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Emily Ramsey

*University of Nebraska at Omaha*, [ealien@gmav.unomaha.edu](mailto:ealien@gmav.unomaha.edu)

Lisa Kelly-Vance

*University of Nebraska at Omaha*, [lkelly-vance@unomaha.edu](mailto:lkelly-vance@unomaha.edu)

Joseph A. Allen

*University of Nebraska at Omaha*, [josephallen@unomaha.edu](mailto:josephallen@unomaha.edu)

Olivia Rosol

*University of Nebraska at Omaha*, [obabe@gmav.unomaha.edu](mailto:obabe@gmav.unomaha.edu)

Michael Yoerger

*University of Nebraska at Omaha*, [myoerger@unomaha.edu](mailto:myoerger@unomaha.edu)

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Autism Spectrum Disorder Prevalence Rates in the United States:

Methodologies, Challenges, and Implications for Individual States

Emily Ramsey, Joseph Allen, Lisa Kelly-Vance, and Michael Yoerger

University of Nebraska at Omaha

Arts & Sciences Hall 347

6001 Dodge St.

Omaha, NE 68182

Phone: 402-554-2592

Fax: 402-554-2556

Email: [ealien@unomaha.edu](mailto:ealien@unomaha.edu)

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### Abstract

Many different studies have been conducted to determine the prevalence rates of Autism Spectrum Disorder (ASD) in the United States. The methodologies of these studies have varied, resulting in a multitude of publications with differing prevalence rates. Because there is such a wide range in the results of prevalence studies, it may be difficult for individual states to determine their rates. Accurate prevalence rates are important to obtain for many different reasons including increasing advocacy and awareness, increasing funding, and proper allocation of services for individuals with ASD and their families. Additionally, prevalence studies can be used to assess which groups are more at risk for ASD based off location and environmental factors. This paper describes different methodologies that can be utilized to determine ASD prevalence rates, the strengths and weaknesses of each method, and the challenges to determining accurate rates. Implications for future prevalence studies will be addressed and recommendations will be provided.

*Keywords:* autism, autism spectrum disorder, prevalence rates, intervention, decision-making

Autism Spectrum Disorder Prevalence Rates in the United States: Methodologies, Challenges,  
and Implications for Individual States

Autism Spectrum Disorder (ASD) is a developmental disorder that includes deficits in communication and social interactions and involves displaying repetitive patterns of behavior (CDC, 2012). Individuals may receive a medical diagnosis of ASD and/or an educational verification of ASD. There are many differences between a medical diagnosis of ASD and an educational verification of ASD (Hawkins, 2009). A medical diagnosis is typically made by a physician, psychiatrist, licensed mental health practitioner, or clinical psychologist and is based off criteria from the Diagnostic Statistical Manual of Mental Disorders (DSM-V) of the American Psychological Association (Autism Society, 2015). The medical criterion for ASD has significantly changed over time (European Commission, 2005; Saracino et al., 2010) to be more inclusive. More specifically, ASD is a term now used to include several related disorders including Autism, Asperger Syndrome, Pervasive Developmental Disorder- Not Otherwise Specified, Rett Syndrome, and Childhood Disintegrative Disorder (CDC, 2012). In the past 55 years, the diagnostic criterion for ASD has changed at least six times. The first criterion utilized in the 1960s to diagnose ASD was known as Kanner's Criteria (Saracino et al., 2010). This criterion changed in the 1970s to Lotter's and Rutter's criteria followed by the DSM-III (1980s), DSM-IV (1994), and the DSM-V (2013) (Fombonne, Quirke, & Hagen, 2009). These diagnostic changes involved expanding the criteria to define autism as a spectrum disorder that is broader in scope. These changes in definition have led to significant increases in prevalence rates over time.

In contrast, an educational verification is made by a team of school professionals, known as a multidisciplinary team, using criteria from the Individuals with Disabilities Education Act (IDEA) (Hawkins, 2009). Educational verifications are used to determine if a child qualifies for

special education services. A medical diagnosis of ASD does not automatically qualify an individual to have an educational verification of ASD. Similarly, an educational verification of ASD does not mean a child will receive a medical diagnosis. The differences in medical and educational diagnoses are important to consider when determining the prevalence rates of ASD (Hawkins, 2009). The purpose of this paper is to describe different methodologies that can be used to determine ASD prevalence rates, the strengths and weaknesses of each method, the challenges to determining accurate rates, and the implications for future prevalence studies. We conclude by including a series of recommendations to those engaging in future ASD prevalence studies.

#### Importance to Determining ASD Prevalence Rates

Accurate prevalence rates are important to obtain for many reasons including increased advocacy and awareness, increased funding, and proper allocation of services for individuals with ASD and their families (Rice et al., 2012). Additionally, prevalence studies can be used to assess which groups are more at risk for ASD based off location, and environmental factors (Rice et al., 2012). Acquiring a more comprehensive understanding of these numbers may allow government agencies, nonprofit organizations, educational agencies, and philanthropists, to be better informed about how best to direct their efforts in helping individuals with autism receive the resources they need (Nonkin Avchen et al., 2011).

Accurate prevalence rates may also have an impact on families who are need of additional services. While schools offer many supports for individuals with ASD, they do not always have the funding or resources to provide the necessary outside services to these individuals (Boswell, Zablotzky, & Smith, 2014). Families in need of additional resources often rely on the supports of outside agencies to enhance their children's development. For example,

many families rely on programs that work with children when school is not in session and after graduation including transition and adult ASD programs. In order to be able to provide for these individuals, agencies must be able to accurately apply for funding and appropriately plan for ASD services (Boswell et al., 2014).

Finally, accurate prevalence rates may help service organizations accurately plan for needed services (Boswell et al., 2014). One commonality across prevalence studies over the years is reported increases in ASD prevalence rates (Fombonne, 2003). Increased rates can have implications for service providers as they may be unprepared to meet the needs of a growing population of individuals with ASD (Bureau of Autism Services, 2009). Knowing the number of individuals with ASD by location may help organizations determine where there is more need for ASD programs and where to allocate more funding (Boswell et al., 2014).

#### Methodologies to Determining the Prevalence Rates of ASD

Many different studies that have been conducted to determine the prevalence rates of ASD (Blumberg et al., 2013; Bureau of Autism Services in Pennsylvania, 2009; & CDC, 2012; 2013). The methodologies of these studies have varied, resulting in a multitude of publications with differing prevalence rates (Zaroff & Uhm, 2011). Determining the true prevalence rates of ASD is challenging. The typical methodologies utilized to provide health information, such as health surveys and registries, are difficult to create (European Commission, 2005) and do not exist in most states throughout the United States. Despite these difficulties, many studies have contributed to our knowledge of ASD prevalence rates. There are different methodologies to determining ASD prevalence rates including analyzing special education data, records review surveillance, surveys, and registries (Fombonne et al., 2009; Rice et al., 2012). Consumers need to be aware of these methodologies when utilizing prevalence rates so they understand the

limitations and implications of these studies (Fombonne et al., 2009). A more in depth understanding of methodologies can help consumers better interpret and appropriately utilize reported prevalence rates. This section will review multiple prevalence methodologies and provide the benefits and limitations to these studies. In all cases, these studies obtained informed consent from participants thereby following ethical guidelines as required by institutional review boards for research.

The most common and widely cited ASD prevalence study is conducted by the Center for Disease Control and Prevention's (CDC) Autism and Developmental Disabilities Monitoring Network (ADDM). The ADDM Network has conducted multiple studies to determine the prevalence rates of Autism Spectrum Disorder (ASD) in the United States starting in 2000. Data are collected using a records-review surveillance method which involves a review of professional evaluations of 8 year-old children from 11 sites in the United States (CDC, 2014). These sites are located in Alabama, Arizona, Arkansas, Colorado, Georgia, Maryland, Missouri, New Jersey, North Carolina, Utah, and Wisconsin. Examples of the evaluations that are reviewed include records from special education, pediatric health, psychologists, neurologists, psychiatrists, developmental pediatricians, physical therapists, etc. The source files are then examined to determine if there are any 'triggers' for ASD documented in the records such as not interacting with others or receiving an ASD diagnosis (CDC, 2012). Finally, each record is reviewed by trained individuals to determine if a child meets the qualifications for ASD under the DSM-IV. The CDC's latest research study found the overall ASD prevalence rate to be 14.7 per 1,000 (1 in 68) for children age 8 years old (CDC, 2014). However, it is important to note that the prevalence rates vary when looking at each individual state (see Figure 1). For instance, New

Jersey's prevalence rates were 21.9 per 1,000 while Alabama's rates were 5.7 in 1,000. Both of which are markedly different from the overall ASD prevalence rate.

There are many benefits to using a screening method to determine ASD prevalence estimates. For instance, the CDC's method resulted in the identification of individuals who had not previously been diagnosed with ASD which may have led to more complete results. Because more individuals are receiving classifications of ASD, the surveillance methodology often results in higher prevalence estimates (Rice et al., 2012). The surveillance system helps to identify children who might have otherwise been missed due to the large variations in ASD symptoms (Nonkin Avchen et al., 2011). The surveillance method may also provide more accurate prevalence rates compared to surveys based on parental reports or examinations of service provider registries because this method did not rely on a previously documented diagnoses. Additionally, it is more feasible to assess records than to screen each child individually (Nonkin Avchen et al., 2011).

While there are many benefits to the ADDM data collection process, there are also limitations. First, the data collected by the ADDM only includes 8 year-old children within 11 sites (CDC, 2014). In 2010, data started to be collected on 4 year-old children; however, this still leaves out a large number of children diagnosed with ASD. For example, individuals who were diagnosed before and after age 8 would not be included in this study. The surveillance sites included in the ADDM studies were not chosen to be representative of the United States or of the individual state where they are located (CDC, 2012). Thus, using these numbers to identify ASD rates in the United States could be misleading. Additionally, not all of the sites had access to educational records. Only six out of nine sites in the 2010 ADDM surveillance data had access to educational records (CDC, 2014). Educational records provide critical information on the



prevalence rates of ASD. Lack of educational records would create a large underestimate of the prevalence of ASD because it would not include any child verified within the school system without a medical diagnosis. Another limitation is that the clinicians did not directly observe children to validate their diagnoses (Mandell & Lecavalier, 2014). It is argued that the reviewers in this study were determining ASD diagnoses even though the community clinician may have already determined the child did not have an ASD diagnoses (Mandell & Lecavalier, 2014). Conversely, records surveillance methods may result in the same amount of false positives as true positives (Nonkin Avchen et al., 2011).

#### Previous ASD Prevalence Rates Studies

Despite the CDC's limitations, their ASD studies are a vast improvement from previous methodologies in estimating ASD prevalence rates. Prior to the CDC's surveillance studies which began in 2000, the only data used to determine ASD national prevalence rates were state reports of the number of students ages 3-21 receiving special education services with an ASD verification (Shattuck, 2006). The CDC's method is arguably the best method for determining prevalence rates; however, it is very costly and time consuming. This process may not be feasible for states to conduct due to funding and lack professional support. States may decide to collect their own ASD prevalence rate data to make decisions based off the specific characteristics of their population (Boswell, Zablotsky, & Smith, 2014). Studies have shown that ASD prevalence rates differ per state due to the heterogeneous sociodemographic variables of each state. Even regions of a state can differ in prevalence because of differences in their population characteristics (Boswell, Zablotsky, & Smith, 2014). This is why individual states should consider collecting information about their own state in place of using the rates of other states.

While many large scale studies have been conducted across the United States, individual states have done smaller scale prevalence studies. The Bureau of Autism Services in Pennsylvania (2009) conducted a study using a records review system to determine the prevalence rates of ASD in Pennsylvania. A records review system involves analyzing the data of individuals who have already been diagnosed with autism (Rice et al., 2012). Researchers gathered data from multiple institutions throughout the state including the Pennsylvania Departments of Public Welfare and Education, county services programs, children and youth offices, early intervention programs, behavioral health agencies, and the U.S. Department of Education's Rehabilitation Services Administration. Data from these agencies were merged by using identifiable information to ensure there was no duplication of records. Results showed there were 19,862 individuals diagnosed with autism in the state of Pennsylvania in 2005. Data was also collected from various counties and compared to the state-wide data. Autism prevalence rates varied depending on the county with autism proportion rates ranging from .09% to .32% (Bureau of Autism Services, 2009).

A benefit of the Bureau of Autism Services' method was the collaboration that occurred across different organizations. Collaboration is important and essential for this type of study to be conducted. However, this can be a difficult process for states due to privacy regulations in the state. Specific privacy regulations will be addressed in the following section. Another benefit to this method was that it can be utilized in future studies to assess trends in state-wide data over time. It is also important to note the limitations of this study. First, individuals not receiving ASD related services from these organizations and those who had not received formal diagnoses of ASD were not counted in these rates (Bureau of Autism Services in Pennsylvania, 2009). This can lead to a vast underestimation of individuals with ASD (Fombonne et al., 2009).

Furthermore, many adults with ASD were not included in the administrative datasets.

Individuals with ASD who had an alternate primary diagnoses may have been missed. Another challenge with registries is that organizations may use difference assessment tools to diagnose ASD (Zaroff & Uhm, 2011). For instance, using broad mental health measures may result in lower ASD prevalence rates compared to studies using ASD specific measurements for assessment purposes (Posserud, Lundervold, Lie, & Gillberg, 2010). Also direct testing methods may vary depending on the testing and interview methods (Wong & Hui, 2008).

The next prevalence methodology involves clinicians individually assessing a small population of individuals through multiple assessment tools to evaluate cognitive, adaptive, and social communication skills. Nonkin Avchen and colleagues (2011) conducted a study to determine the ASD prevalence rates from a sample of 374 individuals. Each individual was assessed by a trained clinician using the Differential Ability Scales, Vineland Adaptive Behavior Scales-II, the Social Communication Questionnaire, ADI-R, and the ADOS (Nonkin Avchen et al., 2011). The advantage to this methodology is that clinicians were using the same assessment tools to determine ASD verifications. However, prevalence studies that involve direct assessment of individuals typically result in higher estimates compared to studies based on previously existing records (Baron-Cohen et al., 2009). Also, direct screening of individuals can be affected by low response rates and potential false screening results (Rice et al., 2012; Nonkin Avchen et al., 2011). Individual assessments may provide accurate estimates; however, it is very time consuming and may not be feasible for a larger population (Nonkin Avchen et al., 2011).

The last prevalence methodology that will be addressed is survey methods. Survey methods can be beneficial because they are relatively inexpensive, time effective, and are easy to administer. Blumberg and colleagues (2013) conducted a study to determine the prevalence of

ASD by analyzing parent reports of school-age children. Data from the National Survey of Children's Health (NSCH) was collected and analyzed to determine trends in ASD over time. The NSCH consists of a telephone survey for parents of children ages 0-17 in the United States. Children were determined to have an ASD diagnosis if their parent reported that their child had received a diagnosis from a doctor or other health care provider. Results showed there was an increase in the ASD prevalence rates for children ages 6-17 from 2007 (1 in 86) to 2011-2012 (1 in 50). More specifically, there was a higher prevalence rate for individuals ages 14-17 in 2011-2012 compared to 2007 (Blumberg et al., 2013).

This survey methodology has the benefits of feasibility, time, and cost. This method is much more feasible and less time consuming than the CDC process because all of the questions are conducted over the phone and individuals are not assessed using the DSM-IV TR. It is also less expensive because the researchers did not need to hire professionals to diagnose individuals. While there are benefits to this method, there are also many limitations. For instance, the prevalence estimates are prone nonresponse bias or parent bias in reporting ASD diagnoses. There was no evaluation of educational or medical reports to confirm these diagnoses (Blumberg et al., 2013). Additionally, these diagnoses were not all verified by the same professional. There could have been professional errors or differences in the usage of ASD diagnostic criteria for these diagnoses.

#### The Challenges to determining Autism Prevalence Rates

As just reviewed, there are many differences in prevalence rates depending on the methodology of the study. Each method presents challenges to determining accurate rates. Determining the prevalence rates of ASD in the United States can be complicated. These complications may differ depending on the state. The first challenge is that the diagnostic

criterion for ASD has significantly changed over time (Saracino et al., 2010). These changes have had vast impacts on the prevalence estimates of ASD. For instance, Kielinen et al. (2000) conducted a study to determine how a different diagnostic criterion affects overall ASD prevalence rates. They applied different ASD criteria to the same 39,216 children and found significant differences in prevalence rates. For instance, when using Kanner's diagnostic criteria, they found a prevalence rate of 2.3 per 10,000 children. Next the researchers used the broader ICD-10 and DSM-IV ASD criteria and found a prevalence rate of 6.1 per 10,000. Finally, they used the ICD-10 criteria for ASD (PDD) and found a rate of 7.6 per 10,000 children. Thus, their results showed that broadening the ASD diagnostic criteria led to changes in the prevalence rates of ASD over time (Kielinen et al., 2000; Saracino et al., 2010).

The next challenge is that professionals may differ in the way they apply the ASD diagnostic criteria, even though they may be using the same standards. One reason this occurs is because of the impact of insurance coverage (Fombonne et al., 2009). Insurance agencies may play a role in the decision making process for determining whether a child qualifies under the ASD diagnostic criteria. While insurance coverage for ASD services is growing throughout the United States, many insurance agencies still do not cover treatment services for individuals with ASD (National Conference of State Legislatures, 2012). Some states require insurance agencies to cover ASD treatment services while others argue this is the responsibility of parents or school systems. Others fear mandating insurance coverage for ASD would increase insurance premiums around 1 to 3 percent (Council for Affordable Health Insurance, 2009). Currently, thirty-seven states have laws related to ASD insurance coverage. Other states may have limited coverage under mental health coverage (National Conference of State Legislatures, 2012). Because of the high cost of services for ASD, many parents cannot afford to pay for these services out of

pocket. The Harvard School of Public Health (2006) estimated it costs \$3.2 million to care for an individual with ASD over his or her lifetime. Thus, many parents request that clinicians diagnose their child with an alternate diagnoses related to ASD that is covered by insurance agencies. In order to help these individuals receive services, many clinicians are using alternate diagnoses for ASD (Saracino et al., 2010).

Relatedly, there are also differences in the way school teams verify ASD (Brock, 2006). The IDEA diagnostic criteria for ASD may be interpreted differently depending on the professional and on state regulations. For instance, some multidisciplinary teams prefer to identify younger children with symptoms of ASD as developmentally delayed until the age of 9. The Individuals with Disabilities Education Improvement Act (2004) declared states may use either the disability categories for eligibility determinations or a verification of developmental delay for individuals ages birth through 9. Others may choose to verify the child with ASD at an earlier age. This is dependent on the members of the multidisciplinary team and state regulations.

Additionally, many professionals substitute diagnostic categories within the school system (Brock, 2006; Fombonne et al., 2009). Shattuck (2006) analyzed information from the Department of Education in the United States and found that professionals altered their diagnoses categories over the years. For instance, from 1994 to 2003, autism prevalence rates increased from 0.6 to 3.1 per 1,000 while the prevalence rates for mental retardation and learning disabilities declined by 2.8 and 8.3 per 1,000 (Shattuck, 2006). Brock (2006) also analyzed information from the United States Department of Education and found increased rates of Autism with lower rates of mental retardation, emotional disturbance, and specific learning disability. Thus, perhaps increased school verifications of Autism are due to multidisciplinary teams using autism verifications instead of mental retardation, emotional disturbance, and

specific learning disability (Brock, 2006; California Department of Developmental Services, 2003).

Another challenge to determining prevalence rates is many states do not currently have a universal system of collecting data about individuals with ASD across organizations. Complications that make it difficult to collect data across organizations are medical and educational confidentiality and privacy regulations. Medical institutions follow confidentiality and privacy regulations set by the Health Insurance Portability and Accountability Act (HIPAA) (Department of Health and Human Services, 2003). The Department of Education follows the confidentiality regulations set by the Family Educational Rights and Privacy Act (FERPA) (U.S. Department of Education, 2015). To determine prevalence rates of ASD by previous diagnoses, researchers would need to access individually identifiable information such as name, date of birth, location, etc. (Bureau of Autism Services, 2009). Individually identifiable information would be required to cross reference medical and educational records to determine if an individual had a medical diagnosis, an educational verification, or both. In order to obtain records with identifiable information, HIPAA and FERPA regulations require that researchers obtain consent from each individual with ASD (Department of Health and Human Services, 2003; U.S. Department of Education, 2015). Thus, researchers would need to obtain consent from thousands of individuals before they could gain access to their records to determine ASD prevalence rates. This process would also lead to inaccurate prevalence rates because many individuals may not respond to a consent request form. Due to the requirement of HIPAA and FERPA to gain permission from individual families, it would not be feasible to access existing data in a state where there is no collaboration between different organizations serving individuals with ASD. While HIPAA and FERPA are both extremely important components to protecting

confidentiality, they make it challenging for researchers to conduct an analysis of the prevalence rates across both medical and educational institutions.

### Implications and Recommendations

There are many implications to using different methodologies in determining ASD prevalence rates. For instance, prevalence rates vary depending on the methodology, research location, and regulations of the state. Because there is such a wide range in the results of prevalence studies, it may be difficult for individual states to determine their rates. Most states refer to the CDC study to estimate their prevalence rates, however, there is variability depending on the state. Additionally, the CDC is potentially not representative of the states outside of the 14 states that were analyzed in their study. This poses the question, what prevalence rates can and should be utilized by these missing states? Some may use the national rates published by the CDC while others may refer to the rates of states closest in proximity. The problem that arises when using rates of other states that are close in proximity is the fact that laws and regulations are different depending on the state. For instance, ASD educational qualification criteria and insurance regulations may be different (Council for Affordable Health Insurance, 2009). Differences in insurance regulations can affect prevalence rates because lack of coverage tends to lead professionals to use alternate diagnoses (in order to get more coverage for ASD related services). So if these differences are true, how can individual states determine ASD rates that are specific to their area?

As previously described, there are many different methodologies that can be utilized to determine individual state prevalence rates of ASD such as replicating the CDC study for a smaller population that is representative of the state, administering a prevalence rate survey, or conducting individual assessments for a smaller representative sample. (Fombonne et al., 2009).



It is recommended that the strengths and weaknesses of each methodology be analyzed before states make a decision on how to determine their ASD prevalence rates. For instance, if choosing to create a registry, states need to be aware of the HIPAA and FERPA regulations that protect the confidentiality of individuals. If they choose to conduct a parent survey, states need to be aware that their rates may be affected by nonresponse bias and are reliant on parent reports (Blumberg et al., 2013). It is suggested that states become familiar with the challenges they may come across and create plans to address these concerns before choosing an appropriate methodology.

Another recommended option is to create consistent data collection systems or registries to increase efficiency in determining prevalence rates each year. It is suggested that states have similar data collection systems across agencies to improve communication and interpretation of data and to increase efficiency (Bureau of Autism Services, 2009). It is also recommended that states link existing registries to other databases from service providers, medical institutions, or research institutions to further improve the accuracy of ASD prevalence rates (Rice et al., 2012).

Finally, it is recommended that states and researchers focus on improving collaboration efforts of professionals and stakeholders (Rice et al., 2012). Professionals can work to improve the communication between individuals with ASD and their families, researchers, service providers, and government officials about prevalence rates and the service needs of the community. Organizations can create partnerships between public and private sources to support ASD research by increasing advocacy and research funding (Rice et al., 2012).

### Conclusion

Researchers should continue to identify and utilize methodologies to accurately determine ASD prevalence rates. One way to further enhance this effort is to collaborate with

other researchers and professionals who are conducting studies on the prevalence rates of other diagnoses (such as ADHD). Studying these methodologies, in addition to the methodologies utilized in ASD prevalence studies, can provide researchers with more insight on how to conduct future studies (Rice et al., 2012). Knowledge of the strengths and limitations of various methodologies as well as the anticipated challenges to an ASD prevalence study will help individual states to make more informed decisions and determine more accurate prevalence rates.

#### Compliance with Ethical Standards

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Ethical Approval: This article does not contain any studies with human participants performed by any of the authors. Informed consent was obtained from all individual participants included in the study.

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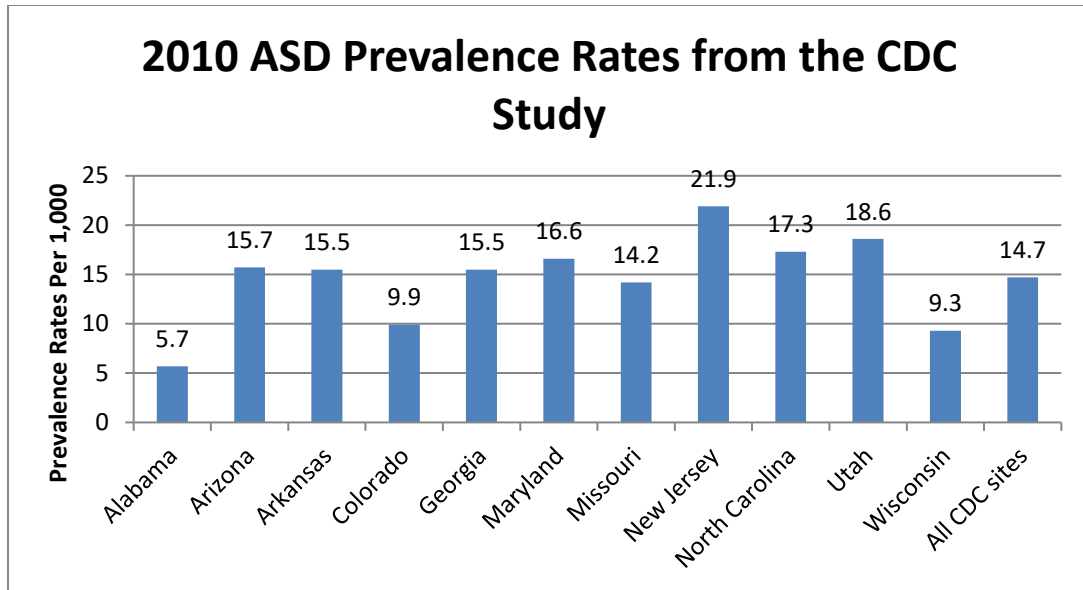


Figure 1. ASD Prevalence Rates from the 2010 CDC Study (published in 2014).