

# **BALLARD BRIEF**

November 2022

## **Inadequate Healthcare Services Among Individuals with Autism in the United States**

Gabby Sutton-Clark



# Summary

Healthcare innovation has been a pressing topic in public discourse across the United States for centuries. Advances have taken place in several healthcare fields, such as maternal and fetal medicine, cardiology, and surgical specialties; however, healthcare for individuals with autism spectrum disorder (ASD) has not received the same attention and care. A general lack of access to healthcare services, communication barriers, lack of ASD-specific provider training, and the physical healthcare environment all contribute to the inadequate healthcare experiences and services individuals with ASD receive. As a result, individuals with ASD not only seek healthcare less frequently for their health concerns but also feel far less confident in their healthcare provider's ability to provide quality care. As a direct result of this inadequate healthcare, the physical well-being and overall quality of life of individuals with autism suffer disproportionately. Improved medical training for

healthcare providers and ASD-supporting medical programs may alleviate this issue and address the unique healthcare needs of this population.

# Key Terms

**Autism Spectrum Disorder (ASD)**—Autism spectrum disorder is a complex neurodevelopmental disorder in which an individual experiences challenges with social interactions, repetitive or atypical behaviors, and restricted interests and can also present communication challenges and difficulty interpreting and regulating emotions and physical movements.<sup>1</sup>

**Comorbidities**—Health conditions that commonly co-occur with another health condition.<sup>2</sup> Several comorbidities often occur with autism, specifically including gastrointestinal issues, seizures, and sleep disorders.<sup>3,4</sup>

**Developmental-Behavioral**

**Pediatrics**—A medical subspecialty of pediatrics that focuses on diagnosing

and treating concerns related to growth and development in children.<sup>5</sup>

**Healthcare Providers**—Credentialed providers with diagnostic and prescriptive authority delivering healthcare services to patients in a medical environment. Commonly referred to as ‘providers,’ this paper defines healthcare providers as nurse practitioners, physician assistants, general physicians, and specialists.

## Context

### *Q: What is autism spectrum disorder (ASD)?*

**A:** ASD is a neurodevelopmental disorder characterized by social, communication, and behavioral challenges.<sup>8</sup> Many individuals on the autism spectrum also experience sensory challenges.<sup>9</sup> As the fastest-growing developmental disorder in the US, ASD now affects approximately 1 in 44 children in the US, although estimates vary.<sup>10</sup> Current estimates indicate that ASD prevalence has

**Neurotypical**—Behavior that is consistent with typical neurological and developmental function.<sup>6</sup> This term is commonly used to contrast behaviors between individuals with autism and their (neurotypical) counterparts without autism.<sup>7</sup>

increased 241% since 2000.<sup>11, 12</sup> There is no single known cause of ASD; instead, current research credits several factors, including genetic and environmental factors, that may cause ASD.<sup>13</sup>

### *Q: How is ASD diagnosed and treated?*

**A:** While there are no known medical tests that can reveal this disorder on a biological level,<sup>14, 15, 16</sup> medical providers can make diagnoses by gathering a patient’s developmental history, closely observing behaviors, and noting patient and caregiver

descriptions of symptoms.<sup>17</sup> To be diagnosed with ASD, individuals must exhibit persistent deficits in the three following areas: social, communication, and behavioral.<sup>18, 19</sup> Some examples of social deficits include a lack of interest in other's interests or conversations, difficulty understanding social cues, lack of eye contact, and difficulty with social-emotional reciprocity.<sup>20, 21</sup> Some behavioral symptoms of ASD include repetitive movements, fixation on certain objects or specific routines, difficulty with transitions, aggressive outbursts, increased or decreased sensitivity to sensory stimuli, and hyperactive or catatonic (unresponsive) behavior.<sup>22, 23</sup> Some communication symptoms of ASD include delayed or absent speech, repetitive phrases, difficulty regulating volume, as well as monotone or other atypical vocal tones and vocalizations.<sup>24</sup> It should be noted, however, that symptoms of this condition occur on a spectrum, meaning every individual with ASD is unique in their specific presentation and severity of symptoms.<sup>25, 26</sup> As such, some

individuals with ASD may exhibit minor symptoms with no significant barriers to daily functioning, while others experience severe challenges that significantly impact daily functioning.<sup>27</sup>

Given symptoms of ASD occur on a spectrum, treatments for ASD are often determined on a case-by-case basis after evaluation from several providers.<sup>28</sup> Common treatments for ASD specifically include behavior and communication therapies such as speech and language therapy, which focuses on the patient's language use and comprehension skills. Another treatment option is applied behavior therapy (ABA), which uses positive reinforcement to teach patients new skills that can be applied to multiple situations. Educational treatments and home treatments are also available outside the provider's office.<sup>29</sup> Finally, medications may be appropriate to manage an individual's ASD symptoms, from antidepressants for an individual's anxiety to prescriptions for an ASD patient's potential comorbidities, such as gastrointestinal

problems or seizures.<sup>30, 31</sup> While there is no cure for ASD, these treatments seek to alleviate symptoms and facilitate a life of independence for individuals with ASD.<sup>32</sup>

***Q: What is considered “adequate healthcare?”***

**A:** Adequate healthcare refers to the ability of an individual to access and receive healthcare that addresses any physical and mental health condition in need of treatment. For this discussion, adequate healthcare refers to individuals with autism having access to the same healthcare opportunities as their neurotypical counterparts. These healthcare opportunities may relate to ASD-specific care, such as ASD diagnosis. However, this brief will refer to individuals with ASD receiving ASD-specific care, especially ASD diagnosis, and general medical treatment often unrelated to ASD, such as bloodwork and regular checkups.

Adequate healthcare can be further defined by the six following characteristics: effectiveness, efficiency, equity, patient-centeredness,

safety, and timeliness.<sup>33</sup> An example of healthcare that qualifies as effective is when patients receive healthcare based on current best practices in medicine that providers integrate into their treatment plans.<sup>34</sup> An example of patient-centeredness is the referral process, in which one provider refers a patient to another specialized provider to ensure the patient receives care that meets all of their healthcare needs.<sup>35</sup> For instance, a primary care provider or pediatrician may refer a patient with autism to a gastroenterologist to manage ASD-related gastrointestinal issues.<sup>36</sup> Finally, an example of timeliness is the diagnostic process, with shorter diagnostic time periods and fewer visits. For the purposes of this brief, any healthcare provider that does not meet all six criteria is considered inadequate healthcare.

This brief will not discuss the mental healthcare of patients with ASD because treatment options for mental health vary significantly from standard treatment protocols for physical health conditions. For example, while

psychotherapy is a frontline treatment for a variety of mental health conditions, it is not a frontline treatment for physical ailments. Furthermore, while mental health experts often address psychological symptoms of ASD, this brief is focused primarily on the physical symptoms of ASD, and the challenges patients with ASD face in seeking this physical healthcare. This brief will also not discuss care provided via telehealth—or other electronic, remote care platforms—as they are newer developments in healthcare and contain their own unique barriers to care (i.e., a lack of or limited access to electronic devices, internet connectivity issues, limited and misdiagnoses due to a lack of technical competency and comprehensive physical examinations).<sup>37</sup> Instead, this brief will solely address inadequate, in-person healthcare.

***Q: Who is most affected by ASD and this lack of adequate healthcare?***

**A:** ASD affects certain demographics more than others, thus leading to disproportionate impacts on one's healthcare experience. For instance, ASD is found in all ethnic groups but has a slightly higher prevalence among Caucasians.<sup>38, 39</sup> Specifically, it is found 1.1 times more often in Caucasians than black individuals and 1.2 times more common in Caucasians than Hispanics.<sup>40</sup> Research suggests that a possible reason for a higher incidence of ASD among certain ethnic populations may be more closely related to socioeconomic status rather than genetic factors. As such, children from ethnic or racial minority groups, lower income backgrounds, and rural regions experienced the most profound delays in diagnosis and were less likely to seek specialized healthcare services compared to children of the same age but of a higher socioeconomic level.<sup>41,</sup>

<sup>42, 43, 44, 45, 46</sup>

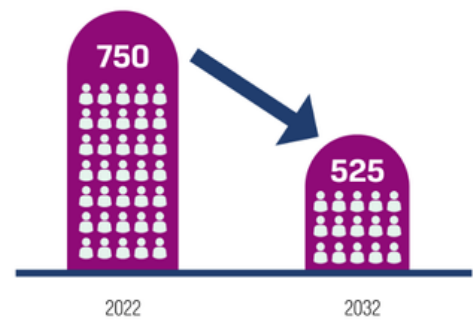
For example, ASD is diagnosed 4 times more often in males than females.<sup>47</sup> Research suggests that some reasons for this disparity in ASD diagnoses between males and females include the tendency for females to display fewer restricted interests or repetitive behaviors than males and exhibiting more socially accepted interests.<sup>48</sup> Another reason for this diagnostic disparity between males and females is the tendency for females with ASD to mirror the behaviors of their neurotypical counterparts, effectively lowering the diagnosis of ASD with lesser symptoms.<sup>49, 50, 51</sup> The reasons behind this diagnostic disparity indicate why females with ASD may be less affected by inadequate healthcare than males with ASD in the US.

***Q: Who typically provides care for individuals with ASD?<sup>52</sup>***

**A:** Individuals with ASD often require a diverse healthcare team to address their healthcare needs. Some of these providers include primary care providers, neurologists,

developmental-behavioral pediatricians, gastroenterologists, and physical therapists.<sup>53, 54, 55</sup> One specific provider, a developmental-behavioral pediatrician (DBP), treats developmental concerns like ASD in children.<sup>56</sup> DBPs are pediatricians who undergo an additional 3 years of subspecialty training in developmental and behavioral concerns in children.<sup>57</sup> Of an estimated 33,620 pediatricians in the US,<sup>58</sup> less than 750 are board-certified DPBs;<sup>59</sup> and over the next decade, approximately one-third of existing DBPs expect to retire.<sup>60</sup> These shortages affect who is able to provide care for individuals with ASD and how often.

30% of DBPs in the United States are expected to retire in the next 10 years.



## ***Q: What is the history of ASD in the United States?***

**A:** In the early twentieth century, researchers and the general public associated symptoms of autism with schizophrenia and other severe psychiatric disorders. In 1911, a psychiatrist from Switzerland first coined the term “autism,” but this term did not identify ASD as its own disorder. As a result of this association between autism and schizophrenia, treatments in the early 1900s included electroconvulsive therapy (a treatment in which electric pulses were sent through an individual’s body, inducing brief seizures and hypothetically altering one’s brain chemistry) and other treatments.<sup>61</sup>

Throughout the twentieth century, autism’s definition evolved to refer to social or emotional problems in children rather than a psychiatric condition. In 1943, Dr. Leo Kanner first described autism as a social and emotional disorder. Further research sought to address the causes of autism. For instance, researchers from the

1950s to the 1970s hypothesized that autism was caused by apathetic mothers, leading to treatments such as removing the child from their home. These efforts to alleviate symptoms of autism and understand its root causes culminated in harmful treatments, including physical restraints, shock therapy, and others.<sup>62, 63</sup> Ongoing research later disproved these theories because autism was increasingly linked to biological factors such as brain development.<sup>64</sup>

In 1980, ASD was officially classified in the Diagnostic and Statistical Manual of Mental Disorders (DSM) as its own developmental disorder.<sup>65, 66</sup> Later editions of the DSM recognized autism as a spectrum of developmental behaviors and conditions ranging from mild to severe.<sup>67</sup> These editions also broadened diagnosis criteria, increasing the diagnosis of autism in the US to 1 in 1,400. With the US Department of Education’s 1991 ruling that children with autism qualify for special services, the number of children diagnosed with autism has grown over the years.<sup>68</sup> In 2013, the DSM



introduced the term autism spectrum disorder (ASD) with two criteria: “persistent impairment in reciprocal social communication and social interaction” and “restricted, repetitive patterns of behavior.”<sup>69</sup>

While no standard treatment for ASD exists, treatments today target symptoms and behaviors from multiple angles. Examples of treatment are applied behavioral analysis (ABA) therapy, speech and language therapy, cognitive-behavior therapy (CBD), and medication.<sup>70, 71</sup> Although advocacy groups are challenging the efficacy of treatments like ABA, these treatments are widely recognized and utilized and are the leading treatments for behavioral components of ASD today.<sup>72,</sup>

73

***Q: Where is this issue most prevalent in the US?***

**A:** There is an overall lack of autism services in both rural and urban areas in the United States, with 83.86% of US



As for healthcare itself, rural communities seem to be disproportionately affected by a decreased level of access to quality healthcare.<sup>78</sup> Furthermore, 35% of individuals with ASD living in rural regions reported significant difficulties accessing services due to a lack of available services compared to 23% of individuals with ASD living in urban areas.<sup>79</sup> In lieu of these services, some parents in rural areas refer to schools as an indirect health system.<sup>80</sup> As such, in rural areas, 88% of parents of youth with ASD report communicating with their provider about their child’s needs, while 93% of parents of youth with ASD in urban areas report communicating with their provider regarding their child’s needs.<sup>81</sup>

# Contributing Factors

## *Access to Healthcare Services*

One of the overarching barriers to quality healthcare for individuals with ASD is the overall accessibility of qualified healthcare providers and the proximity of medical facilities themselves. This accessibility can be further divided up into provider shortages and inadequate transportation, both of which impair an individual with ASD's access to healthcare services.

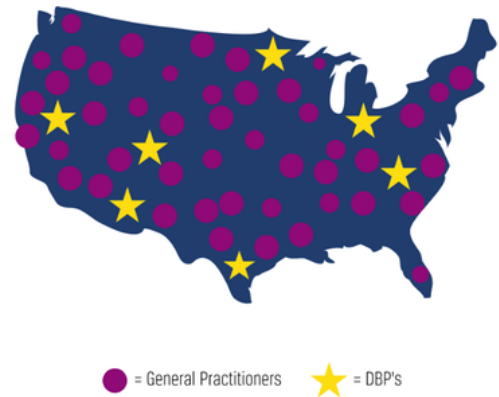
## **Shortage of Providers**

A shortage of healthcare providers contributes to the lack of adequate care for individuals with autism as it decreases access to the general and specialty healthcare providers who treat patients with ASD. It is currently estimated that by 2034 there will be a shortage of 37,800–124,000 physicians in both primary and specialty care settings in the United States.<sup>82</sup> With the COVID-19 pandemic significantly

exacerbating this shortage, 47% of US healthcare workers plan to leave their current roles in healthcare by 2025.<sup>83</sup>

<sup>84</sup> Additionally, due to the pandemic, 58% of surveyed practices reported increased wait times to access their services.<sup>85</sup>

Of an Estimated 33,620 Pediatricians in the U.S., Less Than 750 Are Board-Certified DPBs.



With such profound shortages in healthcare providers overall, underserved populations such as individuals with autism suffer disproportionately due to a lack of access to qualified providers who can address their complex healthcare needs.<sup>86</sup> While DPBs can be a beneficial resource for children with ASD, a national survey of 40 children's

hospitals reported that developmental-behavioral pediatrics was the highest-ranked subspecialty and reported their shortages negatively affected their ability to deliver healthcare.<sup>87</sup> The significance of this for patients with ASD is that one of the top specialties dedicated to caring for individuals with developmental concerns like autism is the one specialty with the highest rate of access and healthcare delivery barriers. In addition to DBP shortages, developmental pediatrics also had the second-longest reported wait time for evaluations at 18.7 weeks, closely following the longest reported wait time of pediatric genetic counseling, another subspecialty in high demand for diagnosing patients with suspected ASD,<sup>88</sup> with a wait time of 20.8 weeks.<sup>89</sup> Because the two specialties with the longest wait times are both in high demand for patients with ASD in both diagnosing and treating ASD symptoms long term, most individuals with autism do not have access to the comprehensive healthcare they need.<sup>90,</sup>

91, 92

## **Transportation**

*Due to limited research on the nationwide experiences of individuals with autism and transportation challenges, this section will refer primarily to an infrastructure and transportation report of New Jerseyan participants.*

Transportation issues contribute to a lack of access to healthcare for individuals with ASD as they decrease physical accessibility to healthcare facilities. A study of surveyed New Jerseyan participants (who either had ASD or were family members of individuals with ASD) reported several transportation issues: judging distance and speed of cars, issues with loud traffic, difficulty navigating public transit, using directions or maps and planning public transportation trips, to name a few.<sup>93</sup> These challenges to transportation persist via both public and private forms of transportation. As a result of these public transportation barriers, 97.6% of surveyed New Jerseyans with autism reported relying on others for a ride to important

activities such as school, work, social events, and healthcare-related trips.<sup>94</sup> As for medical and healthcare appointments, 61.6% of respondents reported relying on others for transportation.<sup>95</sup> However, 72.8% of surveyed participants reported missing activities (including but not limited to medical appointments) at least some of the time due to the unavailability of these individuals to provide transportation.<sup>96</sup> Furthermore, compared to their neurotypical counterparts, which generally express confidence in traveling independently, individuals with ASD in one study reported mixed levels of confidence due to several challenges with transportation.<sup>97</sup> The transportation challenges hinder an individual with ASD's ability to access healthcare services.

Distance to facilities is an additional complicating component of accessing healthcare facilities for individuals with autism, particularly in rural regions. On average, it is estimated that US residents travel approximately 9.9 miles one way to access healthcare facilities.<sup>98</sup> While

this distance may be overcomeable by some, individuals in rural regions, on average, travel more than twice the distance than their urban-living counterparts (17.8 and 8.1 miles one-way, respectively).<sup>99</sup> In these underserved regions, waitlists are longer, and 42% of rural-living citizens report "having to travel to another city for a diagnosis."<sup>100</sup> As such, in addition to a shortage of qualified healthcare providers, both proximity to services and transportation remain viable issues in the physical accessibility to healthcare services.<sup>101</sup>



### ***Communication Barriers***

Communication issues are significant barriers to adequate access to healthcare because when patients with autism cannot communicate their healthcare needs, it is harder for them

to receive the care and treatments they need. As is common with many components of ASD, the communicative abilities of individuals on the autism spectrum vary drastically, with some individuals communicating verbally with little noted impairment, while others are minimally verbal—speaking very few words at a time, or nonverbal—using nonverbal communication methods entirely. Although communicative abilities vary, an estimated 25–40% of individuals on the autism spectrum are either minimally verbal or nonverbal.<sup>102, 103, 104</sup> One example of minimally verbal communication is when individuals do not speak in more than two-word phrases at a time<sup>105</sup> or only speak a few words by the age of 5,<sup>106</sup> although approximately 30% of individuals with autism remain minimally verbal after the age of 5.<sup>107</sup> For minimally verbal or nonverbal individuals with autism, some of the most utilized communication methods include communication boards, sign language, Picture Exchange Communication System (PECS), and Speech Generating

Devices (SGDs).<sup>108</sup> These communication barriers remain complex due to their unique nature, with fluctuations based on the severity of ASD symptoms. Due to a variety of communication barriers, only 57% of surveyed patients with ASD reported that their providers understood what they were trying to communicate as compared to 86% of patients without ASD.<sup>109</sup> Similarly, more than half of surveyed patients in another study reported frequently being unable to communicate thoughts, wants, or needs.<sup>110</sup> These difficulties act as a barrier to communication between the provider and the patient, thus inhibiting care.<sup>111</sup> Other communication challenges for autism patients, more evidently with fully verbal patients, arise from difficulty knowing how to describe symptoms or communicate discomfort.<sup>112</sup> For example, individuals with autism may struggle to relate to common adjectives in the medical field. Some examples of commonly used descriptions that people with autism struggle to use or relate to are sharp,

dull, achy, crampy, tender, acute sudden-onset, long-term, on or off, etc. As for minimally verbal and non-verbal individuals on the autism spectrum, vocalizations such as grunts, groans, involuntary vocalizations, or even repeated shouting of a particular phrase (whether related to the healthcare visit or not) are common methods of communicating discomforts such as pain, or even positive emotions like happiness and excitement.<sup>113</sup> However, these vocalizations can sound alike and, as a result, be easily mistaken for each other. Other studies identify behaviors such as grimacing, injuring one's self, or furrowing one's brow as further methods of expressing pain—behaviors equally subjective and difficult for providers, especially providers unfamiliar with the patient's needs.<sup>114</sup> When patients with ASD are unable to effectively communicate their medical needs with healthcare providers, their access to appropriate treatments and adequate healthcare suffers.

Finally, patients with autism also struggle to understand what their healthcare providers are

communicating. More specifically, 75% of surveyed patients with ASD reported they could “sometimes or usually” understand what their provider was communicating, as compared to 92% of patients without ASD.<sup>115</sup> These communication barriers can detract significantly from a potentially beneficial healthcare interaction and further frustrates efforts to provide quality care for patients with ASD.

### ***Lack of Formal Provider Training***

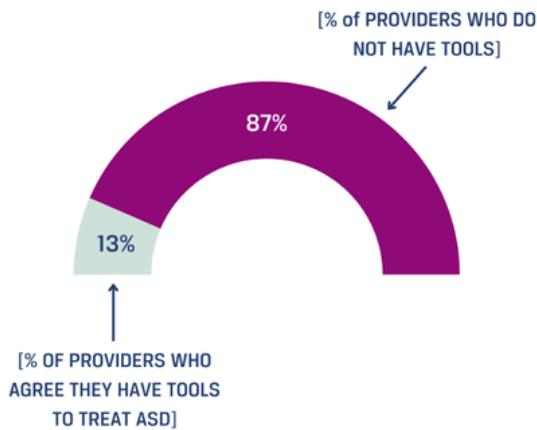
Lack of formal provider training contributes to inadequate care for individuals with ASD because when providers do not have specialized, formal training for treating this population, access to personalized care and treatments for patients with ASD suffers.<sup>116</sup> For this brief, formal training for healthcare providers is defined as ASD-specific education provided through higher education institutions such as nurse practitioner and physician assistant training and medical school residency.

Due to time constraints and competing specialties taught in formal residency, DBP is not a clinical priority for many higher education institutions in comparison to the listed core specialties, leading to gaps in provider skills and confidence in treating individuals with ASD. Required core rotations in medical school range from a minimum of 4 weeks (in most cases) to 12 weeks, depending on the specialty.<sup>117, 118</sup> By contrast, a DBP rotation was not mandated in medical school residency until 1997, when a one-month rotation was implemented.<sup>119</sup> Even then, the governing body of this rotation asserts that the actual implementation and compliance rates of this mandate are “unknown.”<sup>120</sup> As such, DBP requirements often vary widely per institution and can depend on a provider’s specialty.<sup>121</sup> As a result, the providers who received training in DBP still report autism as 1 of the top 3 conditions they feel least comfortable treating.<sup>122</sup> Other alumni remarked that DBP was not required per their institution’s requirements, and some

reported that DBP was not available as an elective specialty rotation either.<sup>123</sup> This lack of formal ASD-specific training through the form of DBP training is significant because healthcare providers, regardless of specialty, are likely to encounter patients with ASD in their respective fields. Therefore, when ASD-specific training is not regulated or provided, it places both patients with ASD as well as providers at a disadvantage because ASD-specific tools can promote successful visits with patients with ASD, regardless of the provider or clinic specialty.

As a result of this lack of training, providers across all healthcare-related departments (both specialty and non-specialty) have reported an inability to give adequate care for patients with autism, with providers citing a lack of formal training as a contributing factor to their inability to provide adequate care.<sup>124, 125</sup> For example, beyond the field of pediatrics, 66.7% of family medicine providers reported not previously receiving any ASD education.<sup>126</sup> Furthermore, when

questioned about treating patients with autism, only 13% of surveyed providers agreed that they had the tools and resources to accommodate ASD patients, leaving the vast majority of 87% of providers without the ability to provide quality care for the rest of the population.<sup>127</sup>



In lieu of formal training, providers report learning how to treat individuals with ASD on their own, through personal connections, or by occasionally attending presentations.<sup>128</sup> In addition, an overwhelming majority of providers requested ASD-specific conferences, as well as checklists of resources for patients and training on overall effective

strategies for providing care for patients with ASD.<sup>129</sup> This inconsistency and overall lack of training perpetuates gaps in providing quality care for this population.<sup>130 131</sup> Therefore, due to the current discrepancies in formal provider training, the complex needs of patients with autism are not comprehensively supported by the US healthcare system.

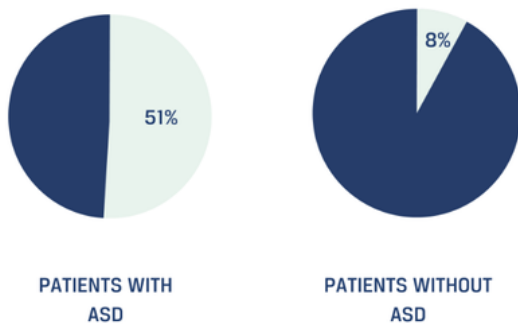
## *The Environment of Healthcare Facilities*

The environment of healthcare facilities in the United States leads to decreased access to healthcare for individuals with ASD because even if patients are able to access healthcare facilities and express their needs in some manner, sensory and environmental barriers within clinics themselves can prevent patients from feeling comfortable enough to stay in the waiting room and wait for their appointment or be able to retain information shared at the appointment. On a facility level, patients and family members of individuals with autism report that loud, bright, and otherwise overstimulating waiting



rooms, untrained staff members, long wait times, and rushed visits all negatively impacted their healthcare experience.<sup>132</sup> When asked about the waiting room experience, 51% of patients with autism reported it as a barrier, whereas only 8% of patients without ASD reported it as a barrier.<sup>133</sup>

**% of Patients Who Reported Waiting Room Environment Was a Barrier to Care (Sensory Related)**



Additionally, while 71% of patients without ASD reported no sensory-related healthcare concerns, only 10% of patients with ASD reported the same.<sup>134</sup> Regarding sensory concerns related to waiting room environments, there were notable discrepancies in responses from patients with ASD versus patients without ASD, with a

significantly higher percentage of patients with ASD reporting sensory issues as a barrier to care as compared to patients without ASD.<sup>135</sup> Due to the various sensory experiences that can contribute to hesitancy in seeking healthcare, when appropriate accommodations are not made, patients with ASD struggle to receive adequate healthcare specific to their needs.<sup>136</sup>

However, in spite of the prevalence of environmental issues, only 14% of surveyed providers reported high confidence in identifying environmental accommodation needs for patients with ASD, and 16% of surveyed providers reported high confidence in making identified accommodations.<sup>137</sup> Another study noted that 35% of both patients with ASD and caregivers of patients with ASD endorsed that sensory discomfort was a barrier to receiving care.<sup>138</sup> This lack of confidence among providers themselves and parents supporting children with autism contributes to the lack of adequate care among patients with autism, as sensory overload can prevent access to or decrease quality healthcare.

Processing sensory input can be a significant challenge for individuals with ASD, as it is estimated that between 75%–80% of children with ASD (or more, depending on how sensory processing is defined) have significant symptoms of Sensory Processing Disorder (SPD), a condition that is known to commonly affect individuals with ASD and results in the over or under processing of sensory information.<sup>139</sup> For those who under process sensory information, SPD can prompt drives such as a desire to touch, taste, or feel certain textures to reduce anxiety and other strong emotions. Due to the unique challenges present in an individual with ASD and sensory issues, a heightened ability to experience sensations, such as smell, sight, and sound, and a diminished ability to filter sensory stimuli, oftentimes, sensory experiences the individuals without ASD may consider ‘normal,’ can be overwhelming for those with ASD and in some cases can result in behavioral issues. This sensory overstimulation can manifest itself in self-injurious manners such as hitting, punching, or otherwise

harming oneself, running away, verbally lashing out, or acting physically aggressive toward others.<sup>140, 141</sup> These behaviors, especially in combination with communication barriers and a lack of adequate provider training, can quickly escalate into behaviors that are not compatible with an outpatient clinical setting and in some cases, can result in dismissal from care.<sup>142</sup>

## Consequences

### *Delayed and Missed Diagnosis*

#### **Delayed Diagnoses**

The first negative consequence of inadequate care for individuals with ASD is significant delays in diagnoses. When ASD diagnoses are delayed or missed overall, it significantly decreases access to ASD-support services such as intervention services and other supports that help improve the quality of life for individuals with ASD. Several studies have noted that parents of children with ASD generally perceive that

explanations of their child's diagnosis were inadequate.<sup>143</sup> Another study reported that 51% of surveyed parents were unsatisfied overall with their child's ASD diagnosis process.<sup>144</sup> Another barrier includes diagnostic clinic delays,<sup>145</sup> with some parents reporting a 6–9 month delay for an initial diagnostic assessment by a DBP.<sup>146</sup> As a result of these delays, many children are not diagnosed until an average of 4.4 years old, which one study reported is 2.2 years after initial ASD concerns were brought up to a provider by parents.<sup>147</sup> Some studies note diagnostic delays lasting into adolescence or even adulthood, when initial signs of ASD can be detected as early as 18 months, with some experts stating signs can begin to be noticed even earlier.<sup>148</sup> In addition to noted shortages of providers who specialize in diagnosing and treating ASD due to the COVID-19 pandemic, 58% of surveyed ASD assessment services reported a longer wait time than pre-pandemic times.<sup>149</sup> Delayed ASD diagnoses have been linked to a reduced quality of life for individuals with ASD due to a lack of

self-understanding and a delay in ASD-related social and emotional resources.<sup>150</sup> These barriers in distance and assessment delays contribute to delayed diagnoses which can interfere with the timeline of treatment; recommended to begin in early childhood for maximum benefit.<sup>151</sup>

### **Missed Diagnoses**

In addition to delayed diagnoses are diagnoses that are missed altogether due to a variety of factors within the assessment and diagnostic process.<sup>152</sup> One study with data from 11 states in the US reported that 25% of observed children who had ASD character traits did not have an ASD diagnosis by age 8.<sup>153</sup> However, a significant gap in US-based research is data on estimated figures of individuals who never receive an ASD diagnosis in their lifetime. When these diagnoses are delayed or missed altogether, it significantly impacts an individual's ability to receive early intervention ASD services, which have been proven to have substantial, long-term, positive effects on life skills and symptom

management for individuals with ASD.<sup>154</sup>

## ***Worsened Health Outcomes***

*In this section, worsened health outcomes are measured via hospitalization rates, as admission criteria are reviewed by multiple providers prior to admission and can be a measurement that is more indicative of significant illness.*



Although it has been established that individuals with ASD experience a higher rate of comorbidities than individuals without ASD,<sup>155, 156</sup> their lack of access to adequate healthcare exacerbates comorbid conditions, and their physical health suffers. Interestingly, many of these comorbid conditions can typically be managed in an outpatient setting, but due to a lack

of access to adequate healthcare (for example, trained providers, sensory-friendly environments, and so on), these conditions often worsen, resulting in increased rates of hospital admissions.<sup>157</sup> One study even suggests that commonly associated “co-occurring conditions” with ASD may be less related to actual comorbidity due to genetic links to ASD and more to do with access disparities and inadequate healthcare services for patients with ASD, meaning, with improved access to adequate healthcare, some of these “co-occurring conditions” may decrease in prevalence.<sup>158</sup>

Regardless of the actual origin of comorbid or co-occurring conditions with ASD, it is well established that inpatient hospitalization rates are significantly higher among patients with ASD than their non-ASD counterparts.<sup>159, 160</sup> When comparing these hospitalization rates, patients with ASD were 3.7 times more likely to be hospitalized than their non-ASD counterparts.<sup>161</sup> Another study found that the percentage of non-mental

health-related hospitalizations among youth with ASD was 55.9%, whereas hospitalization rates for youth without ASD were 22.9%.<sup>162</sup>

While there are various conditions that can lead to hospitalization, multiple studies confirm that a lack of adequate preventative care is a significant causal agent of these hospitalizations and is also a significant contributing factor in morbidity and premature mortality rates in individuals with ASD.<sup>163</sup>

### ***Societal Burden***

When individuals with ASD are unable to receive adequate healthcare, it often results in increased societal spending. In a study that calculated the lifetime societal cost of care for individuals with ASD, it was estimated that between 1990–2020, care costs exceeded \$7 trillion—which is the equivalent of approximately 2 years of total federal revenue for the United States.<sup>164</sup> If these cost-of-care trends continue, one source estimates that by 2029, the societal cost of caring for individuals with ASD will increase to

\$11.5 trillion.<sup>165</sup> If prevalence continues to increase at the past rate, the cost will grow to nearly \$15 trillion.<sup>166</sup> This projected increase in spending may be a combination of increased future prevalence of ASD, inadequate care itself, and other factors. Specific healthcare-related costs included in this estimate are costs for inpatient and outpatient care, hospitalizations, emergency medicine, physician visits, and pharmacy costs.<sup>167</sup> However, significant gaps in access to care and quality of care continue to persist and will continue to exacerbate overall costs for society directly through healthcare costs, costs of informal care, accommodation costs, special education costs, and indirectly through productivity loss of caregivers of individuals with ASD and respite services for individuals with ASD.<sup>168</sup>

## **Practices**

### ***The Medical HOME Model of Healthcare***

## Impact

In the medical HOME model, HOME stands for "Healthy Outcomes Medical Excellence" and is a best practice model of healthcare delivery with a goal to provide care that is accessible, continuous over time,<sup>169</sup> comprehensive, family-centered, coordinated with parents and providers,<sup>170</sup> compassionate and culturally effective for its patients.<sup>171</sup>

One common application of this medical HOME model has been for patients with developmental disabilities and, more specifically, children and youth with special healthcare needs (CYSHCN).<sup>172,</sup>  
173

An example of a clinic that has adopted the medical HOME model of healthcare is the Neurobehavior HOME Program in Salt Lake City, Utah, which, utilizing practices of the medical HOME model, currently treats over 1,200 patients with developmental disabilities (including autism) throughout their lifespan.<sup>174, 175</sup> What is unique about this clinic is that they provide medical care such as annual physical exams, well-

child checks, preventive care, and primary care for a wide range of conditions for individuals with developmental disabilities (such as ASD) that often struggle to receive this care in other settings due to sensory sensitivities and lack of provider training.<sup>176</sup> However, to ensure that patients with ASD receive comprehensive care, the Neurobehavior HOME program also partners with an Autism Spectrum Disorder clinic that focuses on diagnoses, early intervention services, family support, and therapy services.<sup>177</sup> The Neurobehavior Home Program also provides specific resources, such as a twenty-four-seven crisis hotline,<sup>178</sup> information on different types of therapy to help patients with ASD, national ASD organization information, disability-friendly fitness organizations, and toolkits to help families and providers navigate common social and medical ASD-related challenges.<sup>179</sup>

## Gaps

While the Medical HOME model has been associated with increased patient-

provider satisfaction, improved quality of care and preventive care, and decreased incidence of chronic disease, only 25% of children with ASD are patients in a medical HOME.<sup>180</sup>

Additionally, within HOME programs that care for patients with disabilities, patients with ASD are less likely to receive care in a medical HOME compared to other CYSHCN,<sup>181</sup> and when they do receive care, providers in general report feeling less comfortable caring for patients with ASD than other CYSHCN.<sup>182</sup> Other gaps with this model are a lack of consistency in practice implementation, a lack of specialists to work in these settings, and contracts that restrict a patient's ability to see a pediatrician or primary care provider outside of the medical HOME setting.

### ***Increased Provider Training***

#### **Impact**

Additional best practices in improving healthcare for patients with ASD is increasing provider training<sup>183</sup> through increased exposure to patients with ASD in residency programs,<sup>184</sup> offering training for all medical staff levels on

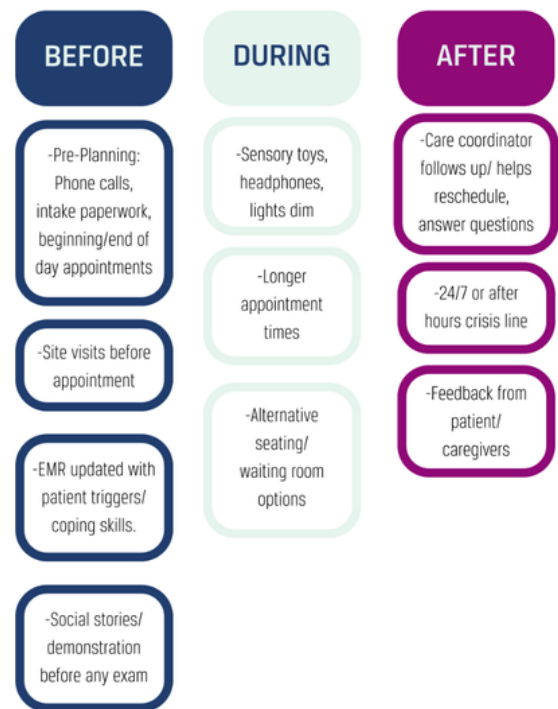
ASD<sup>185</sup> through HR platforms, and providing tips on best practice for ASD care on platforms such as “up-to-date,” a frequently referenced guide of current best practices for providers on a variety of conditions.<sup>186, 187</sup> Several surveyed providers noted that compliance with these practices could increase by incentivizing providers and practices to accept patients with ASD<sup>188</sup> and by compensating providers for their additional time in planning, preparing, and coordinating with other providers regarding care for patients with ASD.<sup>189</sup>

One specific curriculum, known as the Autism Case Training curriculum (ACT), was developed by the CDC and the Maternal Child Health Bureau. The curriculum's purpose is to educate medical providers to better understand, diagnose, and treat ASD through real-life scenarios. The training is composed of 7 modules (each approximately an hour in length), which discuss early warning signs of ASD, communication strategies, treatment options, proper diagnosis, and other topics.<sup>190</sup> The ACT also provides teaching tools, videos, questions and prompts, and relevant

handouts. Although the training has not been enforced nationwide, several studies have examined the curriculum’s effectiveness. For instance, one study had approximately 190 medical students and pediatric residents across various institutions participate in one of the ACT modules.<sup>191</sup> Participants reported an average 16.7% increase in knowledge of ASD and associated practices, and 94% of participants rated the experience as a “useful” or “very useful” addition to their medical training. In addition, 80% stated they would be interested in attending additional ASD training sessions.<sup>192</sup> Finally, according to another study, more than 75% of surveyed primary care providers of all experience levels endorsed that using a social story, having additional information about the patient prior to the appointment, and receiving a list of patient-specific needs was “moderately to extremely important” in providing positive healthcare experiences for adult patients with ASD.<sup>193</sup> This data illustrates the significance of providing additional training for providers so they

can take this training into their practices and improve quality care for patients with ASD in their care.<sup>194</sup>

### Healthcare Visits (Provider Tips)



### Gaps

One of the largest gaps in increasing provider training on ASD is overall provider incentive and compliance with receiving additional training. As the ACT curriculum demonstrates, providers must opt-in to additional training on their own, or a medical institution must



agree to utilize these ASD-specific modules. As such, it is unclear how sustainable these trainings can become unless rigorously assimilated into existing medical training. Finally, while the ACT curriculum is free, medical institutions may need to pay additional costs for effective, standardized training

for interested residents. These and other questions continue to limit the possibility of increased provider training in the US.

# Endnotes

1. “Diagnostic Criteria,” *CDC*, accessed October 7, 2022, <https://www.cdc.gov/ncbddd/autism/hcp-dsm.html>.
2. “Comorbidity: Causes and Health Implications,” *Healthline*, accessed October 7, 2022, <https://www.healthline.com/health/comorbidity>.
3. “Autism’s Clinical Companions: Frequent Comorbidities with ASD,” *Children’s Hospital of Philadelphia*, accessed October 7, 2022, <https://www.chop.edu/news/autism-s-clinical-companions-frequent-comorbidities-asd>.
4. Mohammed Al-Beltagi, “Autism Medical Comorbidities,” *World Journal of Clinical Pediatrics* 10, no. 3 (2021): 15–28, <https://doi.org/10.5409/wjcp.v10.i3.15>.
5. “Developmental Behavioral Pediatrics,” *AAMC*, accessed October 12, 2022, <https://www.aamc.org/cim/explore-options/specialty-profiles/developmental-and-behavioral-pediatrics>.
6. “Neurotypical,” *Merriam-Webster Dictionary*, accessed October 12, 2022, <https://www.merriam-webster.com/dictionary/neurotypical>.
7. *Ibid.*
8. “What is Autism?” *Autism Speaks*, accessed October 12, 2022, <https://www.autismspeaks.org/what-autism>.
9. Jewel E. Crasta et al., “Sensory Processing and Attention Profiles Among Children With Sensory Processing Disorders and Autism Spectrum Disorders,” *Frontiers in Integrative Neuroscience* 14, no. 22 (May 2020): 1, <https://doi.org/10.3389/fnint.2020.00022>.
10. “Autism and Developmental Disabilities Monitoring (ADDM) Network,” *CDC*, accessed October 12, 2022, <https://www.cdc.gov/ncbddd/autism/addm.html#:~:text=CDC%20estimates%20that%20about%201,the%20United%20States%20during%202018>.
11. “Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018,” *CDC*, accessed October 12, 2022, <https://www.cdc.gov/mmwr/volumes/70/ss/ss7011a1.htm>.
12. “Autism Prevalence is Now 1 in 44, Signifying the Eighth Increase in Prevalence Rates Reported by the CDC Since 2000,” *PR Newswire*, Cision US, accessed October 12, 2022, <https://www.prnewswire.com/news-releases/autism-prevalence-is-now-1-in-44-signifying-the-eighth-increase-in-prevalence-rates-reported-by-the-cdc-since-2000-301436766.html>.
13. “Autism Spectrum Disorders—Symptoms and Causes,” *Mayo Clinic*, accessed October 12, 2022, <https://www.mayoclinic.org/diseases-conditions/autism-spectrum-disorder/symptoms-causes/syc-20352928>.
14. Andre A. S. Goldani et al., “Biomarkers in Autism,” *Front Psychiatry* 5, no. 14 (August 2014), <https://doi.org/10.3389/fpsy.2014.00100>.
15. “The Early History of Autism,” *Smithsonian Magazine*, January 2016, <https://www.smithsonianmag.com/science-nature/early-history-autism-america-180957684/>.
16. “Screening and Diagnosis of Autism Spectrum Disorder,” *CDC*, accessed October 12, 2022, <https://www.cdc.gov/ncbddd/autism/screening.html#:~:text=Diagnosing%20autism%20spectrum%20disorder%20>.
17. *Ibid.*
18. Laura Carpenter, “DSM-5 Autism Spectrum Disorder,” *University of Washington*, February 2013, [https://depts.washington.edu/dbpeds/Screening%20Tools/DSM-5\(ASD.Guidelines\)Feb2013.pdf](https://depts.washington.edu/dbpeds/Screening%20Tools/DSM-5(ASD.Guidelines)Feb2013.pdf).
19. “What Are the Symptoms of Autism,” *Autism Speaks*, accessed October 12, 2022, <https://www.autismspeaks.org/what-are-symptoms-autism>.
20. “Attention Deficit Hyperactivity Disorder, Autism Spectrum Disorder, and Learning Disabilities (Pediatric),” *Columbia Doctors*, accessed October 12, 2022, <https://www.columbiadoctors.org/treatments-conditions/attention-deficit-hyperactivity-disorder-autism-spectrum-disorder-and-learning-disabilities-pediatric>.
21. “Diagnostic Criteria for 299.00 Autism Spectrum Disorder,” *CDC*, accessed October 12, 2022, <https://www.cdc.gov/ncbddd/autism/hcp-dsm.html>.
22. Jan M. Downey and Mary E. McDonald, “Catatonia in Autism Spectrum Disorder,” *Association for Science in Autism Treatment* 16, no. 3 (2019), <https://asonline.org/research-treatment/clinical-corner/catatonia/>.
23. “Signs and Symptoms of Autism Spectrum Disorder,” *CDC*, accessed October 12, 2022, <https://www.cdc.gov/ncbddd/autism/signs.html#:~:text=People%20with%20ASD%20often%20have,have%20some%20of%20these%20symptoms>.
24. “What is Autism Spectrum Disorder?” *Stanford Children’s Hospital*, accessed October 12, 2022, <https://www.stanfordchildrens.org/en/topic/default?id=what-is-autism-spectrum-disorder-160-23#:~:text=Unusual%20speech,or%20movie%20theaters%2C%20for%20example>.
25. “Autism Spectrum Disorder,” *National Institute of Mental Health*, accessed October 12, 2022, <https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd>.
26. “What is Autism?” *Autism Speaks*, accessed October 12, 2022, <https://www.autismspeaks.org/what-autism>.
27. “Autism Spectrum Disorder,” *Mayo Clinic*, accessed October 12, 2022, <https://www.mayoclinic.org/diseases-conditions/autism-spectrum-disorder/symptoms-causes/syc-20352928#:~:text=The%20disorder%20also%20includes%20limited,range%20of%20symptoms%20and%20severity>.
28. *Ibid.*
29. “Treatment and Intervention Services for Autism Spectrum Disorder,” *CDC*, accessed October 12, 2022, <https://www.cdc.gov/ncbddd/autism/treatment.html#:~:text=Developmental%20approaches%20are%20often%20combined,people%20with%20ASD%20communicate%20verbally>.
30. “Autism Spectrum Disorder,” *Mayo Clinic*, accessed October 12, 2022, <https://www.mayoclinic.org/diseases-conditions/autism-spectrum-disorder/diagnosis-treatment/drc-20352934>.
31. Norah L. Johnson et al., “Translating Research to Practice for Children With Autism Spectrum Disorder: Part I: Definition, Associated Behaviors, Prevalence, Diagnostic Process, and Interventions,” *Journal of Pediatric Health Care* 30, no. 1 (2016): 15–26, <https://doi.org/10.1016/j.pedhc.2015.09.008>.
32. Karen Prillinger et al., “Repeated Sessions of Transcranial Direct Current Stimulation on Adolescents With Autism Spectrum Disorder: Study Protocol for a Randomized, Double-Blind, and Sham-Controlled Clinical Trial,” *Frontiers in Psychiatry* 12, no. 680525 (August 2021), <https://doi.org/10.3389/fpsy.2021.680525>.
33. “Understanding Quality Measurement,” *Agency for Healthcare Research and Quality*, accessed October 12, 2022, <https://www.ahrq.gov/patient-safety/quality-resources/tools/ctoolbx/understand/index.html>.

34. Laura Hull and William Mandy, "Camouflaging Autistic Traits Questionnaire (CAT-Q)," *Encyclopedia of Autism Spectrum Disorders*, Springer, January 2021, [https://doi.org/10.1007/978-3-319-91280-6\\_102327](https://doi.org/10.1007/978-3-319-91280-6_102327).
35. "Understanding Quality Measurement," Agency for Healthcare Research and Quality.
36. Ibid.
37. Shilpa N. Gajarawala and Jessica N. Pelkowski, "Telehealth Benefits and Barriers," *The Journal for Nurse Practitioners* 17, no. 2 (February 2021): 218–221, <https://doi.org/10.1016/j.nurpra.2020.09.013>.
38. "Spotlight On: Racial and Ethnic Differences in Children Identified with Autism Spectrum Disorder (ASD)," CDC, accessed October 12, 2022, <https://www.cdc.gov/ncbddd/autism/addm-community-report/differences-in-children.html>.
39. Giuseppina Chiri and Marji Erickson Warfield, "Unmet Need and Problems Accessing Core Health Care Services for Children with Autism Spectrum Disorder," *Maternal and Child Health Journal* 16, no. 5 (2011): 1081–91, <https://doi.org/10.1007/s10995-011-0833-6>.
40. "Spotlight On: Racial and Ethnic Differences in Children Identified with Autism Spectrum Disorder (ASD)," CDC.
41. Brandon S. Aylward, Diana E. Gal-Szabo, and Sharief Taraman, "Racial, Ethnic, and Sociodemographic Disparities in Diagnosis of Children with Autism Spectrum Disorder," *Journal of Developmental and Behavioral Pediatrics* 42, no. 8 (2021): 682–689, <https://doi.org/10.1097/DBP.0000000000000996>.
42. "Identification, Evaluation, and Management of Children With Autism Spectrum Disorder," *American Academy of Pediatrics* 145, no. 1 (January 2020), <https://doi.org/10.1542/peds.2019-3447>.
43. Amber M. Angell, Allison Empey, and Katherine E. Zuckerman, "Chapter Four - A Review of Diagnosis and Service Disparities Among Children With Autism From Racial and Ethnic Minority Groups in the United States," *International Review of Research in Developmental Disabilities* 55 (2018): 145–180, <https://doi.org/10.1016/bs.iridd.2018.08.003>.
44. Brandon S. Aylward, Diana E. Gal-Szabo, and Sharief Taraman, "Racial, Ethnic, and Sociodemographic Disparities in Diagnosis of Children with Autism Spectrum Disorder."
45. Jeffrey F. Hine et al., "Enhancing Developmental-Behavioral Pediatric Rotations by Teaching Residents How to Evaluate Autism in Primary Care," *Autism* 25, no. 5 (2021): 1492–1496, <https://doi.org/10.1177/1362361320984313>.
46. "Rates of Parent-Centered Developmental Screening: Disparities and Links to Services Access," *American Academy of Pediatrics* 128, no. 1 (2011): 146–155, <https://doi.org/10.1542/peds.2010-0424>.
47. "Data & Statistics on Autism Spectrum Disorder," CDC, accessed October 12, 2022, <https://www.cdc.gov/ncbddd/autism/data.html>.
48. Meng-Chuan Lai et al., "Sex/Gender Differences and Autism: Setting the Scene for Future Research," *Journal of the American Academy of Child and Adolescent Psychiatry* 54, no. 1 (January 2015): 11–24, <https://doi.org/10.1016/j.jaac.2014.10.003>.
49. Ibid.
50. Camilla Gesi et al., "Gender Differences in Misdiagnosis and Delayed Diagnosis among Adults with Autism Spectrum Disorder with No Language or Intellectual Disability," *Brain Sciences* 11, no. 7 (2021): 912, <https://doi.org/10.3390/brainsci11070912>.
51. Laura Hull et al., "Gender Differences in Self-Reported Camouflaging in Autistic and Non-Autistic Adults," *Autism* 24, no. 2 (February 2020): 352–363, <https://doi.org/10.1177/1362361319864804>.
52. Julie N. Youssef, Dana C. Won, and Heidi M. Feldman, "Primary Care Physicians/Subspecialty Pediatricians," in *Handbook of Interdisciplinary Treatments for Autism Spectrum Disorder* (Cham: Springer, 2019), [https://doi-org.erl.lib.byu.edu/10.1007/978-3-030-13027-5\\_12](https://doi-org.erl.lib.byu.edu/10.1007/978-3-030-13027-5_12).
53. "Autism Spectrum Disorder," *Mayo Clinic*, accessed October 29, 2022, <https://www.mayoclinic.org/diseases-conditions/autism-spectrum-disorder/diagnosis-treatment/drc-20352934#:~:text=If%20your%20child%20shows%20any,developmental%20pediatrician%2C%20for%20an%20evaluation>.
54. "Complex Gastrointestinal Issues in Autism," *TACA*, accessed October 29, 2022, <https://tacanow.org/family-resources/complex-gi-issues-in-autism/>.
55. "Developmental and Behavioral," *Council of Pediatric Subspecialties*, accessed October 29, 2022, <https://www.pedsubs.org/about-cops/subspecialty-descriptions/developmental-and-behavioral/#:~:text=To%20become%20a%20Developmental%2DBehavioral%20pediatrician%2C%20you%20must%20complete%20a,NRMP%20Pediatric%20Specialties%20Fall%20match>.
56. "Pediatric Development and Behavior Care," *University Children's Health*, accessed October 29, 2022, <https://www.universityhealthsystem.com/pediatrics/services/developmental-disorders>.
57. Ibid.
58. "29–1221 Pediatricians, General," *US Bureau of Labor Statistics*, accessed October 29, 2022, <https://www.bls.gov/oes/current/oes291221.htm>.
59. Amy Kelly, "Addressing a National Shortage of Autism Specialists," *Autism Spectrum News*, April 14, 2022, <https://autismspectrumnews.org/addressing-a-national-shortage-of-autism-specialists/>.
60. Ibid.
61. Elizabeth Sinclair, "History of Autism Treatment," *Applied Behavior Analysis Programs Guide*, accessed October 29, 2022, <https://www.appliedbehavioranalysisprograms.com/history-autism-treatment/>.
62. Eman Ahmed Zaky, "Autism Spectrum Disorder (ASD); The Past, The Present, and The Future," *Journal of Child and Adolescent Behavior* 5 (2017): e116, <https://doi.org/10.4172/2375-4494.1000e116>.
63. Elizabeth Sinclair, "History of Autism Treatment."
64. Ibid.
65. Lina Zeldovich, "Autism Diagnosis—The Evolution of Autism as a Diagnosis," *Spectrum News*, May 9, 2018, <https://www.spectrumnews.org/news/evolution-autism-diagnosis-explained/#:~:text=The%20DSM%2DIII%2C%20published%20in,developmental%20disorder%E2%80%9D%20distinct%20from%20schizophrenia>.
66. Nicole E. Rosen, Catherine Lord, and Fred R. Volkmar, "The Diagnosis of Autism: From Kanner to DSM-III to DSM-5 and Beyond," *Journal of Autism and Developmental Disorders* 51 (2020): 4253–4270, <https://doi.org/10.1007/s10803-021-04904-1>.
67. "History of Autism: When Was Autism First Diagnosed?" *Otismo*, July 5, 2021, <https://otsimo.com/en/history-of-autism-when-was-autism-first-diagnosed/#:~:text=Autism%20was%20first%20officially%20identified,Asperger's%20syndrome%20to%20the%20diagnosis>.
68. Jessica Wright, "The Real Reasons Autism Rates Are Up in the US," *Scientific American*, March 3, 2017, <https://www.scientificamerican.com/article/the-real-reasons-autism-rates-are-up-in-the-us/#:~:text=Autism%20didn't%20make%20its,6%20of%20the%20previous%20items>.
69. Lina Zeldovich, "Autism Diagnosis—The Evolution of Autism as a Diagnosis."
70. "Treatment and Intervention Services for Autism Spectrum Disorder," CDC.
71. Elizabeth Sinclair, "History of Autism Treatment."
72. Eman Ahmed Zaky, "Autism Spectrum Disorder (ASD); The Past, The Present, and The Future."

73. Gary Shkedy, Dalia Shkedy, and Aileen H. Sandoval-Norton, “Long-term ABA Therapy is Abusive: A Response to Gorycki, Ruppel, and Zane,” *Advances in Neurodevelopment Disorders* 5 (2021): 126–134, <https://doi.org/10.1007/s41252-021-00201-1>.
74. Michael Ning et al., “Identification and Quantification of Gaps in Access to Autism Resources in the United States: An Infodemiological Study,” *Journal of Medical Internet Research* 21, no. 7 (2019): e13094, <https://doi.org/10.2196/13094>.
75. Ligia Antezana et al., “Rural Trends in Diagnosis and Services for Autism Spectrum Disorder,” *Frontiers in Psychology* 20, no. 8 (2017): 590, <https://doi.org/10.3389/fpsyg.2017.00590>.
76. Marlene B. Lauritsen et al., “Urbanicity and Autism Spectrum Disorders,” *Journal of Autism and Developmental Disorders* 44, no. 2 (2014): 394–404, <https://doi.org/10.1007%2Fs10803-013-1875-y>.
77. J. G. Williams, J. P. T. Higgins, and C. E. G. Brayne, “Systematic Review of Prevalence Studies of Autism Spectrum Disorders,” *Archives of Disease in Childhood* 91, no. 1 (2006): 8–15, <https://doi.org/10.1136/adc.2004.062083>.
78. Michael Ning et al., “Identification and Quantification of Gaps in Access to Autism Resources in the United States: An Infodemiological Study.”
79. Ligia Antezana et al., “Rural Trends in Diagnosis and Services for Autism Spectrum Disorder.”
80. Ibid.
81. Ibid.
82. “AAMC Report Reinforces Mounting Physician Shortage,” *AAMC*, June 11, 2021, <https://www.aamc.org/news-insights/press-releases/aamc-report-reinforces-mounting-physician-shortage>.
83. Ibid.
84. Jack Kelly, “New Survey Shows That Up To 47% Of US Healthcare Workers Plan To Leave Their Positions By 2025,” *Forbes*, April 19, 2022, <https://www.forbes.com/sites/jackkelly/2022/04/19/new-survey-shows-that-up-to-47-of-us-healthcare-workers-plan-to-leave-their-positions-by-2025/?sh=47ab50f0395b>.
85. Debbie Spain et al., “Autism Diagnostic Assessments with Children, Adolescents, and Adults Prior to and during the COVID-19 Pandemic: A Cross-Sectional Survey of Professionals,” *Frontiers in Psychiatry* 13 (2022), <https://doi.org/10.3389/fpsyg.2022.789449>.
86. Natasha Malik-Soni et al., “Tackling Healthcare Access Barriers for Individuals with Autism from Diagnosis to Adulthood,” *Pediatric Research* 91 (2022): 1028–1035, <https://doi.org/10.1038/s41390-021-01465-y>.
87. “Pediatric Workforce Shortages Persist,” *Children’s Hospital Association*, accessed October 29, 2022, [https://glin.com/files/documents/bulletin\\_board/chgme\\_workforce\\_shortage\\_fact\\_sheet.pdf](https://glin.com/files/documents/bulletin_board/chgme_workforce_shortage_fact_sheet.pdf).
88. Terisa P. Gabrielsen et al., “Identifying Autism in a Brief Observation,” *Pediatrics* 135, no. 2 (2015): e330–e338, <https://doi.org/10.1542/peds.2014-1428>.
89. “Pediatric Workforce Shortages Persist,” *Children’s Hospital Association*.
90. Natasha Malik-Soni et al., “Tackling Healthcare Access Barriers for Individuals with Autism from Diagnosis to Adulthood.”
91. “Treatment and Intervention Services for Autism Spectrum Disorder,” CDC.
92. Joanne Smith-Young, Roger Chafe, and Rick Audas, “‘Managing the Wait’: Parents’ Experiences in Accessing Diagnostic and Treatment Services for Children and Adolescents Diagnosed With Autism Spectrum Disorder,” *Health Services Insights* 13 (2020), <https://doi.org/10.1177/1178632920902141>.
93. Cecilia Feeley et al., *Detour to the Right Place: A Study with Recommendations for Addressing the Transportation Needs and Barriers of Adults on the Autism Spectrum in New Jersey* (New Jersey: Rutgers, September 2015), [https://vtc.rutgers.edu/wp-content/uploads/2015/10/Detour\\_to\\_the\\_Right\\_Place\\_Technical\\_Report\\_2015.pdf](https://vtc.rutgers.edu/wp-content/uploads/2015/10/Detour_to_the_Right_Place_Technical_Report_2015.pdf).
94. Ibid.
95. Ibid.
96. Ibid.
97. Derserri Yan-Ting Chee et al., “Viewpoints on Driving of Individuals with and without Autism Spectrum Disorder,” *Developmental Neurorehabilitation* 18, no. 1 (2015): 26–36, <https://doi.org/10.3109/17518423.2014.964377>.
98. Marvellous Akinlotan et al., *Rural-Urban Variations in Travel Burdens for Care: Findings from the 2017 National Household Travel Survey* (Texas: Southwest Rural Health Research Center, July 2021), <https://srhrc.tamhsc.edu/docs/travel-burdens-07.2021.pdf>.
99. Ibid.
100. Michael Ning et al., “Identification and Quantification of Gaps in Access to Autism Resources in the United States: An Infodemiological Study.”
101. Lawrence C. Pellegrini and Kimberley H. Geissler, “Disability, Federal Disability Benefits, and Health Care Access After the Affordable Care Act,” *Journal of Disability Policy Studies* 31, no. 4 (March 2021): 244–254, <https://doi.org/10.1177/1044207320919959>.
102. V. Rose et al., “The Proportion of Minimally Verbal Children with Autism Spectrum Disorder in a Community-based Early Intervention Programme,” *Journal of Intellectual Disability Research* 60, no. 5 (2016): 464–477, <https://doi.org/10.1111/jir.12284>.
103. “Autism Statistics and Facts,” *Autism Speaks*, accessed October 30, 2022, <https://www.autismspeaks.org/autism-statistics-asd#:~:text=Associated%20Challenges,people%20with%20autism%20are%20nonverbal>.
104. Lisa Jo Rudy, “What is Nonverbal Autism?” *VeryWell Health*, accessed October 30, 2022, <https://www.verywellhealth.com/what-is-nonverbal-autism-260032>.
105. V. Rose et al., “The Proportion of Minimally Verbal Children with Autism Spectrum Disorder in a Community-based Early Intervention Programme.”
106. Nancy C. Brady et al., “Predicting Progress in Word Learning for Children with Autism and Minimal Verbal Skills,” *Journal of Neurodevelopmental Disorders* 13, no. 36 (2021), <https://doi.org/10.1186/s11689-021-09386-x>.
107. Ibid.
108. “7 Autism Behavior and Communication Strategies,” *National University*, accessed October 30, 2022, <https://www.nu.edu/resources/7-autism-behavior-and-communication-strategies/>.
109. Christina Nicolaidis et al., “Comparison of Healthcare Experiences in Autistic and Non-Autistic Adults: A Cross-Sectional Online Survey Facilitated by an Academic-Community Partnership,” *Journal of General Internal Medicine* 28 (2013): 761–769, <https://doi.org/10.1007/s11606-012-2262-7>.
110. C. Walsh et al., “Development and Evaluation of a Novel Caregiver-report Tool to Assess Barriers to Physical Healthcare for People on the Autism Spectrum,” *Research in Autism Spectrum Disorders* 79 (November 2020): 101680, <https://doi.org/10.1016/j.rasd.2020.101680>.
111. Marji Erickson Warfield et al., “Physician Perspectives on Providing Primary Medical Care to Adults with Autism Spectrum Disorders (ASD),” *Journal of Autism and Developmental Disorders* 45, no. 7 (2015): 2209–2217, <https://doi.org/10.1007/s10803-015-2386-9>.

112. Vanessa Vogan et al., "Tracking Health Care Service Use and the Experiences of Adults with Autism Spectrum Disorder without Intellectual Disability: A Longitudinal Study of Service Rates, Barriers and Satisfaction," *Disability and Health Journal* 10, no. 2 (2017): 264–270, <https://doi.org/10.1016/j.dhjo.2016.11.002>.
113. Norah L. Johnson et al., "Translating Research to Practice for Children With Autism Spectrum Disorder: Part I: Definition, Associated Behaviors, Prevalence, Diagnostic Process, and Interventions," *Journal of Pediatric Health Care* 30, no. 1 (2016): 15–26, <https://doi.org/10.1016/j.pedhc.2015.09.008>.
114. Ibid.
115. Christina Nicolaidis et al., "Comparison of Healthcare Experiences in Autistic and Non-Autistic Adults: A Cross-Sectional Online Survey Facilitated by an Academic-Community Partnership."
116. Marji Erickson Warfield et al., "Physician Perspectives on Providing Primary Medical Care to Adults with Autism Spectrum Disorders (ASD)."
117. Brendan Murphy, "The Science of Scheduling: When to do Key Medical School Rotations," *American Medical Association*, December 17, 2019, <https://www.ama-assn.org/residents-students/medical-school-life/science-scheduling-when-do-key-medical-school-rotations#:~:text=Lasting%20between%20four%20and%20eight,them%20as%20they%20see%20fit>.
118. "Planning for Rotations," *American Osteopathic Association*, accessed October 30, 2022, <https://osteopathic.org/students/rotations/planning-for-rotations/>.
119. Nili E. Major, "Autism Education in Residency Training Programs," *AMA Journal of Ethics*, accessed October 30, 2022, <https://journalofethics.ama-assn.org/article/autism-education-residency-training-programs/2015-04>.
120. Ibid.
121. Ibid.
122. Craig D. Boreman et al., "Resident Training in Developmental/Behavioral Pediatrics: Where Do We Stand?" *Clinical Pediatrics* 46, no. 2 (March 2007): 135–145, <https://doi.org/10.1177/0009922806290456>.
123. Ibid.
124. David Mason et al., "A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults," *Journal of Autism and Developmental Disorders* 49 (2019): 3387–3400, <https://doi.org/10.1007/s10803-019-04049-2>.
125. Marji Erickson Warfield et al., "Physician Perspectives on Providing Primary Medical Care to Adults with Autism Spectrum Disorders (ASD)."
126. Mengühan Araz Altay, "Family Physicians' Awareness of Autism Spectrum Disorder: Results from a Survey Study," *Open Access Macedonian Journal of Medical Sciences* 7, no. 6 (2019): 967–972, <https://doi.org/10.3889/oamjms.2019.199>.
127. Ousseny Zerbo et al., "A Study of Physician Knowledge and Experience with Autism in Adults in a Large Integrated Healthcare System," *Journal of Autism and Developmental Disorders* 45, no. 12 (2015): 4002–4014, <https://doi.org/10.1007/s10803-015-2579-2>.
128. Ibid.
129. Ibid.
130. Ibid.
131. Natasha Malik-Soni et al., "Tackling Healthcare Access Barriers for Individuals with Autism from Diagnosis to Adulthood."
132. Youssra Saqr et al., "Addressing Medical Needs of Adolescents and Adults with Autism Spectrum Disorders in a Primary Care Setting," *Autism* 22, no. 1 (2017): 51–61, <https://doi.org/10.1177/1362361317709970>.
133. Mary Doherty et al., "Barriers to Healthcare and Self-reported Adverse Outcomes for Autistic Adults: a Cross-sectional Study," *BMJ* 12 (2020): e056904, <https://doi.org/10.1101/2020.04.01.20050336>.
134. Ibid.
135. Ibid.
136. Leah I. Stein Duker et al., "Examining Primary Care Health Encounters for Adults With Autism Spectrum Disorder," *The American Journal of Occupational Therapy* 73, no. 5 (2019): 7305185030p1–7305185030p11, <https://doi.org/10.5014/ajot.2019.037226>.
137. Christina Nicolaidis et al., "Development and Psychometric Testing of the AASPIRE Adult Autism Healthcare Provider Self-Efficacy Scale," *Autism* 25, no. 3 (April 2021): 767–773, <https://doi.org/10.1177/1362361320949734>.
138. Leah I. Stein Duker et al., "Examining Primary Care Health Encounters for Adults With Autism Spectrum Disorder."
139. Eric P. Hazen et al., "Sensory Symptoms in Autism Spectrum Disorders," *Harvard Review of Psychiatry* 22, no. 2 (2014): 112–124, <https://doi.org/10.1097/01.HRP.0000445143.08773.58>.
140. Lisa Jo Rudy, "What is Nonverbal Autism?"
141. Frank von den Boogert et al., "Sensory Processing and Aggressive Behavior in Adults with Autism Spectrum Disorder," *Brain Sciences* 11, no. 1 (2021): 95, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7828723/>.
142. Jolie Strauss et al., "Medical Encounters for Youth With Autism Spectrum Disorder: A Comprehensive Review of Environmental Considerations and Interventions," *Clinical Medical Insights: Pediatrics* 13 (2019): 1179556519842816, <https://doi.org/10.1177/1179556519842816>.
143. Amber Makino et al., "Parent Experiences of Autism Spectrum Disorder Diagnosis: a Scoping Review," *Review Journal of Autism and Developmental Disorders* 8 (2021): 267–284, <https://doi.org/10.1007/s40489-021-00237-y>.
144. Susan Siklos and Kimberly Kerns, "Assessing the Diagnostic Experiences of a Small Sample of Parents of Children with ASD," *Research in Developmental Disabilities* 28, no. 1 (2007): 9–22, <https://doi.org/10.1016/j.ridd.2005.09.003>.
145. Ibid.
146. Amy Kelly, "Addressing a National Shortage of Autism Specialists."
147. Katharine Zuckerman et al., "Timeliness of Autism Spectrum Disorder Diagnosis and Use of Services Among US Elementary School-Aged Children," *Psychiatric Services* 68, no. 1 (2017): 33–40, <https://doi.org/10.1176/appi.ps.201500549>.
148. "Screening and Diagnosis of Autism Spectrum Disorder," *CDC*, accessed October 30, 2022, <https://www.cdc.gov/ncbddd/autism/screening.html#:~:text=Doctors%20look%20at%20the%20child's,final%20diagnosis%20until%20much%20older>.
149. Debbie Spain et al., "Autism Diagnostic Assessments with Children, Adolescents, and Adults Prior to and during the COVID-19 Pandemic: A Cross-Sectional Survey of Professionals."
150. Gray Atherton et al., "Autism Through the Ages: A Mixed Methods Approach to Understanding How Age and Age of Diagnosis Affect Quality of Life," *Journal of Autism and Developmental Disorders* 52 (2022): 3639–3654, <https://doi.org/10.1007/s10803-021-05235-x>.
151. "Early Intervention For Autism," *NIH*, accessed October 30, 2022, <https://www.nichd.nih.gov/health/topics/autism/conditioninfo/treatments/early-intervention>.
152. Hus Y. and Segal O., "Challenges Surrounding the Diagnosis of Autism in Children," *Neuropsychiatric Disease and Treatment* 17 (2021): 3509–3529, <https://doi.org/10.2147/NDT.S282569>.

153. “One-fourth of Children with Autism are Undiagnosed,” *ScienceDaily*, January 9, 2020, [www.sciencedaily.com/releases/2020/01/200109130218.htm](http://www.sciencedaily.com/releases/2020/01/200109130218.htm).
154. “Early Intervention for Autism,” NIH.
155. “Autism’s Clinical Companions: Frequent Comorbidities with ASD,” *Children’s Hospital of Philadelphia*, July 1, 2017, <https://www.chop.edu/news/autism-s-clinical-companions-frequent-comorbidities-asd>.
156. Mohammad Al-Beltagi, “Autism Medical Comorbidities,” *World Journal of Clinical Pediatrics* 10, no. 3 (2021): 15–28, <https://doi.org/10.5409/wjcp.v10.i3.15>.
157. Dorothea Iannuzzi et al., “Emergency Department Utilization of Adolescents and Young Adults with Autism Spectrum Disorder,” *Journal of Autism and Developmental Disorders* 52 (2022): 617–622, <https://doi.org/10.1007/s10803-021-04969-y>.
158. Eric Rubenstein and Lauren Bishop-Fitzpatrick, “A Matter of Time: The Necessity of Temporal Language in Research on Health Conditions that Present with Autism Spectrum Disorder,” *Autism Research* 12, no. 1 (2018): 20–25, <https://doi.org/10.1002/aur.2010>.
159. Dorothea Iannuzzi et al., “Emergency Department Utilization of Adolescents and Young Adults with Autism Spectrum Disorder.”
160. Jolie Strauss et al., “Medical Encounters for Youth With Autism Spectrum Disorder: A Comprehensive Review of Environmental Considerations and Interventions.”
161. Dorothea Iannuzzi et al., “Emergency Department Utilization of Adolescents and Young Adults with Autism Spectrum Disorder.”
162. Jolie Strauss et al., “Medical Encounters for Youth With Autism Spectrum Disorder: A Comprehensive Review of Environmental Considerations and Interventions.”
163. Eric Rubenstein and Lauren Bishop-Fitzpatrick, “A Matter of Time: The Necessity of Temporal Language in Research on Health Conditions that Present with Autism Spectrum Disorder.”
164. Janet Cakir, Richard E. Frye, and Stephen J. Walker, “The Lifetime Social Cost of Autism: 1990–2029,” *Research in Autism Spectrum Disorders* 72 (April 2020): 101502, <https://doi.org/10.1016/j.rasd.2019.101502>.
165. Ibid.
166. Ibid.
167. Ibid.
168. Ibid.
169. Carlyna Todorow, James Connell, and Renee Turchi, “The Medical Home for Children with Autism Spectrum Disorder: an Essential Element whose Time has Come,” *Current Opinion in Pediatrics* 30, no. 2 (April 2018): 311–317, <https://doi.org/10.1097/MOP.0000000000000605>.
170. Ibid.
171. “About Medical Home,” *Medical Home Portal*, accessed October 30, 2022, <https://www.medicalhomeportal.org/medical-home>.
172. “About Neurobehavior HOME,” *University of Utah*, accessed October 30, 2022, <https://healthcare.utah.edu/hmhi/programs/home/about-us.php>.
173. Julie N. Youssef, Dana C. Won, and Heidi M. Feldman, “Primary Care Physicians/Subspecialty Pediatricians.”
174. “About Neurobehavior HOME,” *University of Utah*.
175. “Neurobehavior HOME Program,” *University of Utah*, accessed October 30, 2022, <https://healthcare.utah.edu/hmhi/programs/home/>.
176. Ibid.
177. “Autism Spectrum Disorders Clinic,” *University of Utah*, accessed October 30, 2022, <https://healthcare.utah.edu/hmhi/treatments/autism-clinic/#overview>.
178. “Neurobehavior HOME Program,” *University of Utah*.
179. “Best Practices, Resources and Guidelines,” *University of Utah*, accessed October 30, 2022, <https://healthcare.utah.edu/hmhi/programs/home/resources-guidelines.php>.
180. Paul S. Carbone et al., “A Comparison of Ambulatory Care Sensitive Hospitalizations Among Children With and Without Autism Spectrum Disorder,” *Children with Special Health Care Needs* 15, no. 6 (2015): 626–635, <https://doi.org/10.1016/j.acap.2015.07.006>.
181. Carlyna Todorow, James Connell, and Renee Turchi, “The Medical Home for Children with Autism Spectrum Disorder: an Essential Element whose Time has Come.”
182. Ibid.
183. Marji Erickson Warfield et al., “Physician Perspectives on Providing Primary Medical Care to Adults with Autism Spectrum Disorders (ASD).”
184. Ibid.
185. “Certified Autism Center for Hospitals,” *International Board of Credentialing and Continuing Education Standards*, accessed October 30, 2022, <https://ibcces.org/hospital/>.
186. Leah I. Stein Duker et al., “Examining Primary Care Health Encounters for Adults With Autism Spectrum Disorder.”
187. “About | Up to Date,” *Wolters Kluwer*, accessed October 30, 2022, [https://www.wolterskluwer.com/en/solutions/uptodate/about?\\_ga=2.182136295.1705352978.1659411333-1752592917.1658856699](https://www.wolterskluwer.com/en/solutions/uptodate/about?_ga=2.182136295.1705352978.1659411333-1752592917.1658856699).
188. Marji Erickson Warfield et al., “Physician Perspectives on Providing Primary Medical Care to Adults with Autism Spectrum Disorders (ASD).”
189. Ibid.
190. “Autism Case Training: A Developmental-Behavioral Pediatrics Curriculum,” *CDC*, accessed October 30, 2022, <https://www.cdc.gov/ncbddd/actearly/autism/curriculum/class.html#:~:text=The%20%E2%80%9CAutism%20Case%20Training%20>.
191. Nili E. Major, “Autism Education in Residency Training Programs.”
192. Nili E. Major et al., “Autism Training in Pediatric Residency: Evaluation of a Case-Based Curriculum,” *Journal of Autism Developmental Disorders* 43 (2013): 1171–1177, <https://doi.org/10.1007/s10803-012-1662-1>.
193. Leah I. Stein Duker et al., “Examining Primary Care Health Encounters for Adults With Autism Spectrum Disorder.”
194. Nili E. Major et al., “Autism Training in Pediatric Residency: Evaluation of a Case-Based Curriculum.”