non-ASD individuals (45% male; mean age not reported)	A smaller proportion of all ED visits among ASD group were for adults (31%) compared to all ED visits among PC group (89%)*	3a
Mental Health Visits					
Reference (Author, year)	**Study Purpose**	**Data Source**	**Sample Characteristics**	**Key Findings**	**Quality Score**
Maddox et al., 2018	To identify differences in psychiatric treatment use between adults with anxiety and depression with and without ASD	Medicaid data (2008-2009)	N= 268 ASD individuals (69% male; mean age not reported) N= 1,072 Non-ASD individuals (69% male; mean age not reported)	ASD adults were less likely to receive talk therapy for anxiety/depression or group therapy ((p < 0.05), but more likely to receive case management (p < 0.001) for mental health conditions than the PC; Among those receiving talk therapy, ASD adults averaged more visits per month (p < 0.001)	3a

Table 3: Evidence table

Table 3: Continued

Shea et al., 2018	To compare healthcare service utilization and costs between individuals with either ASD or ID	Medicaid data (2001 and 2005)	N= 2,054 ASD individuals (78% male; mean age not reported) N= 12,316 individuals with ID (56% male; mean age not reported)	80% of ASD adults utilized psychiatric outpatient services compared to 69% of adults in the ID group; Outpatient psychiatric utilization decreased by 19% among the ASD group over 4 years, but by 27% among the ID group*	3a
Esbensen et al., 2010	To examine differences between adults with Down syndrome and ASD adults on functional abilities and health service usage	ASD Data from 2000-2001 (Seltzer et al., 2003) (parent interviews) Down syndrome data from 1997-1998 (Krauss & Seltzer, 1999)	N= 70 ASD individuals (69% male; mean age=37) N= 70 individuals with DS (66% male; mean age=37)	ASD adults were more likely to receive psychological or psychiatric services than adults with DS ($p < 0.001$)	3b
Hospitalizations					
Reference (Author, year)	**Study Purpose**	**Data Source**	**Sample Characteristics**	**Key Findings**	**Quality Score**
Shields et al., 2019	To compare hospital admissions related to self-injurious behavior and ideation among adults with and without ASD	NIS (2014)	N= 5,341 ASD individuals (74% male; mean age not reported) N= 16,023 Non-ASD individuals (74% male; mean age not reported)	ASD adults were nearly twice as likely as PC adults to be hospitalized for self-injurious behavior and ideation ($p \leq 0.001$)	3a
Multiple Outcomes					
Reference (Author, year)	**Study Purpose**	**Data Source**	**Sample Characteristics**	**Key Findings**	**Quality Score**
Hand et al., 2019	To compare the incidence of ACS-admissions among four cohorts: ASD-only, ASD + ID, ID-only, and PC's	State-level administrative billing data (2000-2015)	N= 241 ASD individuals (85% male; mean age not reported) N= 243 ASD individuals with co-occurring ID (78% male; mean age not reported) N= 1,148 individuals with ID (63% male; mean age not reported) N= 2,255 PC's (81% male; mean age not reported)	ED Utilization: ASD and PC adults did not statistically differ on risk of having an ACS-ED visit; Proportion of individuals who had an ACS-ED visit: 14.9% (ASD), 9% (ASD + ID), 23.2% (PC), 14% (ID)* Hospitalization: ASD adults with co-occurring ID were more likely to have an ACS-hospitalization than PC adults ($p < 0.01$), but ASD adults without co-occurring ID did not differ from PC on risk of an ACS-hospitalization; Proportion of individuals who had an ACS-hospitalization: 2.6% (ASD), 10% (ASD + ID), 7% (PC), 5.8% (ID)*	3a

Table 3: Continued

Vohra et al., 2016	To examine trends, type of ED visits, and average ED charges for adults with and without ASD	NEDS (2006-2011)	N= 25,527 ASD individuals (76% male; mean age not reported) N= 76,581 Non-ASD individuals (76% male; mean age not reported)	ED utilization: ASD adults' and PC adults' rates of ED visits increased over time at similar rates Hospitalization: 34% of ASD ED visits led to a hospitalization where only 11% of ED visits among PC adults led to a hospitalization*	3a
Vohra et al., 2017	To examine the prevalence and association of co-occurring conditions with healthcare utilization patterns and expenditures of ASD adults and non-ASD adults	Medicaid data (2000-2008)	N= 1,772 ASD individuals (71% male; mean age not reported) N= 5,320 Non-ASD individuals (71% male; mean age not reported)	ED Utilization: ASD adults and PC adults did not statistically differ in terms of mean number of ED visits per year Hospitalization: ASD adults significantly less likely to be hospitalized than PC adults ($p < 0.001$)	3a
McDermott et al, 2015	To compare hospital encounters (hospitalizations and ED visits) among adolescents and young adults with ASD and either FXS, ID, or PC	State-level data (Medicaid and State health plan-2000-2010)	N= 2,592 ASD individuals (76% male; mean age not reported) N= 125 individuals with FXS (71% male; mean age not reported) N= 10,685 individuals with ID (58% male; mean age not reported) N= 26,804 PC individuals (62% male; mean age not reported)	ED Utilization: Relative to PC adults, ASD adults were more likely to have an ED visit OR=1.5(95% CI=1.3-1.7); Adjusted rates of ED visits compared to other groups: ($18.4\%_{ASD}$ vs $27.9\%_{ID}$), ($19.4\%_{ASD}$ vs $17.0\%_{FXS}$)* Hospitalization: Relative to the PC, ASD adults had higher odds for an inpatient hospitalization OR=5.7(95% CI=4.5-7.3); Adjusted rates of hospitalization compared to other groups: ($6.7\%_{ASD}$ vs $12.7\%_{ID}$), ($6.7\%_{ASD}$ vs $7.3\%_{FXS}$)*	3a
Ames et al., 2020	To examine differences in healthcare utilization among four cohorts: ASD, ADHD, DM, and PC's	KPNC Health System (2014-2015)	N = 4,123 ASD individuals (81% male; mean age=18) N = 20,615 individuals with ADHD (81% male; mean age=18) N = 2,156 individuals with DM (48% male; mean age not reported) N = 20,516 PC individuals (81% male; mean age=18)	ED Utilization: ASD adults less likely to use ED than ADHD OR=0.66(95% CI=0.60-0.73) and DM OR=0.50(95% CI=0.43–0.58) adults, but did not statistically differ from PC Hospitalizations: ASD adults more likely to be hospitalized than ADHD OR=1.81(95% CI=1.52-2.16) and GP OR=2.45(95% CI=2.01-2.97), but less likely to be hospitalized than DM adults OR=0.66(95% CI=0.52–0.83) Mental Health Visits: ASD adults had higher odds of utilization and mean number of mental health visits than all comparison cohorts	3a

Table 3: Continued

				PC: OR=10.87(95% CI=9.90-11.94), AMR: 7.1 (p < 0.0001); ADHD: OR=1.73(95%CI=1.60-1.86), AMR=1.63(p < <0.0001); DM: OR=4.65(95%CI=3.96–5.45), AMR=2.53 (p < 0.0001) Primary Care: ASD adults had greater primary care utilization than PC adults OR=1.38(95% CI=1.27–1.49) and ADHD adults OR=1.09(95% CI=1.01-1.18), but lower than that of DM adults OR=0.42(95% CI=0.36–0.48) Preventive Services: ASD adults more likely to receive well-adult medical exam OR=2.07(95% CI=1.86-2.30), flu vaccine OR=1.82(95% CI=1.69–1.96), less likely to have pelvic exam OR=0.53(95% CI=0.40–0.70) than GP adults; More likely to receive well-adult medical exam OR=2.11(95% CI=1.90–2.34), flu vaccine OR=1.54(95% CI=1.43–1.66), less likely to receive pelvic exam OR=0.52 (95% CI=0.40–0.69) than ADHD adults; More likely to receive flu vaccine OR=1.15(95% CI=1.02–1.29), but less likely to receive pelvic exam OR=0.71(95% CI=0.52–0.97) than DM adults	3a
Zerbo et al., 2018	To compare health care utilization patterns and cost among insured adults with ASD, adults with ADHD, and PC adults with neither condition	KPNC Health System (2012)	N= 1,507 ASD individuals (73% male; mean age=29) N= 9,042 individuals with ADHD (73% male; mean age=29) N = 15,070 PC's (73% male; mean age=29)	ED utilization: ASD adults did not statistically differ from ADHD or PC adults on odds of ED use Hospitalization: ASD adults more than twice as likely as ADHD adults OR=2.1(95% CI=1.6-2.9) to be hospitalized for an ACS diagnoses, but no differences were found when compared to PC adults Mental Health Visits: ASD adults had higher utilization and mean number of visits for mental health than ADHD adults: OR=1.6(95% CI=1.4–1.8), AMR=1.9(95% CI=1.7-2.2) and PC adults: OR=11.5(95% CI=10.0–13.2), AMR=11.7(95%CI=9.3–14.8)	3a

Table 3: Continued

				Primary Care: ASD adults had higher utilization of primary care than ADHD OR=1.2(95% CI=1.1-1.3) and PC OR=1.3(95% CI=1.2–1.4) adults Preventive Services: ASD adults more likely to receive an influenza vaccination OR=2.6(95% CI=2.3-2.9), cholesterol screening OR=1.7(95% CI=1.2–2.5), and diabetes screening OR= 1.8(95% CI=1.3-2.5) than PC adults, but less likely to have cervical cancer screening OR=0.6(95% CI=0.5–0.8); More likely to receive flu vaccine OR=2.3 (95% CI=2.1–2.7), cholesterol screening OR=1.7(95% CI=1.2–2.5), diabetes screening OR=1.8(95% CI=1.3–2.5) but less likely to receive cervical cancer screening OR=0.7(95% CI=0.5–0.9) than ADHD adults	3a
Nicolaidis, et al., 2013	To assess the healthcare experiences (e.g., patient-provider communication, healthcare utilization patterns) of autistic adults versus those of non-autistic adults	Online Survey	N= 209 ASD individuals (41% male; mean age=37) N= 228 Non-ASD individuals (34% male; mean age=40)	ED Utilization: ASD adults had a greater odds of using the ED than PC adults OR=2.1(95% CI=1.8-3.8) Hospitalization: ASD and PC adults were equally likely to have been hospitalized in the past year Preventive Services: ASD adults were less likely to receive a tetanus vaccination OR=.05(95% CI=0.3-0.9) or a and Pap smear OR=0.5(95% CI=0.2-0.9) than PC adults	3b

Abbreviations:
ED=Emergency Department; ASD=Autism Spectrum Disorder; ID=Intellectual Disability; ADHD=Attention Deficit Hyperactivity Disorder; KPNC=Kaiser Permanente Northern California; ACS=Ambulatory Care Sensitive; DM=Diabetes Mellitus; PC=Population Control; NIS=National Inpatient Sample; NEDS=National Emergency Department Sample; FXS=Fragile X Syndrome; DS=Down Syndrome; NTDC=Non-traumatic dental condition; OR=Odds Ratio; CI=Confidence Interval; AMR=Adjusted Mean Ratio; * = reported findings are descriptive statistics only; 3a=Higher Quality Cross Sectional Study; 3b=Lower Quality Cross Sectional Study

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Chapter 5: Healthcare service use patterns among autistic adults: A systematic review with narrative synthesis

Abstract

Objective: Autistic adults often have complex healthcare needs and therefore have a high need for healthcare services, from primary care to inpatient hospital services. This population experiences unique barriers to healthcare that impact the health services that they use. We sought to conduct a systematic review on the service utilization patterns of autistic adults relative to populations of non-autistic adults to inform the healthcare system about how this population interacts with the healthcare system.

Methods: We systematically searched six research databases (Pubmed, Embase, CINAHL, Psyc INFO, Web of Science, and Scopus) to identify articles examining autistic adults' healthcare utilization patterns relative to non-autistic adult populations. Inclusion criteria included: 1) discrete sample of autistic adults, 2) quantitative design, 3) reports use (e.g., odds) of specified healthcare service(s) among autistic adults, 4) compares use to that of non-autistic adults, and 5) uses US healthcare data. Health services of interest included: 1) emergency department (ED) use, 2) hospitalizations, 3) primary care use, 4) preventive services, and 5) outpatient visits for mental health conditions.

Results: Our search strategy identified N = 2,964 unique articles. Data were ultimately extracted from N=16 articles. ED utilization was examined in 12 studies, hospitalization in 8 studies, outpatient mental health visits in 5 studies, preventive services in 3 studies, and primary care visits in 2 studies. Among included studies, autistic adults' service use patterns were compared to those of non-autistic population controls, adults with intellectual disability, and adults with attention-deficit/hyperactivity disorder. Autistic adults most commonly had a higher frequency or odds of utilization of healthcare services relative to these comparison groups.

Conclusions: Autistic adults may utilize healthcare services to a greater degree than many other adult populations. Frequent use of tertiary healthcare services may reflect that lower levels of care are not meeting autistic adults' needs. Future research should further examine primary and secondary healthcare services received by autistic adults and identify targets for improvement, as well as emphasize training healthcare providers to care for autistic adults which may ultimately reduce autistic adults' high utilization of the ED and inpatient services.

Introduction

Each year approximately 50,000 autistic individuals reach adulthood (Interagency Autism Coordinating Committee (IACC), 2017). Reaching adulthood has implications for many aspects of autistic adults' lives, including their interaction with the healthcare system. Autistic adults often have a high number of co-occurring physical and mental health conditions (Bishop-Fitzpatrick & Rubenstein, 2019; Croen et al., 2015; Hand, Angell, et al., 2020; Lai et al., 2019) that require access to healthcare services that are tailored to meet their unique needs as autistic individuals. For example, autistic adults might require individualized methods of communication with their healthcare providers (Nicolaidis et al., 2015), more time to process information (Dern & Sappok, 2016), or modifications to portions of healthcare visits to accommodate sensory sensitivities (Saqr et al., 2018). Patient-centered accommodations like these are necessary for the healthcare system to provide high quality patient-centered care for this growing population.

However, the healthcare system in the United States is largely unprepared to meet autistic adults' unique healthcare needs, an issue which has been voiced nationally as important to address (Interagency Autism Coordinating Committee (IACC), 2017). Few adult healthcare providers are trained to provide care for autistic adults (Unigwe et al., 2017; Zerbo et al., 2015). As a result, autistic adults often experience disparities in access to services when they reach adulthood (Nathenson & Zablotsky,

2017). These disparities contribute to autistic adults' high rates of unmet healthcare needs (Nicolaidis et al., 2013a) and frequent utilization of services like the emergency department (Liu et al., 2017). Such service use patterns may result in autistic adults incurring high healthcare costs for suboptimal healthcare (Zerbo et al., 2018).

A better understanding of autistic adults' healthcare utilization patterns is necessary to prepare the healthcare system and its providers to meet this population's needs. This systematic review is therefore a valuable contribution to the literature, as it systematically identifies and synthesizes the available evidence pertaining to autistic adults' healthcare utilization patterns. Findings from this review will offer a clear picture to researchers, clinicians, and other stakeholders of how this growing population interacts with the healthcare system compared to other populations. This information is valuable because it will inform needed changes to the healthcare system both now and in the future; providing direction for targeted efforts to increase autistic adults' access to patient centered care and emphasizing the need for providers to be trained to care for this population. These factors provide the rationale for this review, and led the researchers to pose the review question, "How do healthcare service use patterns among autistic adults differ from other populations?"

Methods

We conducted a systematic review of the literature on the healthcare utilization patterns of autistic adults compared to non-autistic adult populations. Our review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009). The study protocol for

this review is registered with PROSPERO, the International Prospective Register of Systematic Reviews (registration # CRD42020213499).

Inclusion Criteria

Studies were included in this review if they met the following inclusion criteria: 1) included a discrete sample of autistic adults or a sample consisting primarily of autistic adults (adulthood was defined conventionally as ≥ 18 years of age), 2) had a quantitative design, 3) reported frequency of utilization of the specified health service area(s) among autistic adults, 4) compared utilization in the service area(s) to a non-autistic adult comparison group, and 5) described utilization patterns in the United States. Services of interest included 1) emergency department (ED) use, 2) hospitalizations, 3) primary care use, 4) preventive services, and 5) outpatient visits for mental health conditions. While other services could have been included in this review, these services were chosen intentionally, as they are services that have been described in the available literature as identified by the authors' preliminary literature review.

Exclusion Criteria

Studies were excluded if they did not include any autistic adults, or if the sample was comprised primarily of non-autistic adults (e.g., the sample was comprised of adults who have different kinds of developmental disabilities of which autism was not the majority). Qualitative studies, unpublished research, non-peer reviewed research, reviews, non-human studies, books, case studies, and presentations were excluded. Studies that did not utilize US healthcare data, and those that did not compare autistic

adults' healthcare utilization to a non-autistic adult comparison group were also excluded.

Search Strategy

In accordance with best practice (Moher et al., 2009), we developed our search strategy with the assistance of a research librarian. We searched for articles in six distinct research databases to promote a comprehensive search of the available literature. These databases included PubMed, Embase, Web of Science, Scopus, CINAHL, and Psyc Info. The search strategy was modified slightly for two databases (Pubmed and Embase) due to their unique indexing terms and search refinement capabilities. All searches were conducted by DG on 10/15/2020 and contained phrases and keywords pertaining to autism, adulthood, and the specified healthcare services. We also reviewed the reference lists of included articles to identify any additional studies that fit the inclusion criteria but were not captured in the electronic database searches. To gather the most recent evidence pertaining to autistic adults' healthcare utilization patterns, we refined the database searches to only include articles that were published from the years 2010-2020. An example search strategy (Pubmed) is provided below. The search strategies for all databases and number of articles identified from each before deduplication is available in the Supplementary Materials.

(autism spectrum disorder[mesh] OR autism[tw] OR autistic[tw] OR asd[tw]) AND (adult[mesh] OR adult[tw] OR adults[tw] OR adulthood[tw]) AND (hospitalization[mesh] OR emergency service, hospital[mesh] OR emergency medical services[mesh] OR emergency medicine[mesh] OR emergency treatment[mesh] OR emergency[tw] OR emergencies[tw] OR primary healthcare[mesh] OR primary care[tw] OR primary healthcare[tw] OR primary health care[tw] OR preventive health services[mesh] OR preventive[tw] OR preventative[tw] OR mental health services[mesh] OR mental health services[tw] OR mental healthcare[tw] OR mental health care[tw] OR mental

health[mesh] OR patient acceptance of healthcare[mesh] OR utilization[tw] OR utilisation[tw] OR health services for persons with disabilities[mesh]) NOT “adult spinal deformity”

Study Screening

One rater (DG) imported batches of retrieved articles into the Covidence systematic review platform so that retrieved articles could be screened in an organized and efficient fashion. The Covidence platform has an algorithm that automatically removes duplicate articles and imports them into the first stage of study screening, which for this review was title and abstract screening. DG and one other rater (MK) independently reviewed article titles and abstracts to determine inclusion vs exclusion using a checklist developed specifically for this study (Table 4). Items within the checklist were divided into an inclusion and an exclusion section. Items could be marked as “Yes” “No” or “Cannot Tell.” If any items were marked as “Yes” in the exclusion section of the table, the rater marked the article for exclusion within Covidence. If none of the items in the exclusion section were marked as “Yes”, and all those in the inclusion section were marked as “Yes”, the rater included the article within Covidence. Articles for which items were marked as “Yes” or “Cannot Tell” in the inclusion section, or for which items in the exclusion section were marked “Cannot Tell” but none were marked “Yes” received a vote of “Maybe”. Articles that were marked for inclusion by both raters, marked as “Maybe” by both raters, or marked for inclusion by one rater and “Maybe” by the other rater proceeded to the full text review stage.

Conflicts were defined as one rater marking an article for inclusion or “Maybe” and the other marking the article for exclusion within Covidence. If DG and MK

disagreed if an article should proceed to the full text review stage, they attempted to resolve the conflict via discussion. If consensus was not achieved via discussion, another rater (BH) provided a third vote to determine if the article would be excluded or move on to the full text review stage. This process is depicted in Figure 4.

Full Text Review

At the full text review stage, a similar screening process was utilized. DG and MK independently reviewed the full text articles to determine if they would be excluded or move forward to the data extraction phase. A checklist like the one used in the title and abstract screening phase was developed for use at the full text review stage (Table 5). To proceed to data extraction, all items in the inclusion section of the checklist had to be marked as “Yes”, and none of the items in the exclusion section could be marked as “Yes”. This process is depicted in Figure 5. Conflicts were defined as one rater marking “Yes” and the other marking “No”. Conflicts were resolved in the same manner as they were in the title and abstract screening phase, with BH providing a third vote when DG and MK did not reach consensus via discussion.

Evidence Appraisal

Included studies were assessed for quality by the lead author using the LEGEND (Let Evidence Guide Every New Decision) evidence appraisal tools from Cincinnati Children’s Hospital (Clark et al., 2009). The LEGEND quality assessment tools are specific to study design and support a thorough assessment of the quality of research studies, evaluating critical features salient to study quality such as congruency of the research question(s) with the study design, sample selection procedures, and

appropriateness of statistical methods. Results from the evidence appraisals for included studies were used to inform the interpretation of the results of each study. According to the LEGEND system, levels of research evidence can range from 1a (e.g., high quality systematic reviews) to 5b (e.g., case reports). Smaller numbers indicate more rigorous study designs. Articles are also denoted with either an “a” (indicating “good quality), or a “b” (indicating “lesser quality”).

Data Extraction and Synthesis

One rater (DG) used the Covidence data extraction platform to extract the following data from studies that proceeded to the data extraction phase: 1) study purpose, 2) data source, 3) study sample, 4) sample demographic characteristics, 5) service(s) examined, and 6) key findings. These data were exported from Covidence into an Excel spreadsheet and then organized into an evidence table.

We took a narrative approach to synthesize and analyze the results of this review. Our approach was informed by the European Social Research Council’s guidance on conducting narrative syntheses in systematic reviews (Popay et al., 2006). First, we conducted a preliminary synthesis, whereby included studies were tabulated and organized by service type (Table 3). Second, we looked for broad patterns in the data across service categories (e.g., study size and data source). Finally, we investigated relationships in the data among individual service categories and used these data along with the quantity (i.e., number of studies) and quality (i.e., results of critical appraisals) of the evidence to guide our conclusions.

Results

The results of our search strategy at each stage of the review are shown in Figure 6. Our search strategy identified 2,964 unique articles, and we ultimately included 16 articles in this systematic review.

Description of Included Studies

Important features of included studies can be found in Table 6. All studies employed cross-sectional designs. Data sources were predominantly at the state or national level (e.g., Medicaid claims), with two studies collecting data via interview or survey. ED utilization was examined in 12 studies, hospitalization in 8 studies, mental health visits in 5 studies, preventive services in 3 studies, and primary care visits in 2 studies. Across all studies, >248,000 autistic adults were included (one study did not report a specific sample size). Eleven studies compared health service use between only an autism and non-autism population comparison group (PC), and three studies (Ames et al., 2020; Benevides et al., 2020; Zerbo et al., 2018) included an autism group with more than one comparison group (e.g., attention-deficit/hyperactivity disorder (ADHD) and PC). Two studies reported only descriptive statistics as indicators of service utilization between autistic and non-autistic groups (Iannuzzi et al., 2015; Shea et al., 2018). Studies varied in their report of participant demographic characteristics, with 10 studies not reporting the mean age of autistic or non-autistic adults. Among the studies that reported the mean age of autistic adults, mean age ranged from 14-37. Proportions of males in the samples of autistic adults were between 41-85%.

Quality of the Evidence

Studies were assessed for quality using the LEGEND (Clark et al., 2009) critical appraisal tools. Thirteen studies were rated as “good-quality” (3a), and three studies (Benevides et al., 2020; Esbensen et al., 2010; C. Nicolaidis et al., 2013) were rated as “lesser-quality” (3b).

Large sample sizes of autistic adults were a strength across studies, with 12 out of 16 studies including over 1,000 autistic adults. The smallest sample of autistic adults was N=70 (Esbensen et al., 2010). Case ascertainment procedures were a strength across the majority of included studies as well, primarily done via one or two (Liu et al., 2017; Shea et al., 2018; Zerbo et al., 2018) occurrences of an ICD-9 CM code (299.xx). One study required a clinical interview with diagnosis by a healthcare or education professional (Esbensen et al., 2010), and one reviewed clinical evaluation records against DSM-IV (Diagnostic and Statistical Manual of Mental Disorders) criteria (Hand et al., 2019). One study used participant self-report for case ascertainment (C. Nicolaidis et al., 2013). A majority of studies matched autistic adults to comparison groups on relevant demographic characteristics at ratios ranging from 1:1 to 10:1.

Three studies were rated “lesser quality” primarily because of convenience sampling via the internet (C. Nicolaidis et al., 2013), vagueness regarding recruitment procedures and a relatively small sample size (Esbensen et al., 2010), and limited generalizability coupled with usage of old datasets (Benevides et al., 2020). Two of these studies (Esbensen et al., 2010; C. Nicolaidis et al., 2013) relied on participant

self-report, which may have resulted in inaccurate report of healthcare utilization patterns.

Study Findings

Findings are organized below by healthcare service type. Three comparison groups (diabetes mellitus (DM), Down Syndrome (DS), and fragile-X syndrome (FXS)) were included in only one study each. Utilization patterns among autistic adults relative to these populations as well as significance values for all studies are available in Table 6. Table 7 displays trends in autistic adults' odds or frequency of service use relative to PC or ADHD comparison groups.

Emergency Department Utilization

Studies that compared ED utilization among autistic adults to that of comparison groups of adults with ID, ADHD, or PC's had inconsistent findings. Some studies found that autistic adults had lower ED utilization than ID-only (Benevides et al., 2020), ADHD (Ames et al., 2020), or PC groups (Iannuzzi et al., 2015; Nakao et al., 2014). Additionally, another study reported lower rates of ED use among autistic adults relative to a PC group, but did not test for statistical significance (Iannuzzi et al., 2015). Other studies did not find significant differences in ED utilization between autistic adults and adults with ADHD (Zerbo et al., 2018) and PC groups (Ames et al., 2020; Deavenport-Saman et al., 2016; Hand et al., 2019; Vohra et al., 2016b, 2017; Zerbo et al., 2018). However, three studies found that autistic adults had higher ED utilization than PC groups (Liu et al., 2017; McDermott et al., 2015; C. Nicolaidis et al., 2013).

Inpatient Hospitalization

Among most included studies, autistic adults had greater odds of being hospitalized than PC comparison groups (Ames et al., 2020; Hand et al., 2019; McDermott et al., 2015; Shields et al., 2019). Another study reported higher rates of hospitalization after an ED visit among autistic adults, but did not perform significance testing (Vohra et al., 2016b). However, other studies found that autistic adults had similar odds of hospitalization (Hand et al., 2019; C. Nicolaidis et al., 2013; Zerbo et al., 2018) or were hospitalized less frequently than PC comparison groups (Vohra et al., 2017). Relative to ADHD comparison groups, autistic adults had a higher likelihood of hospitalization for any reason (Ames et al., 2020) or for ambulatory-care-sensitive (ACS) diagnoses (Zerbo et al., 2018).

Outpatient Mental Health Visits

Studies that compared autistic adults' utilization of mental health services to that of PC, ADHD, or ID comparison groups consistently found that autistic adults had greater utilization of these services. This included a significantly higher odds of utilization of outpatient mental health services (Ames et al., 2020; Zerbo et al., 2018), higher mean number of visits (Zerbo et al., 2018), and greater likelihood of case management for mental health conditions (Maddox et al., 2018) relative to the PC. Additionally, autistic adults had a higher odds of utilization of mental health services than ADHD comparison groups (Ames et al., 2020; Zerbo et al., 2018). Autistic adults also used outpatient mental health services more often than adults with ID, but significance testing for these differences was not performed (Shea et al., 2018).

Preventive Services

Studies comparing autistic adults' use of preventive services to a PC comparison group had inconsistent findings. One study (C. Nicolaidis et al., 2013) found significantly lower rates of tetanus vaccination and pap smears among autistic adults relative to a PC group. However, two other studies found that autistic adults were significantly more likely to receive influenza vaccinations than PC groups, but less likely to receive pelvic exams (Ames et al., 2020) and cervical cancer screenings (Zerbo et al., 2018). Similarly, when compared to adults with ADHD, studies consistently found autistic adults to be more likely to receive most preventive services (e.g., influenza vaccination), but less likely to receive others like a pelvic exam (Ames et al., 2020), or cervical cancer screening (Zerbo et al., 2018).

Primary Care Visits

Among included studies, autistic adults were consistently found to have a significantly higher odds of utilization of primary care services when compared to either PC or ADHD comparison groups (Ames et al., 2020; Zerbo et al., 2018).

Discussion

The 16 articles that were included in our systematic review revealed that autistic adults typically had a higher odds or frequency of utilization of healthcare services than comparison groups. Autistic adults' utilization of some services (e.g., preventive services and primary care) were examined in a relatively small number of studies compared to other services (e.g., the ED). As such, patterns of autistic adults' use of

some services were more clear than others. However, our systematic review offers an important contribution to the literature, developing for the first time a clear picture of what is currently known about autistic adults' use of several important services in the US healthcare system. Additionally, this review highlights facets of service use that should be researched in the future. We discuss below key factors that might contribute to the service use patterns observed in this review, as well as the implications of these patterns for autistic adults and the US healthcare system.

Service Use - Access Does Not Mean Quality

Our findings that autistic adults generally utilized healthcare services to a greater degree than comparison groups falls into alignment with what is currently known about this population's health status. Namely, that autistic adults experience a high number of physical and mental health conditions that co-occur with autism (Croen et al., 2015; Hand, Angell, et al., 2020). As such, frequent utilization of services may indicate that this population is seeking the healthcare services that they need to manage or treat these conditions. Importantly, however, some of the services that autistic adults used more frequently than comparison groups were tertiary healthcare services (e.g., the ED and hospitals) (Liu et al., 2017; Shields et al., 2019). Such services are costly for autistic individuals who are frequently underinsured (Vohra et al., 2014), as well as for the healthcare system (AHRQ, 2020). Moreover, frequent utilization of such services may reflect a crucial issue: although autistic adults frequently use lower-level healthcare services (e.g., primary care and outpatient mental healthcare) (Vogan et al., 2017), the care that they receive in these contexts may be inadequate to meet their needs and to

prevent frequent use of tertiary healthcare services. Indeed, autistic adults have frequently reported unmet healthcare needs (Jose et al., 2021; Nicolaidis et al., 2013b; Schott et al., 2020) in myriad settings such as primary care (Duker et al., 2019; Nicolaidis et al., 2015) and secondary care (i.e., specialist services) (Camm-Crosbie et al., 2019b).

Primary Care and Autistic Adults' use of Tertiary Health Services

Among other populations, increased primary care use has been associated with less frequent use of tertiary healthcare services (Fishman et al., 2018; Galarraga et al., 2015; van den Berg et al., 2016), but we did not observe this pattern. While studies consistently indicated that autistic adults had a greater utilization of primary care than comparison groups (Ames et al., 2020; Zerbo et al., 2018), they typically had equal or more frequent use of the ED and hospital as well (McDermott et al., 2015; Vohra et al., 2016b). In the case of hospitalizations, some studies found that autistic adults were more likely than comparison groups to be hospitalized specifically for ambulatory-care-sensitive conditions (i.e., conditions that can be prevented with regular primary care in the community) (Hand et al., 2019; Zerbo et al., 2018). These findings further suggest that primary care services may not be meeting autistic adults' healthcare needs, leading to use of costly higher levels of care. We posit that this pattern may, in part, be related to factors such as providers' lack of experience in providing healthcare for autistic adults (Unigwe et al., 2017), and resulting challenges with patient-provider communication and management of health conditions (Dern & Sappok, 2016; Raymaker et al., 2017).

Importantly, many kinds of preventive services are routinely provided during primary care visits (Dehmer et al., 2017; Kim et al., 2018) and have been shown to reduce the use of tertiary healthcare services (CDC, 2019). It is encouraging that studies in this review found that autistic adults were more likely to receive most preventive services that were examined (Ames et al., 2020; Zerbo et al., 2018) including vaccinations (Ames et al., 2020; Nicolaidis et al., 2013b) and various screening tests (Zerbo et al., 2018). However, a nuanced understanding of autistic adults' preventive service use remains unclear since the studies we identified in this review focused on: (1) preventive services received in exclusively primary care settings; and (2) a limited number of preventive services. Some preventive services are provided routinely in multiple settings (e.g., mammography) (Stanley et al., 2017) or in secondary healthcare settings (e.g., bone density tests) (USPSTF, 2018), and therefore likely would not be fully captured in analyses that exclusively analyzed primary care claims data. Additionally, while there are dozens of recommended preventive care services (USPSTF, 2021), the studies in this review focused on a relatively limited scope of services like vaccinations or cancer screenings.. As such, we have an incomplete picture of autistic adults' preventive care use. To better understand autistic adults' preventive service use, it is important that future studies examine a wider array of preventive services delivered in a variety of settings. Encouragingly, recent evidence indicates that some primary care delivery models may increase receipt of dozens of preventive services among autistic adults . This is a delivery model that is critical to replicate, as it may indicate delivery of higher quality primary care for autistic adults, and

may reduce their use of tertiary healthcare services, particularly for health conditions that are sensitive to ambulatory and preventive care.

Outpatient Mental Healthcare and Autistic Adults' use of Tertiary Health Services

Studies consistently found that autistic adults used outpatient mental health services to a greater degree than comparison groups (Ames et al., 2020; Maddox et al., 2018; Zerbo et al., 2018). This pattern is unsurprising given autistic adults' high prevalence of co-occurring mental health conditions (Lai et al., 2019). However, as with primary care, frequent receipt of outpatient mental healthcare services may indicate autistic adults' access to care but not necessarily to mental healthcare that is high-quality and that meets their needs. Inadequate mental healthcare, therefore, may also contribute to their frequent use of tertiary healthcare services for mental health conditions. Indeed, it is well established that autistic adults are frequently hospitalized for mental health conditions as children and adults (Schlenz et al., 2015; Vohra et al., 2016b; Weiss et al., 2018). Like in other service areas, a lack of providers trained to provide care for autistic adults is characteristic of the mental healthcare landscape (Maddox et al., 2020).

Future Directions

The service patterns observed in this review underscore the nationally recognized need for more providers to be trained to provide care for autistic adults to promote high quality service delivery (Interagency Autism Coordinating Committee (IACC), 2017). Providers trained to provide care for autistic individuals are needed in all healthcare settings, and it is encouraging that providers from various settings, from

primary care (Urbanowicz et al., 2020) to mental healthcare (Maddox et al., 2020), have expressed interest in such training. As the healthcare needs of autistic adults are further elucidated, the need for a healthcare workforce that is eager to learn to meet these needs is paramount to promote high-quality care and reduce autistic adults' high likelihood of hospitalization and ED use.

Limitations

There are a number of limitations to our review that we would like to acknowledge. It is possible that our electronic database search strategy did not capture all published articles relevant to the review question. However, we did consult with a research librarian when developing our search strategy, which increases our confidence that our search strategy was thorough. Many other healthcare services could have been included in this review, which would have provided a more comprehensive picture of autistic adults' service use patterns. The five services that were included in our review, however, are foundational healthcare services for adults regardless of autism status and are those that have been described most often in the available literature. It is therefore unlikely that the omission of other services detracts from the value of our findings. While some sources (e.g., unpublished, non-peer reviewed research, and research from countries other than the US) could have contributed to our findings, we omitted these sources to focus on aggregation of peer-reviewed studies most relevant to the US healthcare system. Finally, our review offers a narrative synthesis as opposed to a meta-analysis. Given the relatively small number of studies included in most service

areas, we feel that this was an appropriate approach to synthesis, still providing a valuable picture of autistic adults' use of important health services.

Conclusion

This systematic review examined autistic adults' utilization of five foundational healthcare services within the US healthcare system. Our findings indicate that, relative to non-autistic adults, autistic adults typically have higher utilization of inpatient services, the ED, outpatient mental health services, primary care, and preventive services. These findings highlight the immediate need for providers trained to care for autistic adults to be available in healthcare settings, as well as for current and future providers to be trained to care for this growing population. Future research should further examine the quality of primary and secondary healthcare services received by autistic adults and identify targets for improvement, which may ultimately reduce autistic adults' high utilization of the ED and inpatient services.

Inclusion:	Yes	No	Cannot Tell
Does the study describe a discrete sample of autistic adults of which the majority are ≥18 years old?			
Does the study compare autistic adults' healthcare utilization to that of a comparison group?			
Was the study conducted in the United States using US healthcare data?			
Exclusion	**Yes**	**No**	**Cannot Tell**
Does the study describe a sample that is not comprised of autistic adults or of which less than half are autistic adults?			
Does the study report healthcare utilization outcome(s) among autistic adults without reference to a comparison group?			
Is the source a qualitative study, unpublished research, a review, non-human study, book, case study, or presentation?			
Was the study conducted outside of the United States using healthcare data from another country?			
Full text article available in English?			

Table 4: Decision matrix of key questions for title and abstract screening

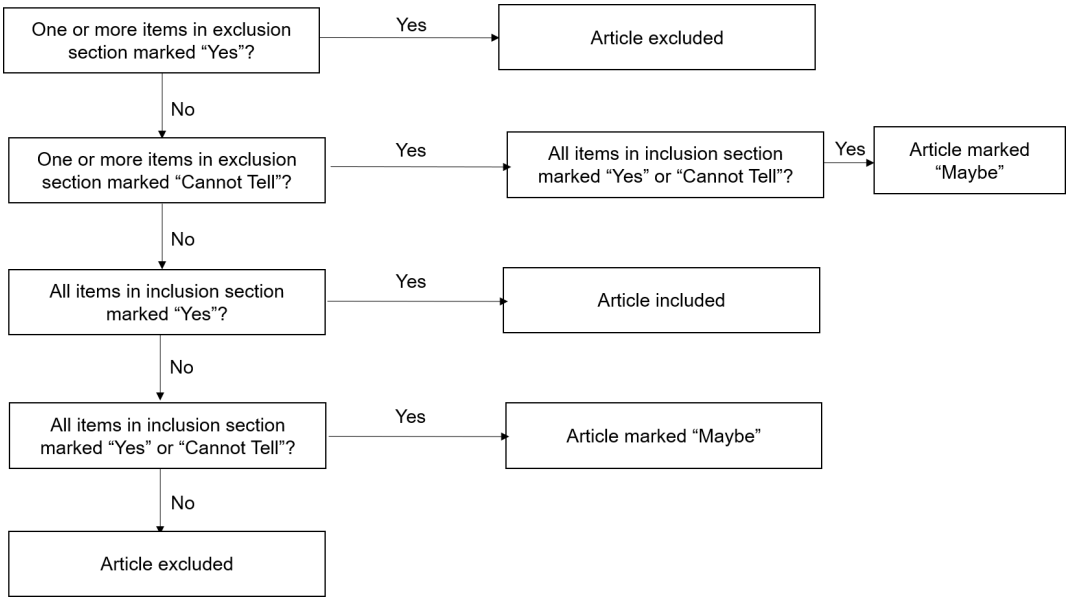

Figure 4: Title and abstract screening process

Inclusion:	Yes	No
Does the study describe a discrete sample of autistic adults of which the majority are ≥18 years old?		
Does the study employ quantitative research methods?		
Does the study report autistic adults' frequency of utilization of one of the specified outcome areas?		
Does the study compare autistic adults' healthcare utilization to that of a comparison group?		
Was the study conducted in the United States using US healthcare data?		
Exclusion	**Yes**	**No**
Does the study describe a sample that is not comprised of autistic adults or of which less than half are autistic adults?		
Does the study report healthcare utilization outcome(s) of interest among autistic adults without reference to a comparison group?		
Is the source a qualitative study, unpublished research, a review, non-human study, book, case study, or presentation?		
Was the study conducted outside of the United States using healthcare data from another country?		
Full text article available in English?		

Table 5: Decision matrix of key questions for full text screening

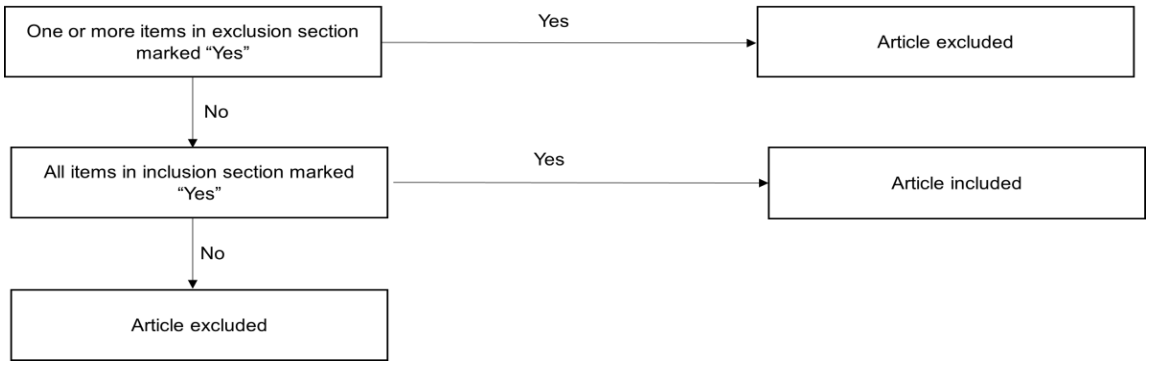

Figure 5: Full text review process

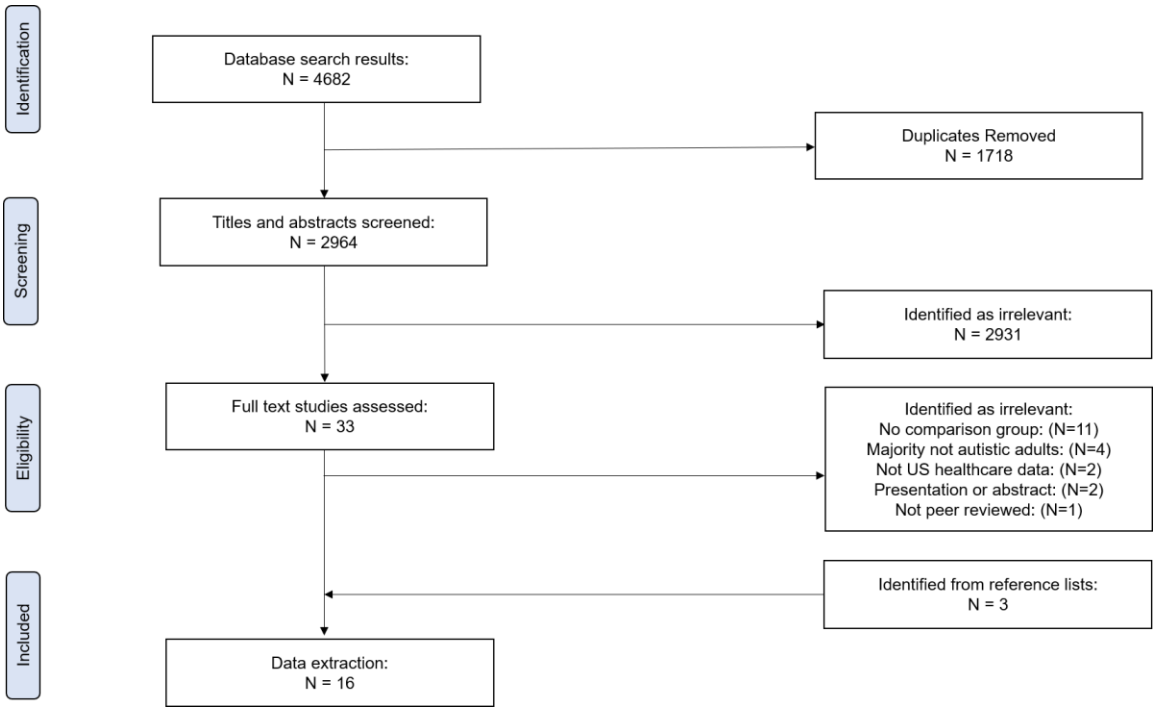

Figure 6: PRISMA flow diagram

ED Utilization					
Reference (Author, year)	**Study Purpose**	**Data Source**	**Sample Characteristics**	**Key Findings**	**Quality Score**
Benevides et al., 2020	To identify rates of ED utilization among transition-age adults with ASD, ASD + ID, and ID only	Medicare data (2010)	N=3,499 ASD individuals (78% male; mean age=23) N=2,048 ASD individuals with co-occurring ID (74% male; mean age=23) N=13,178 individuals with ID (55% male; mean age=24)	Adults with ASD or ASD + ID had fewer annual ED visits than adults with ID-only (p < 0.001)	3b
Nakao et al., 2014	To compare the rates and associated costs of NTDC-related ED visits among individuals with and without ASD	NEDS (2010)	N= ASD individuals reported as <0.1% of adult sample of 103,450,324 (% male not reported; mean age not reported) N= Non-ASD individuals reported as <0.4% of adult sample of 103,450,324 (% male not reported mean age: not reported)	ASD adults had reduced odds of a NTDC-related ED visit compared to the PC (p <0.001).	3a
Liu et al., 2017	To examine rates of ED utilization in ASD individuals compared to individuals without ASD	MarketScan claims data (2005-2013)	N= 87,683 ASD individuals (80% male; mean age=14) N= 56,178,622 Non-ASD individuals (51% male; mean age=16)	ASD adults 18-21 y.o. used the ED at increasing rates over the study period (as high as >30% in a given year) where adults of the same age in PC group had static utilization over the study period (3-4% per year) (p < 0.0001)	3a
Deavenport-Saman et al., 2016	To examine factors associated with ED utilization among individuals with and without ASD	2006–2009 administrative ED discharge data	N= 2,426 ASD individuals (84% male; mean age not reported) N= 155,476 Non-ASD individuals (54% male; mean age not reported)	ASD adults did not statistically differ from PC adults on rates of ED visits per year	3a
Iannuzzi et al., 2015	To identify the most common problems for which ASD and non-ASD individuals present in the ED	NEDS (2010)	N= 109,021 ASD individuals (79% male; mean age not reported) N= 128,849,332 Non-ASD individuals (45% male; mean age not reported)	A smaller proportion of all ED visits among ASD group were for adults (31%) compared to all ED visits among PC group (89%)*	3a
Mental Health Visits					
Reference (Author, year)	**Study Purpose**	**Data Source**	**Sample Characteristics**	**Key Findings**	**Quality Score**
Maddox et al., 2018	To identify differences in psychiatric treatment use between adults with anxiety and depression with and without ASD	Medicaid data (2008-2009)	N= 268 ASD individuals (69% male; mean age not reported) N= 1,072 Non-ASD individuals (69% male; mean age not reported)	ASD adults were less likely to receive talk therapy for anxiety/depression or group therapy (p < 0.05), but more likely to receive case management (p < 0.001) for mental health conditions than the PC; Among those receiving talk therapy, ASD adults averaged more visits per month (p < 0.001)	3a

Table 6: Evidence table

Table 6: Continued

Shea et al., 2018	To compare healthcare service utilization and costs between individuals with either ASD or ID	Medicaid data (2001 and 2005)	N= 2,054 ASD individuals (78% male; mean age not reported) N= 12,316 individuals with ID (56% male; mean age not reported)	80% of ASD adults utilized psychiatric outpatient services compared to 69% of adults in the ID group; Outpatient psychiatric utilization decreased by 19% among the ASD group over 4 years, but by 27% among the ID group*	3a
Esbensen et al., 2010	To examine differences between adults with Down syndrome and ASD adults on functional abilities and health service usage	ASD Data from 2000-2001 (Seltzer et al., 2003) (parent interviews) Down syndrome data from 1997-1998 (Krauss & Seltzer, 1999)	N= 70 ASD individuals (69% male; mean age=37) N= 70 individuals with DS (66% male; mean age=37)	ASD adults were more likely to receive psychological or psychiatric services than adults with DS ($p < 0.001$)	3b
Hospitalizations					
Reference (Author, year)	**Study Purpose**	**Data Source**	**Sample Characteristics**	**Key Findings**	**Quality Score**
Shields et al., 2019	To compare hospital admissions related to self-injurious behavior and ideation among adults with and without ASD	NIS (2014)	N= 5,341 ASD individuals (74% male; mean age not reported) N= 16,023 Non-ASD individuals (74% male; mean age not reported)	ASD adults were nearly twice as likely as PC adults to be hospitalized for self-injurious behavior and ideation ($p \leq 0.001$)	3a
Multiple Outcomes					
Reference (Author, year)	**Study Purpose**	**Data Source**	**Sample Characteristics**	**Key Findings**	**Quality Score**
Hand et al., 2019	To compare the incidence of ACS-admissions among four cohorts: ASD-only, ASD + ID, ID-only, and PC's	State-level administrative billing data (2000-2015)	N= 241 ASD individuals (85% male; mean age not reported) N= 243 ASD individuals with co-occurring ID (78% male; mean age not reported) N= 1,148 individuals with ID (63% male; mean age not reported) N= 2,255 PC's (81% male; mean age not reported)	ED Utilization: ASD and PC adults did not statistically differ on risk of having an ACS-ED visit; Proportion of individuals who had an ACS-ED visit: 14.9% (ASD), 9% (ASD + ID), 23.2% (PC), 14% (ID)* Hospitalization: ASD adults with co-occurring ID were more likely to have an ACS-hospitalization than PC adults ($p < 0.01$), but ASD adults without co-occurring ID did not differ from PC on risk of an ACS-hospitalization; Proportion of individuals who had an ACS-hospitalization: 2.6% (ASD), 10% (ASD + ID), 7% (PC), 5.8% (ID)*	3a

Table 6: Continued

Vohra et al., 2016	To examine trends, type of ED visits, and average ED charges for adults with and without ASD	NEDS (2006-2011)	N= 25,527 ASD individuals (76% male; mean age not reported) N= 76,581 Non-ASD individuals (76% male; mean age not reported)	ED utilization: ASD adults' and PC adults' rates of ED visits increased over time at similar rates Hospitalization: 34% of ASD ED visits led to a hospitalization where only 11% of ED visits among PC adults led to a hospitalization*	3a
Vohra et al., 2017	To examine the prevalence and association of co-occurring conditions with healthcare utilization patterns and expenditures of ASD adults and non-ASD adults	Medicaid data (2000-2008)	N= 1,772 ASD individuals (71% male; mean age not reported) N= 5,320 Non-ASD individuals (71% male; mean age not reported)	ED Utilization: ASD adults and PC adults did not statistically differ in terms of mean number of ED visits per year Hospitalization: ASD adults significantly less likely to be hospitalized than PC adults ($p < 0.001$)	3a
McDermott et al, 2015	To compare hospital encounters (hospitalizations and ED visits) among adolescents and young adults with ASD and either FXS, ID, or PC	State-level data (Medicaid and State health plan-2000-2010)	N= 2,592 ASD individuals (76% male; mean age not reported) N= 125 individuals with FXS (71% male; mean age not reported) N= 10,685 individuals with ID (58% male; mean age not reported) N= 26,804 PC individuals (62% male; mean age not reported)	ED Utilization: Relative to PC adults, ASD adults were more likely to have an ED visit OR=1.5(95% CI=1.3-1.7); Adjusted rates of ED visits compared to other groups: ($18.4\%_{ASD}$ vs $27.9\%_{ID}$), ($19.4\%_{ASD}$ vs $17.0\%_{FXS}$)* Hospitalization: Relative to the PC, ASD adults had higher odds for an inpatient hospitalization OR=5.7(95% CI=4.5-7.3); Adjusted rates of hospitalization compared to other groups: ($6.7\%_{ASD}$ vs $12.7\%_{ID}$), ($6.7\%_{ASD}$ vs $7.3\%_{FXS}$)*	3a
Ames et al., 2020	To examine differences in healthcare utilization among four cohorts: ASD, ADHD, DM, and PC's	KPNC Health System (2014-2015)	N = 4,123 ASD individuals (81% male; mean age=18) N = 20,615 individuals with ADHD (81% male; mean age=18) N = 2,156 individuals with DM (48% male; mean age not reported) N = 20,516 PC individuals (81% male; mean age=18)	ED Utilization: ASD adults less likely to use ED than ADHD OR=0.66(95% CI=0.60-0.73) and DM OR=0.50(95% CI=0.43–0.58) adults, but did not statistically differ from PC Hospitalizations: ASD adults more likely to be hospitalized than ADHD OR=1.81(95% CI=1.52-2.16) and GP OR=2.45(95% CI=2.01-2.97), but less likely to be hospitalized than DM adults OR=0.66(95% CI=0.52–0.83) Mental Health Visits: ASD adults had higher odds of utilization and mean number of mental health visits than all comparison	3a

Table 6: Continued

				cohorts: PC: OR=10.87(95% CI=9.90-11.94), AMR: 7.1 (p < 0.0001); ADHD: OR=1.73(95%CI=1.60-1.86), AMR=1.63(p < <0.0001); DM: OR=4.65(95%CI=3.96–5.45), AMR=2.53 (p < 0.0001) Primary Care: ASD adults had greater primary care utilization than PC adults OR=1.38(95% CI=1.27–1.49) and ADHD adults OR=1.09(95% CI=1.01-1.18), but lower than that of DM adults OR=0.42(95% CI=0.36–0.48) Preventive Services: ASD adults more likely to receive well-adult medical exam OR=2.07(95% CI=1.86-2.30), flu vaccine OR=1.82(95% CI=1.69–1.96), less likely to have pelvic exam OR=0.53(95% CI=0.40–0.70) than GP adults; More likely to receive well-adult medical exam OR=2.11(95% CI=1.90–2.34), flu vaccine OR=1.54(95% CI=1.43–1.66), less likely to receive pelvic exam OR=0.52 (95% CI=0.40–0.69) than ADHD adults; More likely to receive flu vaccine OR=1.15(95% CI=1.02–1.29), but less likely to receive pelvic exam OR=0.71(95% CI=0.52–0.97) than DM adults	3a
Zerbo et al., 2018	To compare health care utilization patterns and cost among insured adults with ASD, adults with ADHD, and PC adults with neither condition	KPNC Health System (2012)	N= 1,507 ASD individuals (73% male; mean age=29) N= 9,042 individuals with ADHD (73% male; mean age=29) N = 15,070 PC's (73% male; mean age=29)	ED utilization: ASD adults did not statistically differ from ADHD or PC adults on odds of ED use Hospitalization: ASD adults more than twice as likely as ADHD adults OR=2.1(95% CI=1.6-2.9) to be hospitalized for an ACS diagnoses, but no differences were found when compared to PC adults Mental Health Visits: ASD adults had higher utilization and mean number of visits for mental health than ADHD adults: OR=1.6(95% CI=1.4–1.8), AMR=1.9(95% CI=1.7-2.2) and PC adults: OR=11.5(95% CI-10.0-13.2), AMR=11.7	3a

Table 6: Continued

				(95%CI=9.3-14.8) Primary Care: ASD adults had higher utilization of primary care than ADHD OR=1.2(95% CI=1.1-1.3) and PC OR=1.3(95% CI=1.2–1.4) adults Preventive Services: ASD adults more likely to receive an influenza vaccination OR=2.6(95% CI=2.3-2.9), cholesterol screening OR=1.7(95% CI=1.2–2.5), and diabetes screening OR= 1.8(95% CI=1.3-2.5) than PC adults, but less likely to have cervical cancer screening OR=0.6(95% CI=0.5–0.8); More likely to receive flu vaccine OR=2.3 (95% CI=2.1–2.7), cholesterol screening OR=1.7(95% CI=1.2–2.5), diabetes screening OR=1.8(95% CI=1.3–2.5) but less likely to receive cervical cancer screening OR=0.7(95% CI=0.5–0.9) than ADHD adults	3a
Nicolaidis, et al., 2013	To assess the healthcare experiences (e.g., patient-provider communication, healthcare utilization patterns) of autistic adults versus those of non-autistic adults	Online Survey	N= 209 ASD individuals (41% male; mean age=37) N= 228 Non-ASD individuals (34% male; mean age=40)	ED Utilization: ASD adults had a greater odds of using the ED than PC adults OR=2.1(95% CI=1.8-3.8) Hospitalization: ASD and PC adults were equally likely to have been hospitalized in the past year Preventive Services: ASD adults were less likely to receive a tetanus vaccination OR=.05(95% CI=0.3-0.9) or a and Pap smear OR=0.5(95% CI=0.2-0.9) than PC adults	3b

Abbreviations:
ED=Emergency Department; ASD=Autism Spectrum Disorder; ID=Intellectual Disability; ADHD=Attention Deficit Hyperactivity Disorder; KPNC=Kaiser Permanente Northern California; ACS=Ambulatory Care Sensitive; DM=Diabetes Mellitus; PC=Population Control; NIS=National Inpatient Sample; NEDS=National Emergency Department Sample; FXS=Fragile X Syndrome; DS=Down Syndrome; NTDC=Non-traumatic dental condition; OR=Odds Ratio; CI=Confidence Interval; AMR=Adjusted Mean Ratio; * = reported findings are descriptive statistics only; 3a=Higher Quality Cross Sectional Study; 3b=Lower Quality Cross Sectional Study

ASD vs PC			
	Lower	Equal	Higher
ED	·	· · · · · ·	· · ·
Hospitalization	·	· · ·	· · · ·
Mental Health			· · ·
Preventive Services	·		· ·
Primary Care			· ·
ASD vs ADHD			
	Lower	Equal	Higher
ED	·	·	
Hospitalization		· ·	· ·
Mental Health			· ·
Preventive Services			· ·
Primary Care			· ·
Key: · = 1 study; ED=Emergency Department; ASD= Autism Spectrum Disorder; PC=Population Control; ADHD=Attention-deficit/Hyperactivity Disorder			

Table 7: Service trends

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Appendix A: Supplementary Materials

Search Strategies Summary

Database	# Results	Strategy
Pubmed	970	Unique- MeSH and search mapping
Embase	1299	Unique- Emtree terms
Scopus	940	Same
Web of Science (Core Collection)	604	Same
CINAHL	241	Same
PsycINFO	628	Same
Total	**4682 (before de-duplication)**	

Database-Specific Strategies:

Pubmed

Autism		Adult		Outcome	Year	# Results
	AND		AND			
(autism spectrum disorder[mesh] OR autism[tw] OR autistic[tw] OR asd[tw])		(adult[mesh] OR adult[tw] OR adults[tw] OR adulthood[tw])		(hospitalization[mesh] OR emergency service, hospital[mesh] OR emergency medical services[mesh] OR emergency medicine[mesh] OR emergency treatment[mesh] OR emergency[tw] OR emergencies[tw] OR primary healthcare[mesh] OR primary care[tw] OR primary healthcare[tw] OR primary health care[tw] OR preventive health services[mesh] OR preventive[tw] OR preventative[tw] OR mental health services[mesh] OR mental health services[tw] OR mental healthcare[tw] OR mental health care[tw] OR mental health[mesh] OR patient acceptance of healthcare[mesh] OR utilization[tw] OR utilisation[tw] OR health services for persons with disabilities[mesh])	2010-2020	**970**
(autism spectrum disorder[mesh] OR autism[tw] OR autistic[tw] OR asd[tw]) AND (adult[mesh] OR adult[tw] OR adults[tw] OR adulthood[tw]) AND (hospitalization[mesh] OR emergency service, hospital[mesh] OR emergency medical services[mesh] OR emergency medicine[mesh] OR emergency treatment[mesh] OR emergency[tw] OR emergencies[tw] OR primary healthcare[mesh] OR primary care[tw] OR primary healthcare[tw] OR primary health care[tw] OR preventive health services[mesh] OR preventive[tw] OR preventative[tw] OR mental health services[mesh] OR mental health services[tw] OR mental healthcare[tw] OR mental health care[tw] OR mental health[mesh] OR patient acceptance of healthcare[mesh] OR utilization[tw] OR utilisation[tw] OR health services for persons with disabilities[mesh])						

Embase

Autism		Adult		Outcome	Year	# Results
	AND		AND			
('autism' OR 'asd' OR 'autism spectrum disorder' OR 'autistic')		('adult' OR 'adulthood' OR 'adults')		('hospitalization' OR 'hospitalizations' OR 'emergency department' OR 'emergency room' OR 'emergency ward' OR 'primary health care' OR 'primary healthcare' OR 'primary care' OR 'primary medical care' OR 'preventive health service' OR 'preventative medicine' OR 'preventive services' OR 'mental health care' OR 'mental healthcare' OR 'mental health services' OR 'mental health service' OR 'health care utilization' OR 'healthcare utilization') AND [2010-2020]/py	2010-2020	**1299**
('autism' OR 'asd' OR 'autism spectrum disorder' OR 'autistic') AND ('adult' OR 'adulthood' OR 'adults') AND ('hospitalization' OR 'hospitalizations' OR 'emergency department' OR 'emergency room' OR 'emergency ward' OR 'primary health care' OR 'primary healthcare' OR 'primary care' OR 'primary medical care' OR 'preventive health service' OR 'preventative medicine' OR 'preventive services' OR 'mental health care' OR 'mental healthcare' OR 'mental health services' OR 'mental health service' OR 'health care utilization' OR 'healthcare utilization') AND [2010-2020]/py						

Scopus

Autism		Adult		Outcome	Year	# Results
(autism OR autistic OR asd OR "autism spectrum disorder")	AND	(adult OR adults OR adulthood)	AND	("hospitalization" OR "hospitalizations" OR "hospital admission" OR "emergency department" OR "emergency room" OR "emergency ward" OR "primary care" OR "primary healthcare" OR "primary health care" OR "primary medical care" OR "preventive health service" OR "preventative medicine" OR "preventive services" OR "mental health services" OR "mental health service" OR "mental healthcare" OR "mental health care" OR "healthcare utilization" OR "health care utilization")	2010-2020	**940**
TITLE-ABS-KEY(autism OR autistic OR asd OR "autism spectrum disorder") AND TITLE-ABS-KEY(adult OR adults OR adulthood) AND TITLE-ABS-KEY("hospitalization" OR "hospitalizations" OR "hospital admission" OR "emergency department" OR "emergency room" OR "emergency ward" OR "primary care" OR "primary healthcare" OR "primary health care" OR "primary medical care" OR "preventive health service" OR "preventative medicine" OR "preventive services" OR "mental health services" OR "mental health service" OR "mental healthcare" OR "mental health care" OR "healthcare utilization" OR "health care utilization") AND (LIMIT-TO (PUBYEAR,2020) OR LIMIT-TO (PUBYEAR,2019) OR LIMIT-TO (PUBYEAR,2018) OR LIMIT-TO (PUBYEAR,2017) OR LIMIT-TO (PUBYEAR,2016) OR LIMIT-TO (PUBYEAR,2015) OR LIMIT-TO (						

PUBYEAR,2014) OR LIMIT-TO (PUBYEAR,2013) OR LIMIT-TO (PUBYEAR,2012) OR LIMIT-TO (PUBYEAR,2011) OR LIMIT-TO (PUBYEAR,2010))

Web of Science (Core Collection)

Autism		Adult		Outcome	Year	# Results
	AND		AND			
('autism' OR 'asd' OR 'autism spectrum disorder' OR 'autistic')		('adult' OR 'adulthood' OR 'adults')		('hospitalization' OR 'hospitalizations' OR 'hospital admission' OR 'emergency department' OR 'emergency room' OR 'emergency ward' OR 'primary health care' OR 'primary healthcare' OR 'primary care' OR 'primary medical care' OR 'preventive health service' OR 'preventative medicine' OR 'preventive services' OR 'mental health care' OR 'mental healthcare' OR 'mental health services' OR 'mental health service' OR 'health care utilization' OR 'healthcare utilization') AND [2010-2020]/py	2010-2020	**604**
TS=('autism' OR 'asd' OR 'autism spectrum disorder' OR 'autistic') AND TS=('adult' OR 'adulthood' OR 'adults') AND TS=('hospitalization' OR 'hospitalizations' OR 'hospital admission' OR 'emergency department' OR 'emergency room' OR 'emergency ward' OR 'primary health care' OR 'primary healthcare' OR 'primary care' OR 'primary medical care' OR 'preventive health service' OR 'preventative medicine' OR 'preventive services' OR 'mental health care' OR 'mental healthcare' OR 'mental health services' OR 'mental health service' OR 'health care utilization' OR 'healthcare utilization') AND PY=(2010-2020)						

CINAHL

Autism		Adult		Outcome	Year	# Results
	AND		AND			
('autism' OR 'asd' OR 'autism spectrum disorder' OR 'autistic')		('adult' OR 'adulthood' OR 'adults')		('hospitalization' OR 'hospitalizations' OR 'hospital admission' OR 'emergency department' OR 'emergency room' OR 'emergency ward' OR 'primary health care' OR 'primary healthcare' OR 'primary care' OR 'primary medical care' OR 'preventive health service' OR 'preventative medicine' OR 'preventive services' OR 'mental health care' OR 'mental healthcare' OR 'mental health services' OR 'mental health service' OR 'health care utilization' OR 'healthcare utilization') AND [2010-2020]/py	2010-2020	**241**
(('autism' OR 'asd' OR 'autism spectrum disorder' OR 'autistic')) AND (('adult' OR 'adulthood' OR 'adults')) AND (('hospitalization' OR 'hospitalizations' OR 'hospital admission' OR 'emergency department' OR						

'emergency room' OR 'emergency ward' OR 'primary health care' OR 'primary healthcare' OR 'primary care' OR 'primary medical care' OR 'preventive health service' OR 'preventative medicine' OR 'preventive services' OR 'mental health care' OR 'mental healthcare' OR 'mental health services' OR 'mental health service' OR 'health care utilization' OR 'healthcare utilization'))

Refine to 2010-2020 after clicking search

PsycINFO

Autism		Adult		Outcome	Year	# Results
	AND		**AND**			
('autism' OR 'asd' OR 'autism spectrum disorder' OR 'autistic')		('adult' OR 'adulthood' OR 'adults')		('hospitalization' OR 'hospitalizations' OR 'hospital admission' OR 'emergency department' OR 'emergency room' OR 'emergency ward' OR 'primary health care' OR 'primary healthcare' OR 'primary care' OR 'primary medical care' OR 'preventive health service' OR 'preventative medicine' OR 'preventive services' OR 'mental health care' OR 'mental healthcare' OR 'mental health services' OR 'mental health service' OR 'health care utilization' OR 'healthcare utilization') AND [2010-2020]/py	2010-2020	**628**
(('autism' OR 'asd' OR 'autism spectrum disorder' OR 'autistic')) AND (('adult' OR 'adulthood' OR 'adults')) AND (('hospitalization' OR 'hospitalizations' OR 'hospital admission' OR 'emergency department' OR 'emergency room' OR 'emergency ward' OR 'primary health care' OR 'primary healthcare' OR 'primary care' OR 'primary medical care' OR 'preventive health service' OR 'preventative medicine' OR 'preventive services' OR 'mental health care' OR 'mental healthcare' OR 'mental health services' OR 'mental health service' OR 'health care utilization' OR 'healthcare utilization'))						

Refine to 2010-2020 after clicking search