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Options for Public Health Surveillance for Autism Spectrum Disorder

Minnesota Department of Health

Report to the Minnesota State Legislature 2014

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Executive Summary

Over the last 20 years, Minnesota has seen large increases in the number of young people with autism spectrum disorder (ASD). Autism spectrum disorders (ASD) are developmental disabilities that cause impairments in social behaviors and communication, and repetitive or restrictive behaviors. ASD is a spectrum disorder and, therefore, affects each individual differently. Because there are no biological or laboratory tests for diagnosing ASD, a diagnosis is based on direct observation of a child's behavior in structured settings. Common behavioral symptoms include lack of eye contact, lack of response to hearing one's name, lack of communicative gestures, repetition of speech of others, repetitive motion with hands, arms or other body parts, strong adherence to routines, and restricted interest in particular objects or topics. Individuals with ASD also often have special health needs because of a variety of associated illnesses, including an increased risk of seizures, gastrointestinal problems, sleep disturbances, and various behavioral or psychiatric conditions.

Children with ASD pose significant challenges to families and have substantial medical and educational service needs, greatly impacting educational, social and medical systems. Core family members face emotional distress and financial struggles when dealing with a child with ASD. Families experience substantial economic burden as a result of the high costs associated with multiple therapies or interventions, and reduced work hours due to the increased time demand of a child with ASD. Heavy burden on the healthcare system can be primarily linked to rising healthcare costs for ASD in the United States, reaching an estimated $60-$90 billion dollars a year. Increased ASD prevalence rates and costs also strain the educational system.

A public health surveillance system for ASD in Minnesota would allow the state to assess the occurrence of ASD in the population and provide data to inform an evidence-based public health response. Minnesota Session Law Chapter 247 (Regular Session 2012) Article 6, Sec. 3, Subd. 2 directed the Commissioner of Health to "develop and submit a report…on the feasibility of establishing a public health surveillance system for ASD." This report summarizes options for and outlines the work needed to develop a public health surveillance system for ASD in Minnesota.

Top Options: Regional Versus Statewide

To ensure data are broadly available for public health ASD prevention and intervention activities in Minnesota, the goals for a population-based public health surveillance system for ASD should include: (1) Estimating prevalence and monitoring trends in ASD; (2) Assuring that children with ASD and their families are linked to appropriate health care and related services; (3) Informing public health policy and programs; (4) Addressing concerns about ASD in communities and educating citizens and professionals about ASD; and (5) Supporting health services and ASD causation research.

Establishing a system for conducting public health surveillance for ASD is complicated by the fact that identifying cases in populations is difficult because of the wide spectrum of symptoms associated with the condition and the lack of a biological or laboratory diagnostic test. Therefore, research into possible models for ASD surveillance was conducted for this report. Several models were identified but only two of these models were commonly used in practice. Each model has distinct advantages and disadvantages:

1. Since 2000, the Centers for Disease Control and Prevention (CDC) has implemented the Autism and Developmental Disabilities Monitoring (ADDM) Network. This is the largest, record-based public health surveillance system for ASD in the U.S. The program is currently conducted in 12 U.S. states funded through a cooperative agreement with the CDC. Data are abstracted from existing health and school records on individuals identified as having an ASD and who reside in a defined geographic area, or "catchment region", representing a base population of approximately 20,000 8-year old children. The objectives of the ADDM Network model are primarily aimed at estimating and tracking trends in ASD population prevalence.

    a. Strengths: Major strengths of the ADDM Network model include implementing a uniform surveillance methodology for data collection and case confirmation, rigorous initial and ongoing training for data abstractors and clinician reviewers, and a uniform ASD surveillance case definition. Case ascertainment is described as active, which means that trained abstractors from the surveillance system enter facilities to identify and abstract the data from records of potential cases. This reduces the burden to staff in data source facilities. The case definition is not limited to 8-year old children with an existing ASD diagnosis; the program attempts to identify children who may have ASD but have not been diagnosed, based on behavioral symptoms documented in their records. The goals of the program are primarily related to estimating and tracking ASD prevalence over time.

    b. Limitations: One important limitation of the ADDM Network model is that the catchment region is restricted to selected counties that represent just a fraction of 8-year old children in a participating state. Consequently, data from the ADDM Network approach cannot be used to inform targeted public health planning and programs at local levels throughout the state, and no data are available to inform public health activities as children transition into adults. Furthermore, because the distribution of racial and ethnic minorities is not uniform in Minnesota, data from the ADDM Network model potentially lacks generalizability to all of Minnesota's populations. This is a substantial limitation because of the pronounced racial and ethnic health disparities in the state. Furthermore, the catchment region may not be representative of the distribution of cases throughout the state (i.e., there are likely more individuals with ASD residing in urban areas closer to ASD services).

2. Statewide ASD surveillance systems based on mandatory reporting have been established in several states where ASDs are notifiable conditions, and four of these states have incorporated ASD surveillance into their state birth defects surveillance systems: Delaware, Indiana, New Jersey, and Washington. In these systems, state statute requires designated facilities and providers to report cases diagnosed with ASD to a specified state government agency. The objectives for population-based mandatory reporting ASD surveillance systems vary somewhat by site, but always include: (1) estimating and tracking ASD prevalence and (2) providing referrals for service. The objectives for the systems located in Indiana and New Jersey also include supporting health services and causal research.

    a. Strengths: Mandatory reporting public health surveillance systems are population-based, statewide, and implement passive case ascertainment methods. In passive case ascertainment, state statute requires designated facilities and providers to report cases diagnosed with ASD to the surveillance system. This method of case ascertainment is less costly than active case ascertainment, because mandatory systems accept case reports for existing ASD diagnoses. The age range for the population covered by mandatory reporting surveillance systems is generally much wider than age criteria established for the populations included in the ADDM Network. Surveillance data that can characterize the burden of ASD through late adolescence has the advantage of being available for use in developing or evaluating programs and policy around the successful transition from childhood to adulthood. Health information technology could make this model readily adaptable to ASD surveillance and a statewide child follow-up program exists that could be readily expanded to include children and adolescents with ASD using data from the surveillance system

    b. Limitations: Passive case ascertainment methods are more burdensome to facilities, especially when systems rely on manual case reporting and data entry. Incomplete case ascertainment and lack of timeliness are important limitations of these passive case ascertainment systems. Another problem with collecting data on existing ASD diagnoses in passive case ascertainment is that diagnostic practices throughout the state may not be consistent. This could lead to incomplete or incorrect reporting for some of areas of the state, leading to a lack representativeness of the system or the possibility of invalid data. Rigorous routine quality assurance and quality control measures are therefore key components of this system's operations to mitigate this limitation.

MDH Recommends Statewide Approach

A review of approaches to public health surveillance for ASD has identified two leading models that could be adopted in Minnesota, a statewide approach or a regional approach. Each approach has strengths and limitations, summarized in Appendix 6. The CDC's ADDM Network model involves a well-established regional approach that has served as the source of data on ASD prevalence rates and trends for the United States. It relies on research teams that actively identify autism cases in a regional area. This approach is less burdensome to reporting facilities, such as clinics and schools. However, if Minnesota were to use this approach, it would not have statewide data and some areas of the state would have no data available to inform local efforts, including efforts that might focus on ethnic or minority populations.

Based on this limitation, this report recommends that if Minnesota implements a surveillance system, it should be a statewide system based on data collection from educational and health records. To ensure complete data are collected, it would be necessary to implement a mandatory reporting system. Additionally, access to health care and education records to conduct routine data completeness and quality control audits would be essential to maximizing the completeness and comprehensiveness of the data in the proposed system.

Implementation Steps and Challenges

Establishing a public health surveillance system is a complex enterprise that requires careful planning and field testing of its components to assure optimal functioning when the system goes into operation. As outlined in the ASD Strategic Plan Report,[i] a working group comprised of ASD professionals in the community, epidemiologists with expertise in public health surveillance, and information technology (IT) staff would be beneficial in planning a statewide ASD public health surveillance system for ASD. Members of the working group would provide expert input on issues related, but not necessarily limited to:

1. Public health surveillance case ascertainment methods that maximize use of electronic transfer of data versus hands-on record reviews and data abstraction.

2. The surveillance case definition for ASD and methods to field test the use of different data sources to ensure the case definition adopted is valid and reliable.

3. Possible quality assurance and quality control approaches as well as data quality standards to ensure that the system achieves and maintains data quality standards, and that all data collected are stored in a secure manner.

[i] Minnesota Autism Spectrum Disorder Taskforce (2012). *ASD Task Force: Strategic Plan Report.* Retrieved from http://www.lcc.leg.mn/asd/2013-14/ASDStrategicPlanReportWEB.pdf

4. The specific data items to be collected from individuals to: (a) ensure that each individual only appears once in the database, (b) determine clinical severity and other characteristics such as low IQ to estimate ASD burden in the population; and (c) provide the necessary information for education, research, and public health program planning, policy development, and evaluation.

5. Use of the data in addressing the goals of the public health surveillance system for ASD. Engaging a separate group of stakeholders in the community including families who have children with ASD to seek input on the goals for case management and long term follow-up would be critical.

6. Enabling legislation needed to administer the system, collect information, and distribute or share data, including rules, for example, on the type of data reported, standard for reporting specific data types, reporting facilities and providers, and data sharing with state agencies and researchers.

Full Report to the Legislature

I. Autism Spectrum Disorder

Autism spectrum disorder (ASD) consists of a group of developmental disabilities associated with persistent deficits in social communication and interaction not accounted for in general developmental delays, as well as restricted, repetitive patterns of behavior, interests, or activities. The *Diagnostic and Statistical Manual of Mental Disorders* (4th edition, text revision) (*DSM-IV-TR*)[1] includes these subtypes: autistic disorder, Asperger syndrome, and pervasive developmental disorder not otherwise specified (PDD-NOS). Although these subtypes were dropped from the *Diagnostic and Statistical Manual of Mental Disorders* (5th edition) (*DSM-V*)[2] currently in use, reference to subtypes is still widespread. Regardless, ASDs are believed to occur in children of all races, ethnicities, and socioeconomic groups and are approximately five times more common among boys compared with girls.[3] The CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network estimated that, in 2008, about 1 in 88 children aged 8 years had an ASD,[4] nearly double from 1 in 150 children aged 8 with an ASD reported in 2002.[5]

Symptoms must be presented in early childhood and impair everyday functioning. ASD is considered a spectrum disorder and, therefore, it affects each individual differently.[6] Common symptoms include lack of eye contact, lack of response to hearing one's name, lack of communicative gestures, repetition of speech of others, repetitive motion with hands, arms or other body parts, strong adherence to routines, and restricted interest in particular objects or topics.[3] At 15-18 months about 25% to 30% of children with ASD have an initial presentation in which they experience gradual or sudden regression of social and communication skills.[7] Other studies have reported up to 50% of children with ASD will experience regression.[8]

There are no biological or laboratory tests for diagnosing ASD. Instead, diagnosis is accomplished in two phases and is based on direct observation of a child's behavior in structured settings. Phase one involves a general developmental screening with a pediatrician or other health care provider. The Academy of Pediatrics recommends that these screenings occur at 9, 18, and 24-30 months of age. The second phase of diagnosis consists of a thorough evaluation by a team of doctors and health professionals, and a referral to early intervention specialists. A reliable diagnosis of ASD can usually be made between the ages of 18-24 months.[6]

Children with ASD often have special health needs because of a variety of associated illnesses or "co-morbidities." These illnesses and conditions can include: an increased risk of seizures; gastrointestinal problems; sleep disturbances; and various behavioral or psychiatric comorbidities (i.e., attention-deficit hyperactivity disorder, intermittent explosive disorder, generalized anxiety disorder, and depressive disorders). About 50% of children with ASD have co-morbid intellectual disability and a significant minority will never develop functional verbal language.

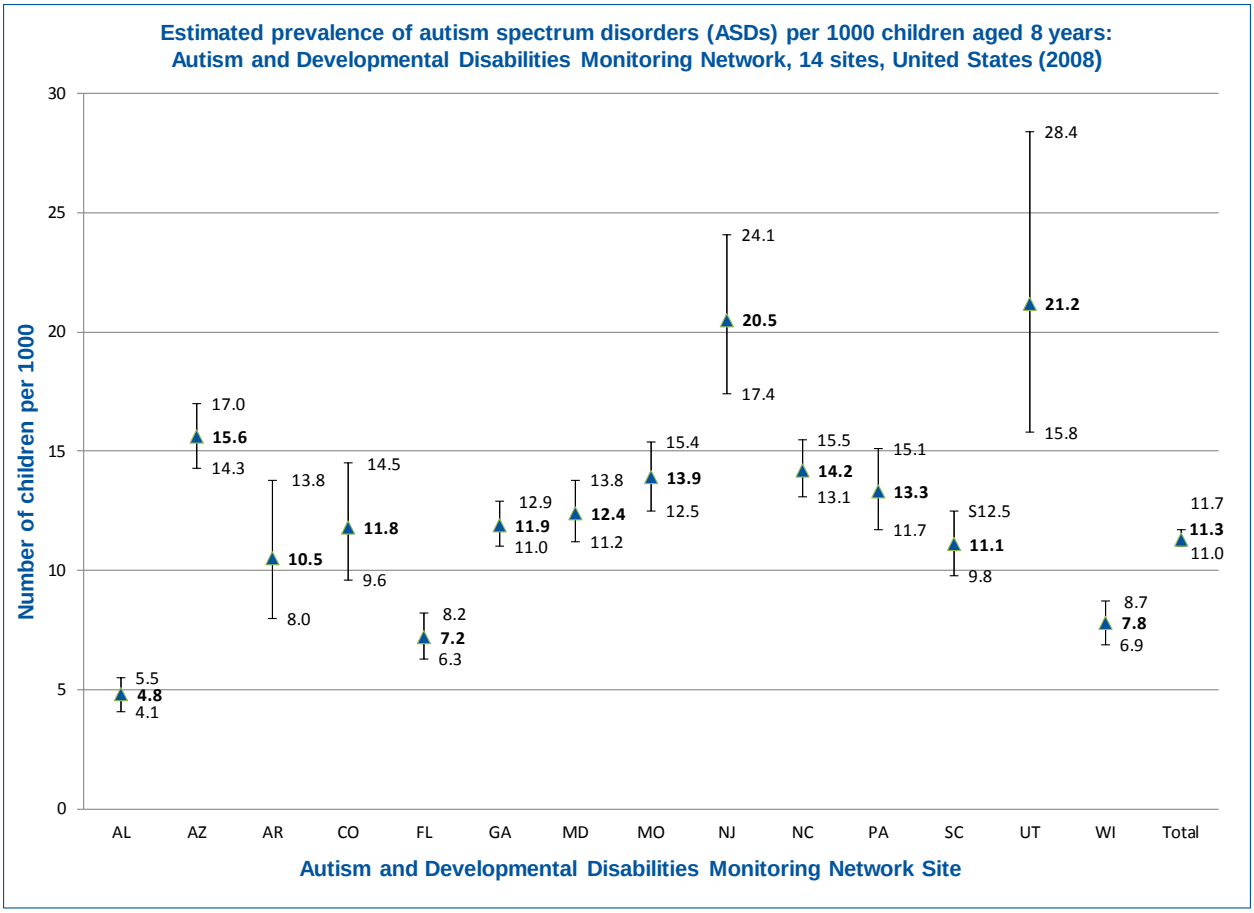
A. Prevalence of autism spectrum disorder

Population prevalence measures the burden of ASD in a defined population. An understanding of ASD prevalence is essential for planning and evaluating public health programs, developing or updating policies, or making decisions about resource allocation. Estimating prevalence in defined populations is necessary for tracking trends in ASD over time. Population prevalence of ASD is formally defined as the proportion of people in a specified population who have a newly diagnosed (incident) ASD or had an existing ASD diagnosis (prevalent) at a specific point in time (point prevalence) or during a specific period of time (period prevalence). Population prevalence is calculated by dividing the number of new and existing ASD cases identified in the population at a given time by an estimate of the size of the (defined) population during the specified time.[9]

Estimating ASD population prevalence is not straightforward because identifying children with ASD in a population is challenging.[10,11] ASD symptoms vary widely in populations. The age at first identification can vary depending on severity[12,13] and other factors like access to services.[14] The symptoms expressed can also be different by age.[15] Furthermore, as mentioned, a diagnosis depends on clinician judgment and parental report rather than on a biological or genetic test with known reliability and validity. There are a variety of diagnostic and evaluation tools used to identify ASD in children and each of these tools differ in being able to detect children who truly have ASD (diagnostic test sensitivity) and do not have ASD (diagnostic test specificity). Additionally, clinicians and professionals in the community do not use these diagnostic tools consistently, reducing the reproducibility of an evaluation. Another complication especially for identifying people with existing diagnoses of ASD in the population is that there are differences in how ASDs are defined and classified in a medical setting such as a medical facility or affiliated specialty clinic compared to an educational setting in the public school system.[16]

One method for reducing the variability in prevalence estimates is to establish a public health surveillance system that uses the same (or uniform) ASD case definition and standard procedures for confirming the presence of an ASD in poten tial cases. This is the approach taken in the CDC's ADDM Network surveillance methodology. However, there is still wide variation in the prevalence estimates across sites that utilize the same ASD case definition and case confirmation procedures. As seen in Graph 1 below, there is a more than a four-fold (21.2/4.8) difference between the highest (Utah) and lowest (Alabama) prevalence estimates.[4] These results suggest that other sources of variation need to be considered when establishing a public health surveillance system to estimate and monitor the prevalence of ASD in populations.

Graph 1: Variation in Prevalence Estimates[4]



A variety of other factors can affect ASD prevalence estimates. Variations can arise because of differences in population characteristics and methods used to collect data.[17,18] Higher prevalence estimates are observed in older (e.g., grade school aged) versus younger (e.g., preschool aged) populations, and in smaller populations (e.g., cities) versus larger (e.g., states) populations. Thus, to reliably estimate ASD prevalence over time, the population needs to be clearly and consistently defined by demographic factors like age and geographic region. Higher prevalence is also estimated when surveillance systems collect data from multiple sources (e.g., health records and school records) compared with systems that collect data from a single source of data (e.g., only health or only school records).[17] Variation within data sources may be important. In particular, some variation in the CDC's ASD prevalence estimates in the chart above can be accounted for by the amount and quality of relevant data in child records, as well as the completeness of case finding efforts at ADDM Network sites (i.e., the number of records that should have been but were not abstracted).[19] The differences in state statutes determining who is eligible for ASD special education services[20] may also play a role among ADDM Network sites that have access to public school special education records.[21]

Although some variability in prevalence is expected, extremely wide variations limit the usefulness of these data for state and local public health. Establishing a public health surveillance system for ASD in Minnesota requires an awareness of potential sources of variation and the methods used in public health surveillance to control for them. But variation in prevalence is not the only consideration. A decision on which approach is best for Minnesota should also consider the goals established for a public health surveillance system for ASD. The goals of the system will be considered in Section II of this report. In subsequent sections, the strengths and limitations of general types of surveillance are briefly considered, and strengths and limitations of two specific approaches will be compared and contrasted in considering possible models for public health ASD surveillance in Minnesota.

B. Causes of autism spectrum disorder

About 10% of ASD cases occur secondary to other primary health conditions, including fragile X syndrome, untreated phenylketonuria, tuberous sclerosis, and fetal alcohol syndrome. The exact causes for the majority of ASD cases are currently unknown. Various environmental, biologic, and genetic components have been associated with ASD. Congenital rubella and prenatal exposure to such prescription drugs as valproic acid and thalidomide have been associated with ASD.[22] Recent research has examined potential associations with the perinatal period. Some prenatal and postnatal factors that have been more consistently associated with ASD include low birthweight, preterm birth, and advanced maternal and paternal age.[23,24]

Multiple factors interact in complex ways to cause autism.[25,26] There is a strong heritable component to ASD risk, and multiple genes have been associated with ASD through identical twin studies. These studies have demonstrated that if one twin has ASD, the other twin will have ASD 36-95% of the time.[15] In addition, parents who have already had a child with an ASD have an increased likelihood of their second child being diagnosed with an ASD. The recognition of shared symptoms and co-morbid conditions between ASD and other conditions including ADHD and epilepsy, in particular, have opened up new lines of research into ASD.[27,28,29,30,31,32] Studies have also shown irregularities in multiple regions of the brain in participants with ASD, noting another potential cause.[15] Researchers have hypothesized that abnormality in the serotonin and neurotransmitter levels may play a role. These abnormalities suggest ASD may occur as a result of a disturbance in normal brain development. This disruption likely occurs during early fetal development supporting additional evidence that the critical period for developing ASD occurs before birth. Findings like these underscore the need to develop a better understanding of the genetics, biology and the neuropsychology of ASD.[26]

Large numbers of participants in studies are needed to conduct causal research, and few states alone will have enough children with ASD to meaningfully study hypothesized causes of ASD. For example, the CDC's Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) Network is conducting the Study to Explore Early Development (SEED).

This study includes 38 counties in 6 participating U.S. states, making it the largest multisite study of genetic, environmental, pregnancy, and behavioral risk factors for ASD.[33] Since 2008, a total of 3,782 families have been enrolled and the study aims to add an additional 2,500 families before the study is completed. (See Appendix 1 for a more detailed list of existing ASD research projects). Because of the large sample sizes needed in studies, the major sources of funding for ASD research in the U.S. are the federal government and private research foundations. Chart 1 displays the relative contributions of grant funding from these sources between 2008 and 2010. Federal funding increased from $143,724,845 (65%) in 2008 to $334,441,512 (82%) in 2010, after American Recovery and Reinvestment Act (ARRA) dollars for ASD research became available in 2009.[34,35] The types of studies also changed slightly since 2008, with a greater proportion of studies into services, biology, infrastructure and surveillance and lower proportions of studies into risk factors, and treatment and interventions (See Chart 2).

Chart 1: Sources of Grant Funding for ASD Research[34,35]

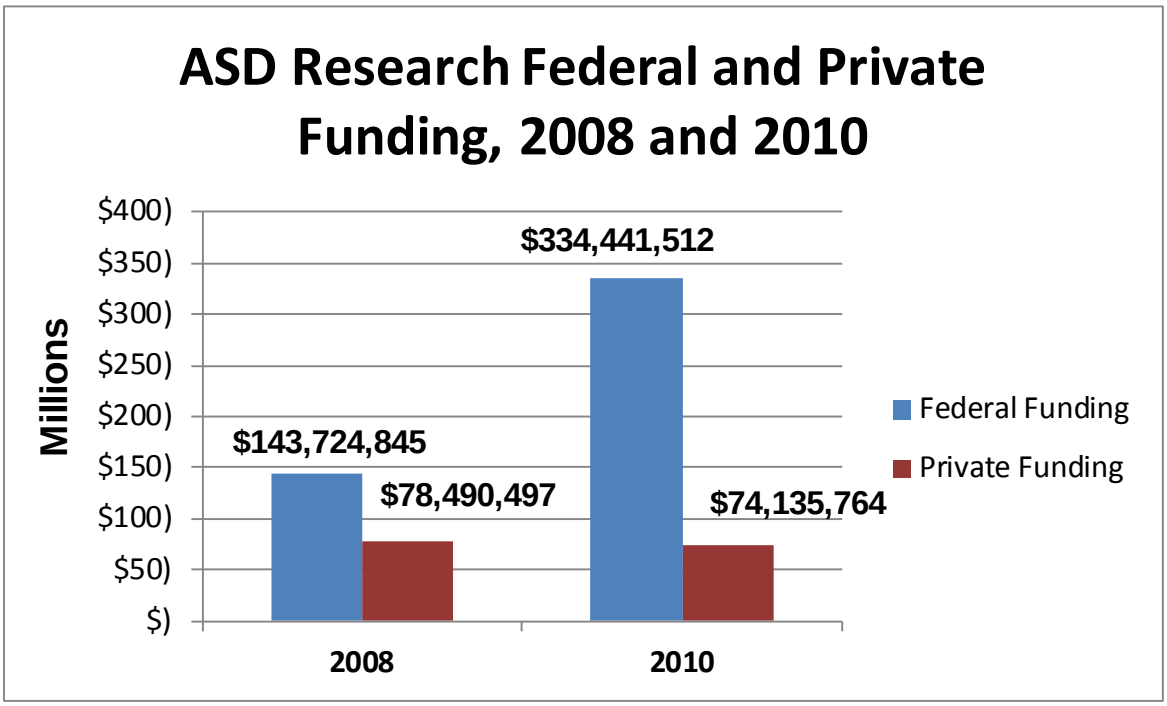
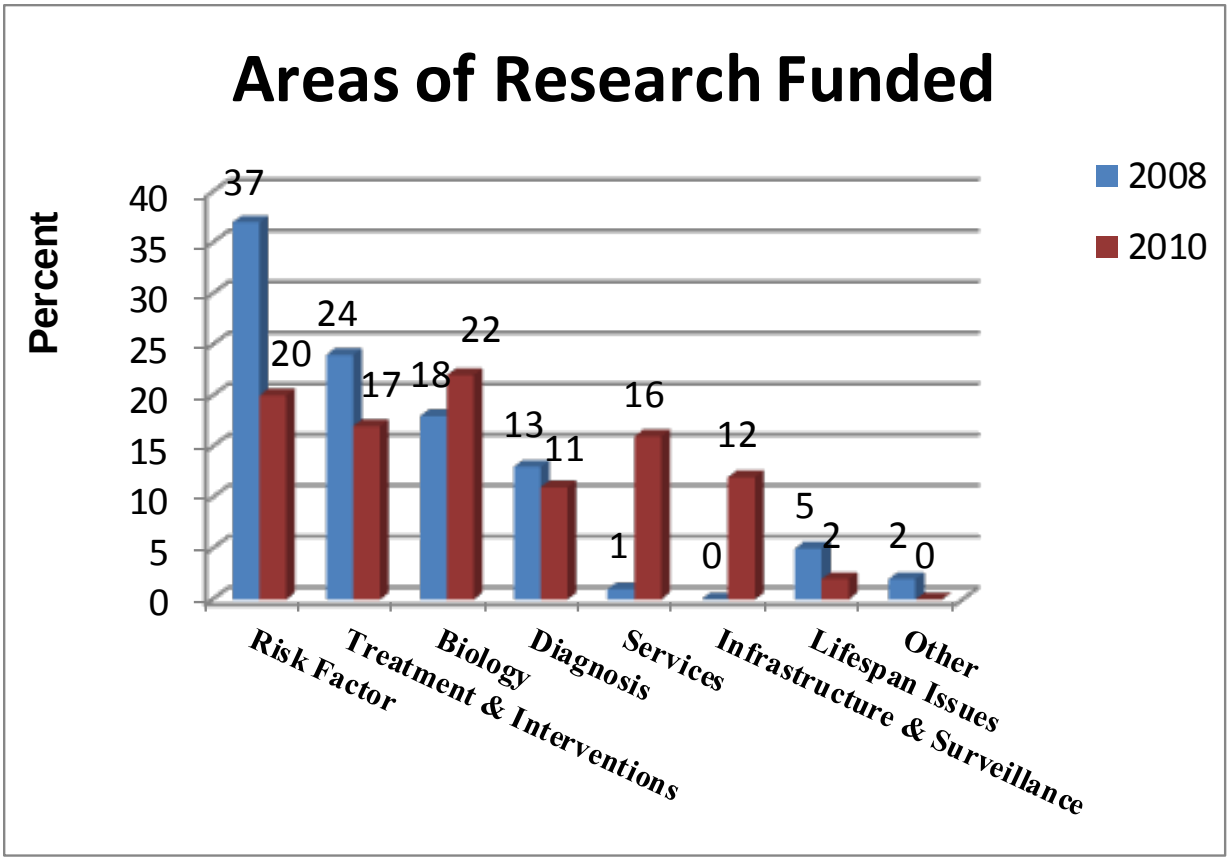


Chart 2: Areas of ASD Research Funded[34,35]



C. Burden

ASD is a major public health problem, with impacts on the family, as well as the health care and educational systems that serve children with a diagnosis of ASD and their families. In 2012, researchers at CDC published a study that showed the average annual medical costs for Medicaid enrolled children with an ASD were $10,709 per child, which was about six times higher than costs for children without an ASD ($1,812). Overall health care costs for ASD in the United States have reached an estimated $60 to $90 billion dollars a year.[38] In addition, ASD educational services are considered to be one of the most intensively staffed and expensive forms of interventions with costs often being three times more than for other educational services. Intensive behavioral interventions for children with ASDs can cost $40,000 to $50,000 per child per year. Increases in the number of children who have been identified with an ASD will significantly impact the overall ongoing costs for both the health care and education systems. In 2000, CDC reported that 1 in 150 children had a diagnosis of ASD but by 2008 the diagnosis of ASD had increased to 1 in 88 children.

To achieve better outcomes for children and to reduce the overall costs associated with ASD, early identification and intervention is critical. Early identification and intervention has been shown to reduce the lifetime costs associated with ASDs by as much as 2/3. This savings can equate to as much as one to two million dollars per person.[36]

Core family members face the greatest burden when dealing with a child with ASD. This burden comes both in the form of emotional distress and financial struggles. The greatest emotional impact is felt by siblings, mothers, and fathers. Siblings often suffer from increased social and behavioral adjustment problems, have an increased risk of internalizing behaviors, and display less intimacy and nurturance throughout their life. Mothers primarily deal with a greater degree of negative feelings leading to an increased rate of depression. In addition mothers are less likely to participate in social activities due to the increased time requirement of a child with ASD, exasperating the emotional burden further. A father's emotional struggles generally stem from stress, pessimism, and depression resulting from the financial hardships associated with an ASD diagnosis in the family. These responsibilities and adversities take a heavy toll on the parent's relationship as well. Parents who have a child diagnosed with ASD generally deal with more conflicts, lower marital happiness, higher stress, less adaptability, and a 70-80% increase in divorce rates.[37]

The economic burden of ASD within a family is similarly substantial. This burden is the result of high costs associated with multiple therapies or interventions, including: intensive behavioral intervention, comprehensive educational interventions, speech language therapy, social skills instruction, and occupational therapy and life skills support. These therapies aim to achieve social communication competence, emotional and behavioral regulation, and functional adaptive skills. ASD can cost a family approximately $60,000 dollars a year out of pocket, with an estimated lifetime cost of $3.2 million dollars.[38] In addition to the enormity of costs associated with ASD, the economic burden is worsened through lost wages. On average, household earnings were approximately 28% or $17,763 dollars less than families with children having no health limitations and, 21% or $10,416 dollars less than families whose children were diagnosed with a different health limitation.[39] This discrepancy in income can be generally attributed to lost work hours due to the increased time demand of a child with ASD. Mothers most often sacrifice full-time status, and often their employment entirely in order to meet the needs of their child. The combination of increased costs and lost wages reduces the amount of savings a family can accumulate, and are the major factors associated with the economic burden of ASD within a household.[40]

D. Intervention and treatment options for autism spectrum disorder

Presently there is no cure for ASD, however early intervention has shown to significantly improved outcomes. For early intervention to be most effective ASD must be identified between the ages of zero to three. Unfortunately, data show that diagnosis is often delayed, with only 18% of diagnoses occurring by the age of three.[41]

There are various treatment options for ASD. Treatment of ASD should aim to minimize core features as well as maximize function independence, quality of life, and family function.[6] When treatment is provided early, the overall outcome of an individual can substantially improve. For this reason treatment should begin as soon as ASD is suspected, even if a definitive diagnosis has not been made. Treatment options are generally separated into either educational/behavioral or pharmaceutical categories. In many cases the use of both is warranted and most effective. The use of medication is not used as the primary form of treatment for ASD. There are few medications that effectively relieve the core symptoms for ASD – communication difficulties, social challenges, and repetitive behavior. As mentioned, there are several "co-morbid" medical and behavioral conditions that often occur with ASD. These conditions can often be controlled and treated with medication.

II. Public Health Surveillance of Autism Spectrum Disorder

The Centers for Disease Control and Prevention (2012) define public health surveillance as:

> …the ongoing, systematic collection, analysis, and interpretation of health data, essential to the planning, implementation and evaluation of public health practice, closely integrated with the dissemination of these data to those who need to know and linked to prevention and control (p. 10).[42]

In essence, public health surveillance systems provide data on counts and rates of cases of a disease in a defined population and time period, and serve as a foundation on which to develop public health disease prevention and control activities. Historically, data from public health surveillance systems have been used to inform governments of the policies and actions needed to protect the public's health from infectious diseases such as cholera, smallpox, tuberculosis, HIV/AIDS, foodborne outbreaks, as well as from chronic diseases including cancer, asthma, and diabetes.[43,44] More recently, public health surveillance has monitored threats from pandemic influenza, bioterrorism events (anthrax), and emerging antibiotic-resistant infections (strep, gonorrhea, tuberculosis).[43] A public health surveillance system for ASD in Minnesota can serve a similar function, providing data to inform a public health response to ASD.

The potential benefits of population-based public health surveillance system in Minnesota are directly related to the goals of the system[44] and, specifically, how the data are used in prevention and intervention activities at the state and local levels. To ensure that data are broadly available

for these activities, the goals for a population-based public health surveillance system for ASD should include: 1) Estimating prevalence and monitoring trends in ASD; 2) Assuring that children with ASD and their families are linked to appropriate health care and related services; 3) Informing public health policy and programs; 4) Addressing concerns about ASD in communities and educating citizens and professionals about ASD; and 5) Supporting health services and ASD causation research. Illustrations of how public health surveillance data for ASD could be used to address these goals are outlined as follows.

1. Estimating prevalence and monitoring trends in ASD

Estimates of population prevalence are needed to characterize the burden of ASD in Minnesota and track trends in prevalence over time. However, reliable and accurate data on ASD population prevalence do not currently exist in Minnesota. Special education administrative data from public schools, though readily available, cannot provide a complete and accurate picture of ASD occurrence in Minnesota, overall or by demographic subgroup.[45,46,47,50] Administrative data track categorical special education eligibility in the public school system under the Individuals with Disabilities Education Act. A child with special education needs may meet the criteria for more than one category, and the program developed for any given child is determined based on the best program option and service setting to meet the needs of that child. Thus, Minnesota children with ASD may or may not be served under the ASD category, and some children who do not have ASD may be served under the ASD category.

National surveys, such as the National Survey of Children's Health[48] or the National Survey of Children with Special Health Care Needs,[49] offer another source of data on ASD occurrence. These data can yield state-specific estimates for the prevalence of parental reported ASD prevalence; however, sample sizes are too small to yield reliable estimates of ASD prevalence by age-groups, race/ethnicity, or smaller geographic regions. Clinic-based registries also exist, but the data from these registries are subject to bias from clinic referral patterns. Further, participants in clinical registries are typically volunteers who are not representative of all individuals who have ASD.

A population-based (i.e., from a known population) public health surveillance system for ASD is needed in Minnesota to estimate ASD prevalence rates for the entire state as well as for counties and regions. The system's data would enable calculation of population prevalence to assess the frequency and severity of ASD for the state overall, as well as population subgroups defined by race, ethnicity, sex, geographic region, and other social or demographic factors. The resulting estimates could be used to accomplish the four other stated goals of the surveillance system.

2. Assuring that children who have ASD and their families are linked to appropriate health care and related services

Children with ASD can have complex medical needs that change as they age into adulthood. Developing a long term follow-up program that leverages existing community partnerships in conjunction with a population-based ASD public health surveillance system would help connect these children and their families to statewide resources and needed services. Data from a Minnesota-based public health surveillance system for ASD could be used in existing follow-up programs to ensure that the services needed for children with ASD are available, accessible, timely, and effective as they age and transition into adulthood.

3. Informing policy and program decisions

Recent analyses of special education administrative data have identified differences in enrollment in ASD special education programs by race/ethnicity both in Minneapolis[50] and the state.[51] Differences in the age at first entry[51] and age of first ASD diagnosis[52] were also identified for some ethnic groups. These patterns may reflect differences in evaluation and assessment practices in Minnesota schools and communities, or they may point to the possibility of underserved populations in Minneapolis (as well as the in state) who are not receiving early and appropriate intervention services for ASD. These differences might also reflect differences in ASD risk between populations, but without a systematic method for collecting population-based data clarifying these patterns in the population is not possible. A public health surveillance system represents the first step in identifying unmet needs or delayed entry into intervention services and offers policy makers or programs opportunities to address issues facing families or systems of care.

Data could also be used in assuring evidence-based interventions and services are accessible in all geographic areas in the state to all cultural and socio-economic groups across the ASD spectrum. If gaps in the system are identified for specific regions of the state or subpopulations, decision makers and public health planners could change policy or develop programs and improve systems to address unmet needs of children and families.

There is interest in understanding the baseline estimates of the time of ASD identification and the estimates of time from identification to access of necessary services.[53] This information would allow policy makers and programs to determine how to best improve screening and referral processes to assure that all children with ASD are identified early and linked promptly to the interventions that will support optimal outcomes.

4. Addressing concerns about ASD in communities, and educating citizens and professionals about ASD

The capacity to address citizen concerns about ASD is inadequate. For instance, in 2008, concerns were expressed in the Somali community of Minneapolis about ASD occurrence in preschool aged children enrolled in Minneapolis Public Schools special education programs. Although administrative data for enrollment in special education programs offered in the public schools were readily available for epidemiological analyses, these data could not provide a clear picture of how ASD population prevalence for Somali children compared with ASD prevalence for other populations in the city.[50] Having statewide baseline and trend data on ASD prevalence would have enabled state epidemiologists to quickly address such concerns for communities throughout the state. The lack of answers, combined with heightened fears in the Somali community that routine childhood vaccinations were the cause of ASD in their children, led to increasing numbers of Somali parents refusing routine immunizations for measles, mumps, and rubella (MMR) for their children. As a result, the incidence of these preventable infectious childhood diseases has increased and overall ("herd") immunity in the population has decreased, creating a second public health problem in the state. Data available from a public health surveillance system for ASD would have enabled state epidemiologists to examine prevalence patterns in the population and address community concerns quickly, and may have alleviated concerns over MMR as a possible cause of ASD.

5. Supporting health services and etiologic research

Experts have recognized that data from a public-health surveillance system cannot be used to study the causes of ASD.[21] But public health surveillance data can broadly support research efforts into the potential causes of ASD. For instance, descriptive analyses may identify variations in prevalence by subgroups of the population defined by age, race, ethnicity, geographic region, and other socio-demographic characteristics. If these differences were substantial, researchers could design studies to examine hypotheses that might explain the observed differences in prevalence. For example, substantially lower ASD prevalence in American Indian children has been observed in Minneapolis. These findings might suggest that there are cultural barriers to accessing diagnostic, evaluation, and intervention services for American Indians. Health services researchers could conduct follow-up studies to examine hypothesized barriers and test specific system interventions that might improve access for this population. Hypotheses regarding factors in the environment could be generated though linkages with ASD public health surveillance data and existing datasets,[21] such as those from the Environmental Tracking Program at the Minnesota Department of Health. If significant associations between ASD prevalence and an environmental factor were uncovered, academic researchers could design epidemiological and clinical studies to investigate these associations more carefully. Finally, data on ASD cases in Minnesota could be used to facilitate connections with academic and other researchers so that families with

children who have ASD could learn about opportunities to participate in multicenter studies of ASD services, treatment, and etiology.

III. Tracking ASD in Other States

Establishing a public health surveillance system is a complex enterprise that requires careful planning to determine the system's objectives, develop a case definition, determine the method of data collection and the appropriate sources of data, determine and possibly develop the data collection instruments, field-test methods, develop and test the analytic approach, develop the dissemination mechanism, and finally determine plans to ensure use of data analyses and interpretation.[44] Other key planning activities include, identifying and engaging stakeholders, and determining and implementing data sharing policies and procedures while assuring data protection and privacy. To ensure complete case finding, access to individual-level protected health information (PHI) and administrative data for children enrolled in special education programs is needed.

To gather information on how states monitor the prevalence and burden of ASD, between 2012 and 2013 MDH performed searches of the academic literature and state websites. A random sample of 20 states was also selected to interview state officials about that state's own experience with ASD surveillance (if any) and validate the information posted on their websites. The results of these investigations provide valuable insights into various methods for surveillance.

The CDC previously identified possible approaches to ASD surveillance summarized in Table 1. Two relatively recent approaches identified in literature reviews and interviews with officials in other states were also added as possible approaches. The public health surveillance approaches displayed below range from the mass screening and evaluation of children in a defined population to identify ASD cases, to analyzing complex survey sampled data to estimate the parental reported prevalence of ASD among children in defined age groups. Each of the seven approaches has strengths and limitations.

Table 1: Approaches to public health surveillance for ASD [ii]

Method	Description	Strengths and limitations
Population screening and evaluation	Screening and evaluating a sample of all children in a population	Can provide high accuracy and identify cases who have not used services, but screening can be costly and time-consuming, and might reflect bias on who participates.

[ii] Adapted from Van Naarden Braun, K., Pettygrove, S., Daniels, J., Miller, L., Nicholas, J., Baio, J., Rice, C. (2007, February 9). Evaluation of a methodology for a collaborative multiple source surveillance network for autism spectrum disorders – Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2002. *Morbidity and Mortality Weekly Report: Surveillance Summaries, 56*(1), 29-40.

Cont'd: Table 1 – Approaches to public health surveillance for ASD

Method	Description	Strengths and limitations
National surveys (e.g., National Survey of Children's Health, National Survey of Children with Special Health Care Needs)	Collecting information via standardized data collection instrument which can be administered as an in-person or telephone interview or as a self-administered questionnaire.	Is representative of national and state characteristics (depending on the sampling design), but might reflect bias on who participates, how ASDs are defined and reported (e.g., parental report). Sample sizes are often too small to provide reliable state and local/regional ASD prevalence estimates.
Registries	Voluntarily including oneself or one's child on a list of people with ASD	Relatively low cost, potentially time-consuming, but includes only individuals with an existing ASD diagnosis, and families who know about the registry and are willing to be on the list.
Administrative data	Gathering ASD data from administrative or service records, such as hospital discharge, Medicaid, and special education records	Relatively low cost, but underestimates prevalence because not all children with ASD are receiving services through these venues for their condition
Systematic record review (e.g., Autism and Developmental Monitoring (ADDM) Network - CDC)	Reviewing health and special education administrative records to identify children with ASD behaviors	Uses multiple data sources to identify children with ASD behaviors who are served in schools and/or clinics. It is time-consuming, resource intensive and relies on the availability of existing records, in addition to the quality and quantity of information in records. This system is not implemented statewide because of costs and resource needs.

Cont'd: Table 1 – Approaches to public health surveillance for ASD

Method	Description	Strengths and limitations
Mandatory reporting	Requires health and service providers to submit ASD case reports to the surveillance program	Surveillance programs typically create case reporting forms to collect data from multiple reporting sources from a facility. Medical information received by the program is generally accepted as reported without verification. Without an active approach to quality assurance, incomplete reporting of cases is possible.

The results of Internet searches and telephone interviews with state officials revealed that the majority of U.S. states do not have public health surveillance systems for ASD, largely because of a lack of funding, resources and support. However, most of these states have a legislative ASD task force that has recommended the establishment of a public health surveillance system for ASD. In Minnesota, the Autism Spectrum Disorder Task Force was charged by the Minnesota Legislature to develop an autism spectrum disorder statewide strategic plan,[iii] with a focus on improving awareness, early diagnosis, and intervention and on ensuring delivery of treatment and services for individuals diagnosed with an ASD. The statewide plan, published in December 2012, was designed to support the efficient use of state and federal dollars and establish an effective system of high quality, evidence-based, interdisciplinary, culturally appropriate services and supports for individuals with ASD and their families in Minnesota. The task force identified that data informed policy was important for meeting the goals of the plan, and include determining ASD prevalence in Minnesota as one of the plan's possible implementation activities.

Some states interviewed reported prioritizing services and referrals to families and children with ASD over tracking population prevalence, primarily because of the complexity and costs associated with establishing and maintaining a public health surveillance system. All states that were interviewed considered public health surveillance of ASD as public health practice and not as research into the causes of ASD. Voluntary registries exist in two states solely to facilitate connections between researchers and families; these voluntary registries are **not** used for estimating the burden of ASD in the population. Only two of these seven approaches to ASD public health surveillance were commonly used in practice in other states. These approaches are described in more detail below.

[iii] Minnesota Autism Spectrum Disorder Taskforce (2012). *ASD Task Force: Strategic Plan Report.* Retrieved from http://www.lcc.leg.mn/asd/2013-14/ASDStrategicPlanReportWEB.pdf

A. ADDM Network: 12 states

The ADDM Network is currently conducted in 12 states funded through a cooperative agreement with the CDC (See Appendix 2). Participating states gather data from existing health and school records on ASD cases residing in a defined catchment region representing a base population of approximately 20,000 8-year old children. The goals of the ADDM Network are six-fold: 1) Obtain as complete a count of the number of children with an ASD in the study sites; 2) Provide comparable population-based ASD prevalence using uniform methodology; 3) Study whether ASDs differ in population subgroups; 4) Collect data over time to examine trends in ASD to assess whether prevalence is changing over time; 5) Provide data to describe the population of (8-year old) children with ASD; and 6) Improve consistency of identification of people with ASD.[10]

The authority for an ADDM Network site to access protected health information (PHI) from health facilities is granted either through state mandate for notifiable disease reporting or local institutional review board processes at individual health facilities.[4,10] Statutory authority for access to PHI allows the sites to make arrangements to access individual level health data at the institutional level by means of contracts or other formal agreements,[4] and is preferred over the time-consuming and costly process of obtaining IRB consent at each individual reporting facility. In early years of the system, there may have been sites in some states without mandates for ASD reporting. It is unclear whether all ADDM Network sites in the current system have authority to access PHI under statutory authority. The authority to access public school special education records is governed by the Family Educational Rights and Privacy Act (FERPA), and arrangements to access special education records vary between sites. At a minimum, some sites may have institutional agreements in place facilitating access, but in at least one state, Colorado, parental consent for access to a child's special education records is required.

The ADDM Network implements a uniform ASD case definition and data collection protocol, in addition to rigorous training and ongoing data quality control and assurance protocols. As described below, identifying ASD cases for prevalence estimation is carried out in two steps: 1) record review and abstraction and 2) clinician review. Prior to carrying out these steps, staff at each reporting facility selects the charts that will be reviewed in step 1, based on a child's residency, age in the surveillance year, and diagnostic codes (medical and health facilities) or enrollment in any special education program during the surveillance year (public and charter schools). The list of ICD codes (medical and health facilities) or special education programs used in the initial record selection at reporting facilities can be found in Appendix 3.

1. In the first step, trained ADDM Network surveillance staff review the selected child records at each facility to identify potential cases. The criteria for identifying potential cases includes one or more of the following: 1) a documented ASD diagnoses or a suspicion of an ASD or ASD test performed by a qualified professional, 2) an ASD special education classification, or 3) any behavioral "triggers", which are descriptions of behavioral symptoms commonly seen in children with ASD. The data from records for potential cases are

abstracted and entered into central project database provided by CDC. The information abstracted contains verbatim text descriptions of a child's development and behaviors from comprehensive evaluations, in addition to health and family histories, diagnostic and educational classification results, and reporting source information.[10]

2. Second, after the records for each child are processed, trained clinician reviewers manually review the composite record for each child to determine whether the information on a child meets the surveillance case definition for ASD,[10] which is based on the DSM-IV-TR with slight modification. Prevalence for 8-year old children in the catchment region during a given surveillance year is estimated as the number of children who met the residency requirements and ASD surveillance case definition in the surveillance year divided by the estimated size of the population of 8-year olds in the catchment area in that surveillance year. Data collection for ASD cases in the ADDM Network is carried out biennially (every other year) and prevalence estimates are available approximately 3 to 4 years after a given surveillance year. For example, ASD prevalence estimates for the 2010 surveillance year are expected to be released sometime in 2014.

The surveillance methods implemented in the ADDM Network attempt to reduce sources of variation that, as described earlier, can impact the size of the resulting ASD population prevalence estimates and create artifactual differences within and across sites both in a given surveillance year and across different surveillance years (trends). A uniform ASD surveillance case definition based on the DSM-IV-TR has been adopted across all the ADDM Network sites. Case finding, data collection, and case determination procedures are detailed and documented. To carry out case finding and data collection procedures, data abstractors receive training and must pass initial and ongoing reliability tests. Clinician reviewers who manually review the case records and make the final case determination are trained and must also pass initial and ongoing reliability tests. To ensure complete case finding, the system uses multiple sources of data for case finding, and attempts to identify children with ASD without a pre-exiting ASD diagnosis are made on the basis of documented behavioral symptoms that are consistent with children who have ASD.[10]

Despite these strengths, as discussed in <u>Section I</u>, prevalence estimates from individual ADDM Network sites show wide variation in magnitude, pinpointing limitations in data sources and how surveillance methods were carried out. As mentioned, ADDM Network sites that do not have any access to special education data report significantly lower prevalence estimates than sites which have access to data from health and school sources. Furthermore, there are other potential limitations that should be considered:

1. <u>Potential for a Lack of Representativeness:</u> The CDC defines the representativeness of a public health surveillance system as the extent to which the system "accurately describes the occurrence of a health-related event over time and its distribution in the population by place [e.g., geographic region] and person [e.g., demographic characteristics such as age and race]." Because the true population prevalence of ASD can only be estimated

and not known exactly, representativeness can be examined by comparing the demographic characteristics of cases identified in the system with those from the population in the catchment region.[54]

Representativeness of a system is an important determinant of whether prevalence and other statistics estimated from a surveillance system can be generalized to populations other than the population in the system's catchment region. The ability to generalize findings is referred to as "generalizability." A lack of representativeness of the system results in a lack of generalizability.

There is some concern that the ADDM Network system comprised of all sites combined potentially lacks representativeness and therefore lacks generalizability to the U.S. overall. The population in the system represents less than 10% of 8-year old U.S. children in 2008,[55] and states participating in the ADDM Network were not selected as a representative sample of U.S. 8-year olds.[4] Instead, participating states were selected in a competitive grant application process on the basis of their ability to implement the CDC's rigorous surveillance protocol[4] in order to achieve the program's primary goal of accurately estimating and tracking ASD prevalence trends over time.

A lack of representativeness within participating states is an even greater concern, because state-specific data are necessary to inform public health responses to ASD at the state and local levels. Per CDC protocol, the catchment region within a participating state is typically comprised of a selected set of contiguous counties, often containing just a fraction of that state's population of 8-year old children in the surveillance year. These counties may not necessarily reflect the demographics and other important characteristics of the rest of the state. One example where there is a probable lack of representativeness is the State of New Jersey, which implements both mandatory reporting of ASD statewide in addition to an ADDM Network site. The ADDM Network catchment region in New Jersey for all surveillance years between 2000 and 2010 (excluding 2008) is located in the northern part of the state, considered a part of the New York Metropolitan Area, and is comprised of Union, Essex, Hudson, and Ocean Counties. The ethnic diversity of the state is not uniformly distributed, with racial and ethnic differences between the catchment region and the rest of the state.[56] In addition to the demographic differences between the ADDM Network study site and the remainder of the state, there are also differences in access to ASD diagnostic and intervention services with the more southern rural counties having few resources than the more urban northern area. The lack of representativeness means that data collected from the ADDM Network site in New Jersey may not be as useful as data from New Jersey's statewide mandatory ASD reporting system for use in ASD public health prevention and control programs at the local levels for much of the state.

The potential lack of representativeness of the ADDM Network model is a major limitation for Minnesota. There is an uneven distribution of the Minnesota population by race and ethnicity. Based on 2011 census data, the majority (61%) of American Indians resides in non-Metropolitan Minnesota whereas the majority (86%) of African Americans resides in the 7-county metropolitan area.[57] There are substantial health disparities among Minnesota's racial and ethnic minority populations. Only a statewide system in Minnesota would provide the needed data both at the state and local levels to develop a public health response to ASD for all Minnesotans.

2. Low Sensitivity, Predictive Value Positive, and Incomplete Case Ascertainment: Completeness of case ascertainment is important in public health surveillance because it measures the extent to which a system identifies all eligible cases in the catchment region. Although most systems usually attempt to identify all eligible cases who meet the inclusion criteria defining the population (e.g., residency, age) and the case definition for the condition or disease of interest, rarely are all eligible cases identified. Two other important attributes include sensitivity and predictive value positive[54] (See Appendix 4). Sensitivity measures the proportion of true ASD cases detected by a surveillance system. Predictive value positive measures the proportion of surveillance system cases that truly has an ASD. These attributes are used to characterize the accuracy of a surveillance system. As a part of routine quality control measures in well-established surveillance systems, designed studies are conducted periodically to assess the completeness of case ascertainment, sensitivity, predictive value positive and other attributes of the system. A surveillance system is then evaluated based on its performance in the study against established data quality standards.[58,59]

There is paucity of published literature documenting both established standards for completeness, sensitivity, predictive value positive and other related measures for the ADDM Network system, and evaluation results comparing the system's performance against these standards or benchmarks. Of the studies in the published literature, only one from 2010 was designed to evaluate the sensitivity and predictive value positive of the ADDM Network surveillance system.[11] Conducted at the ADDM Network site in Georgia, a probability sample of cases in the database was drawn and participating children were clinically evaluated for ASD to determine their "true ASD status." Sensitivity, predictive value positive and other measures were calculated. The sensitivity of the system was estimated at 60% (95% CI: 45%-75%) and the predictive value positive was 79% (95% CI: 66%-93%), implying that a relatively large proportion (40%) of 8-year old children with ASD were incorrectly identified as not having ASD, and approximately 1 in 5 children identified in the system as having ASD actually did not have ASD. The majority of "false negative" cases (11/12) did not have an existing ASD diagnosis documented in their records. Among "false positive" cases, about half had an existing ASD diagnosis in their records. The authors noted, among the other salient but highly technical findings, that ac-

curately identifying cases of ASD across the broad spectrum is difficult even using rigorous case ascertainment and confirmation procedures. Characteristics of the diagnostic tools used in the clinical evaluations and profiles of the cases (low IQ) may have contributed to the high error rates. Importantly, however, in this study ADDM Network surveillance methods did not identify a large proportion of children as having ASD despite the protocol identifying cases only on the basis of documented symptoms in addition to existing diagnoses in records.

3. Time-consuming, Resource Intensive Case Ascertainment and Confirmation Methods: The ADDM Network employs active rather than passive case ascertainment. In active case ascertainment, surveillance system personnel visit reporting source facilities to identify and abstract records for eligible cases. This is in contrast to passive case ascertainment, in which the personnel at the data source facility not only identify eligible cases, but also complete and submit case reports to the surveillance system. Compared with passive case ascertainment, active ascertainment methods have traditionally provided greater numbers of eligible cases to a surveillance system (i.e., more complete case ascertainment), and often have more complete data for the individual items collected resulting in fewer variables missing data (i.e., more comprehensive item reporting). Active systems are also less burdensome to staff in data source facilities.

These procedures, while efficient and cost effective compared to screening and evaluating individuals in a defined population, are still time-consuming and resource intensive. Interviews with staff in former ADDM Network sites provided insight into some of these challenges.

- One state reported that completing record reviews at facilities in rural counties was more time-consuming than facilities in urban areas. Data collected using either active ascertainment (as in ADDM) or a passive approach (as in mandatory reporting discussed below) may lack representativeness in this state because staff also reported that some school districts were not diagnosing cases because "they did not want to hire autism teachers." They reported that they thought the ADDM Network program ended in this state because they were unable to hire an epidemiologist.

- Another former ADDM Network site reported the program was probably discontinued because of an inability to gain access to public school special education records. Staff reiterated that the methods were very resource intensive and time consuming, and noted that it would be difficult to implement ADDM Network methods statewide because the resources and time needed would be substantial.

Additional perspective comes from Minnesota using ADDM Network methodology in a recent study of ASD prevalence study in Minneapolis.[52] The time and resources necessary to establish the relationships and infrastructure needed to implement the methodology were substantial.

B. Mandatory reporting: 7 states

Statewide AD surveillance systems based on mandatory reporting have been established in several states where ASDs are notifiable conditions, including: Delaware, Indiana, New Hampshire, New Jersey, Utah, Washington, and West Virginia. As such, the systems in these states are population-based, statewide, and implement passive case ascertainment methods. Required ASD reporting has been incorporated into four of these states' population-based birth defects surveillance programs: Delaware, Indiana, New Jersey, and Washington.[60] The objectives for population-based mandatory reporting ASD surveillance systems vary somewhat by site, but always include: 1) estimating and tracking ASD prevalence and 2) providing referrals for service. The objectives for the systems located in Indiana and New Jersey also include supporting health services and causal research.

Appendix 5 summarizes selected methods employed in mandatory reporting ASD surveillance systems for these states. The age range for the population covered by mandatory reporting surveillance systems is generally much wider than age criteria established for the populations included in the ADDM Network. There are also differences in age criteria between the states with mandatory reporting. Surveillance data that can characterize the burden of ASD through late adolescence has the advantage of being available for use in developing or evaluating programs and policy around the successful transition from childhood to adulthood. The ASD case definitions for these states differ somewhat depending on whether existing diagnoses were coded using the International Classification for Diseases (ICD) or DSM, or both systems. Finally, there are slight differences in the designated reporting facilities and providers within each of these states.

In these systems, state statute requires designated facilities and providers to report cases diagnosed with ASD to a specified state government agency. Facility and provider personnel identify eligible cases that have an existing ASD diagnosis using diagnostic and billing codes. Age and residency criteria usually determine a case's eligibility for inclusion in the system. Facility personnel also complete and submit paper or electronic case report forms containing demographic and health-related data for eligible cases to the state as appropriate. The authority to access protected health information is provided by statute, but establishing collaborative working relationships with facility staff is important to ensure complete and accurate data, especially if states do not have the authority to enforce ASD case reporting. Access to special education or other records from either the public or private school systems is not governed under state statutes. Therefore, like ADDM Network sites, states with mandatory reporting systems that want to include

special education records from school data sources must seek school district and parental consent to access these records.

Mandatory reporting systems have strengths and limitations. Research published in 2002 examining notifiable infectious diseases reporting systems implemented between 1970 and 1990 identified incomplete case ascertainment and lack of timeliness as primary limitations of passive case ascertainment systems.[61,62] Although electronic submissions and modern information technology have improved passive reporting systems substantially (discussed below), interviews with state officials confirmed that incomplete case ascertainment is a challenge for ASD mandatory reporting systems. As discussed earlier, incomplete reporting of cases has the potential to result in a lack of representativeness and a lack of generalizability. Another potential limitation with passive case ascertainment is that diagnostic practices throughout the state may not be consistent. This could lead to incomplete or incorrect reporting for some of areas of the state, leading to a lack of representativeness or the possibility of invalid data, especially if rigorous routine quality assurance and quality control measures were not key components of the system's operations.

Interviews with state officials identified additional challenges. Inadequate funding was reported as a barrier to improving case reporting in these systems. Two states interviewed reported that a lack of funding was an obstacle to establishing ASD public health surveillance systems in their states. The lack of compliance in reporting ASD cases coupled with a lack of reporting enforcement capability contributed to incomplete reporting and lack of comprehensive data. One state indicated that case reporting from therapists, psychologists, and psychiatrists was difficult to enforce. Incomplete reporting was reported to be more common in rural and school settings. Two states noted that the lack of access to special education data from public schools contributed to under-identification of ASD cases in their states. Finally, one state reported that the southern half of their state did not have sufficient professionals to diagnose ASD in children.

New Jersey's system, established in 2007, reports progress in moving toward more complete and comprehensive reporting. The system has several notable strengths. First, the funding for the registry is stable. The statewide system has an annual budget of $500,000 which pays for two registry full-time equivalent positions, part-time data entry clerks, and information technology support. The system receives its financial support from funds generated from moving violations. This fund also provides funding for special child case management and grant money for autism research in New Jersey (http://www.state.nj.us/health/autism/). Second, the system has authority to conduct quality control audits at facilities to identify missing and incomplete reporting thereby providing a mechanism for quality improvement. Third, the system utilizes information technology to improve the efficiency of the system. Facilities and providers are able to submit case reports electronically, reducing reporting delays as well as manual data entry. The system is linked to case management services to ensure that children and families are referred for needed services. Finally, the database can be linked with relevant health databases located within the health department to foster detailed descriptive analyses of prevalence and populations at risk for ASD.

IV. Proposed Approach in Minnesota

Considering the need for data across the state and balancing the strengths and limitations of two possible models for public health surveillance, a statewide rather than a regional public health surveillance system would foster and support a data-informed public health response to ASD at both the state and local public health levels for Minnesota children and adolescents. Based on the information gathered for this report, a statewide surveillance system based on passive case ascertainment that includes rigorous data quality assurance and quality control practices with automated data collection processes would best achieve the public health surveillance goals of the state. Establishing a new public health surveillance system is complex and costly. However, information technology and follow-up programs already exist in the state. Like other states, a public health surveillance system for ASD could be incorporated into existing data systems and follow-up support to families incorporated into existing programs, ensuring that children and adolescents with ASD and their families are connected to statewide resources and services.

Another advantage of adopting information technology standards is that it could minimize limitations related to completeness of case reporting, timeliness, and even facility burden of current passive reporting systems. The information technology exists to begin to harness these tools for a public health surveillance system for ASD. As early as 1999, the adoption of automated electronic laboratory reporting processes substantially improved the completeness and timeliness of passive reporting systems for notifiable infectious diseases.[61,62] Electronic reporting of case reports has been adopted and well-received in one U.S. mandatory reporting ASD public health surveillance system. Automated reporting from electronic medical records, coupled with the use of natural language processing software, inference rules, data and transmission standards, security, and other features promise sustainable, cost-effective statewide public health surveillance systems for chronic diseases, including ASD. The Electronic Medical Record Support for Public Health Informatics project (ESP) developed at Harvard University already utilizes these features to automate active case ascertainment methods[63] for public health disease surveillance for a variety of notifiable disease as well as diabetes.[64] Recent research into algorithm-based diagnoses using claims data is also promising, with reported results identifying cases with ASD with high positive predictive value, 87.4%.[65]

Incomplete case finding is a primary limitation of passive case ascertainment methods. Therefore, to ensure complete reporting of a system using passive case ascertainment methods, legislation would be needed to mandate the reporting of existing ASD diagnoses from health and mental health records, as well as special education records for individual children. Additionally, legislation permitting access to facility records to conduct routine data completeness and quality control audits would be essential to maximizing the completeness and comprehensiveness of the data in the proposed system.

As mentioned, establishing a public health surveillance system is a complex enterprise that requires careful planning and field testing of the components that make up the system. As outlined in the ASD Strategic Plan Report,[iv] a working group comprised of ASD professionals in the community, epidemiologists with expertise in public health surveillance, and IT staff would be beneficial in planning a statewide ASD public health surveillance system for ASD. Members of the working group would provide expert input on issues related, but not necessarily limited to:

1. Public health surveillance case ascertainment methods that maximize use of electronic transfer of data versus hands-on record reviews and data abstraction. .

2. The surveillance case definition for ASD and methods to field test the use of different data sources to ensure the case definition adopted is valid and reliable.

3. Possible quality assurance and quality control approaches as well as data quality standards to ensure that the system achieves and maintains data quality standards, and that all data collected are stored in a secure manner.

4. The specific data items to be collected from individuals to: (a) ensure that each individual only appears once in the database, (b) determine clinical severity and other characteristics such as low IQ to estimate ASD burden in the population; and (c) provide the necessary information for education, research, and public health program planning, policy development, and evaluation.

5. Use of the data in addressing the goals of the public health surveillance system for ASD. MDH would also engage a separate group of stakeholders in the community including families who have children with ASD to seek input on the goals for case management and long term follow-up.

6. Enabling legislation needed to administer the system, collect information, and distribute or share data, including rules, for example, on the type of data reported, standard for reporting specific data types, reporting facilities and providers, and data sharing with state agencies and researchers.

[iv] Minnesota Autism Spectrum Disorder Taskforce (2012). *ASD Task Force: Strategic Plan Report.* Retrieved from http://www.lcc.leg.mn/asd/2013-14/ASDStrategicPlanReportWEB.pdf.

APPENDICES

Appendix 1: National Research Efforts

CDC CADDRE

http://www.cdc.gov/ncbddd/autism/caddre.html

The Centers for Disease Control and Prevention (CDC) has established regional centers for excellence for ASD in seven states that make up the Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) network. States that are currently part of the CADDRE network include: California, Colorado, Georgia (CDC), Maryland, Michigan (data coordinating center), North Carolina and Pennsylvania.

The three goals of the CADDRE program are to:

1. Conduct center initiated special studies
2. to design and conduct a multisite study of causes and risk factors for ASD
3. To disseminate findings to increase public health awareness

Currently the CADDRE network is working on the Study to Explore Early Development (SEED II) study (explained in next section). Previous to working on the SEED the regional centers worked with the ADDM Network to monitor the prevalence of ASD. They also helped improve community and service provider awareness for ASD as well as increase access to services. The CADDRE network also conducted epidemiologic research into the risk factors for ASD.

Specific CADDRE programs

California: Partnership is a part of the Environmental Health Investigation Bureau and is a partnership between the Department of Developmental Services, Regional Centers, Northern California Kaiser Permanente, clinics, and other providers. Current studies include: Surveillance and Descriptive Epidemiology of Autism Spectrum Disorder, California Autism Study of Twins and Multiples, Kaiser Permanente Childhood Autism Perinatal Study, Hazardous Air {pollutants ad Risk Factors for Autism, Early Markers for Autism, Identification of Early Biologic Markers to Identify Infants at High Risk for Autism and Monitoring of Early Childhood Autism, SEED.

Colorado: Partnership between the Colorado Department of Public Health and Environment and JFK Partners at the University of Colorado. Current Studies: SEED.

Georgia CDC: Partnership between the National Center on Birth Defects and Developmental Disabilities and the Centers for Disease Control and Prevention. Current Studies: SEED

Maryland: Partnership between John Hopkins University and the Kennedy Krieger Institute. Current studies: SEED, Novel Circulating Biomarkers for Autism study, pilot study

to expand Baby Siblings study, NIH is funding a collaboration with Peking University to find out how to best study ASD epidemiology in China.

Michigan: Data Coordinating Center through Michigan State University.

North Carolina: Conducted by University of North Carolina at Chapel Hill. Current Studies: SEED, study to identify genetic factors that might affect mother and infant ability to respond to infection during pregnancy.

Pennsylvania: Partnership between University of Pennsylvania School of Nursing and the Children's Hospital of Pennsylvania. Current Studies: SEED, screening toddlers age 18 to 24 months for early signs of ASD.

Study to Explore Early Development (SEED)

http://www.cdc.gov/ncbddd/autism/seed-faq.html

The SEED study is currently being conducted in the 6 states previously mentioned: California, Colorado, Georgia, Maryland, North Carolina, and Pennsylvania. In total the 6 states study 38 counties nationwide. SEED is the largest multi-site study that is studying risk factors for ASD including genetic, environmental, pregnancy and behavioral factors.
Seed studies three main areas:

1. Physical and behavioral characteristics of children with and without developmental disabilities
2. Medical conditions among children with and without ASD.
3. Risk factors for ASD

So far 3,782 families have been enrolled in the study since 2008 and the study aims to add an additional 2,500 families before the study is completed. Of the 3,782 families that have enrolled in the study, so far 2,206 or 58.1% have completed all of the necessary steps for the study. The second data collection round of SEED, SEED 2 is about to begin data collection of children age 2-5.

Children's parents/caregivers who are enrolled in the study will be asked questions about their child's development and family medical history. The children enrolled in the study then have a physical exam and developmental testing by clinicians. Each child and parent will then give a sample of blood and saliva. The medical records of the mother and child will then be examined.

Interactive Autism Network (IAN)

http://www.ianproject.org/

The Interactive Autism Network (IAN) is a project of the Kennedy Krieger Institute that is a registry for autism research that matches researchers to families that will qualify to participate in

their studies. IAN is currently the largest online autism research effort with 42,874 participants, 400 treatments being studied and 270 studies in progress. The sponsors of IAN are: Autism Speaks, the Simon Foundation, and the National Institute of Mental Health (NIMH). IAN's overall goal is to accelerate and expand autism research.

Currently there are 45 academic institutions, 2 non-profit research groups, 2 national organizations, and 1 private research group currently recruiting adults for their studies.
Both children and adults who have been diagnosed with ASD by a professional are eligible to participate in IAN research. Children under the age of 18 must have a parent or legal guardian enroll them in the research. Adults may be able to provide consent for themselves, however if they aren't able to provide consent for themselves a legally authorized representative must enroll them in the research.

Those that enroll in IAN fill out secure online questionnaires that include information about diagnosis, behavior, environment and services that they receive. Researchers are able to use this information in their research. It also allows families to see what studies in their area or nationally they qualify to participate in.

Topics being studied that are currently recruiting participants include:

- Brain connectivity and autism
- ASD and genetics
- Brain areas and autism
- Language functioning and ASD
- Sensory integration and ASD
- Attention, autism and brain connectivity
- Visual processing and ASD
- Extended family and autism
- Immunology and autism
- Various treatments of autism
- Studying stress of parents with autism
- Sibling studies
- Maternal infections and ASD
- Biomarkers of ASD
- Early detection

IAN currently has three special projects: National Database for Autism Research, IAN genetics, and the Simons Simplex Collection. These projects are described in more detail below.

National Database for Autism Research (NDAR)

http://ndar.nih.gov/ndarpublicweb/faq.html

The National Database for Autism Research (NDAR) is a data repository for the National Institutes of Health (NIH). The purpose of NDAR is to accelerate autism research by providing an infrastructure that can integrate datasets from the same person, such as ge-

netic information, imaging, and clinical assessments that are made on the same person by different studies. This allows for meta-analysis of data and a better quality of research data.

NDAR is currently funded by the following institutes of NIH:

- National Institute of Mental Health
- National Institute of Environmental Health Sciences
- Center for Information Technology
- National Institute of Neurological Disorders and Stroke
- Eunice Kennedy Shriver National Institute of Child Health and Human Development

Currently NDAR has phenotypic, genomic, imaging and pedigree research data that researchers can search. NDAR is currently working on adding other types of data. This allows researchers to share information and data so they can have more robust analysis.

Over 70 NIH grantees share their data with NDAR. In addition to these grantees, other high quality data are accepted from other locations and funding sources.

To access the NDAR data institutions or investigators must complete a data access request form that will be approved or denied by the NDAR Data Access Committee.

IAN Genetics

http://www.iancommunity.org/cs/ian_research/ian_genetics

IAN genetics is collaboration between IAN and the University of California LA that is an initiative to increase the number of genetic samples available in autism research. This program allows people within the IAN network to get blood drawn locally at no charge to them. The labs send the samples directly to researchers. DNA is extracted from the blood and used for research.

There is also an incentive component of this initiative. Families that participate are given $25 Amazon gift cards to each member of the family that contributes DNA.
To be a part of this program the family must have a child with ASD between the ages of 4 and 17. Both parents of the child must be willing to give blood samples to be able to participate. One unaffected sibling between the ages of 4 and 17 is also allowed to participate.

The Simons Simplex Collection

http://www.iancommunity.org/cs/ian_research/simons_simplex_collection

The Simons Simplex Community is a research initiative that focuses on families that only have one person that has autism. This venture is led by the Simons Foundation. So far over 2,700 families have volunteered to be a part of this project and have given extensive

family histories and given DNA. This study aims to look at gene mutations and environmental factors that interfere with DNA by turning specific sections on or off. From this project they hope to understand more about the risk factors for ASD, the causes for ASD and potential treatments.

Autism Genetic Resource Exchange (AGRE)

http://agre.autismspeaks.org/site/c.lwLZKnN1LtH/b.5332889/k.B473/AGRE.htm

The Autism Genetic Resource Exchange (AGRE) is a program created in 1997 by Cure Autism Now that studies families that have more than one member that are on the autism spectrum. AGRE has been run by Autism speaks since 2006 when Cure Autism Now and Autism Speaks merged, however it has dual funding from Autism Speaks and the National Institute for Mental health.

AGRE is currently the largest private repository of clinical and genetic data to be used for autism research that has open access to any scientist. The goal of this program is to accelerate autism research by helping researchers with the time consuming process of recruiting new members and gathering information. AGRE has 2,000 families participating but isn't currently recruiting new families because of limited resources. Currently, more than 150 research groups are using AGRE for their research studies.

Families that participate can complete surveys via the Online System for Clinical Research [20]. Almost 1,200 surveys regarding environmental exposures have been completed and are available to researchers and cover such topics as household exposures, the mother's diet, parent's occupational histories and chemical sensitivities.

In addition to this survey information, as the name implies researchers have access to DNA data. Researchers who are a part of AGRE have access to the following data after being approved for access, depending on their research question:

- High Density SNPs
- Whole genome scan and finemapping
- 426 Genome-Wide high density 10k SNPs
- cell lines, DNA and plasma
- Fragile X screening
- Zygosity
- Autism Diagnostic Interview-Revised and Autism Diagnosis Observation Schedule testing results
- Various Cognitive assessments
- Medical histories
- Answers to surveys via the Online System for Clinical Research
- Demographic data

National Institute of Child Health and Human Development (NICHD) Efforts

http://nichd.nih.gov/research/supported/pages/ace.aspx

The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) currently funds several autism research efforts. NICHD has consolidated their prior research efforts into one more comprehensive program, Autism Center for Excellence program (ACE). ACE is an initiative funded by NICHD, the National Institute of Mental Health, the National Institute of Neurological Disorders, the National Institute of Deafness and Other Communication Problems and the National Institute of Environmental Sciences. The goal of this initiative is to support large studies of ASD to determine the causes and most of effective treatments of ASD.

There are currently 6 ACE research Centers:

- University of California Los Angeles
- University of California San Diego
- University of Illinois at Chicago
- University of Pittsburgh
- University of Washington
- Yale University

There are also 5 ACE Research Networks:

- Drexel University (EARLI study Early Autism Risk Longitudinal Investigation)
- University of California Davis (Early Steps)
- University of California Los Angeles (Genetics Study)
- University of North Carolina Chapel Hill (Infant Brain Imaging Study IBIS Network)
- Wayne State University (Buspirone study B-ACE)

The topics of studies conducted by these centers and networks include:

- Brain differences between those with and without ASD
- Genetics of ASD
- Behavior of those with ASD
- Prenatal and infancy risk factors for ASD
- Treatment of ASD

Autism Tissue Program (ATP)

http://www.autismtissueprogram.org/

The Autism Tissue Program is funded by Autism Speaks and collaborates with the Harvard Brain Tissue Resource Center. The goal of this program is to be a resource to make post mortem brain tissue available to autism researchers. This program covers the cost of brain extraction and

repository for donors. It also oversees how the tissue is distributed and managed. ATP currently has more than 170 brains that can be used for research.

Currently the Autism Tissue Program has four scientific initiatives:

1. Autism Celloidin Library: A collection of age and sex matched brain hemispheres of those that are affected by autism and those who are unaffected. These hemispheres are serially put into 3 separate series. The first series is mounted on a slide and stained with Crysl Violet, the second is mounted on a slide and stained with Gallocianin, and the third is reserved as a floating specimen.
2. Brain Tissue Genetic Repository: From each brain that is collected a small portion is removed and genetic analysis is performed to determine the number of copy number variations and small nucleotide polymorphisms. This data free to researchers.
3. Induced Pluripotent Cell Repository: The skin cells of donors are genetically engineered to be stem cells. These cells are then turned into brain cells. This repository hopes to further stem cell research in the development of autism.
4. Digital Imaging: ATP currently has an initiative in place to try to get 3D digital imaging of the brains that are part of the collection into an on-line library that can be used by researchers anywhere.

Those that wish to make a donation to the Autism Tissue Program, whether they have autism or not, can register with the program and will be given a card to keep in their wallet that tells health professionals that they want their tissue to be donated to ATP in the case of their death [24]. After the donor dies, ATP must be called by either a family member of healthcare professional so that they can prepare to take the sample. ATP provides bereavement counseling to family members of donors.

Unfortunately, the Harvard Brain Tissue Resource center suffered a loss of 147 brains at the end of May because of a malfunctioning refrigeration system. About a third of these brains were from people who were affected by autism. This is a setback to autism researchers everywhere.

Autism Research Institute (ARI)

http://www.autism.com/
https://www.facebook.com/pages/Autism-Research-Institute/135192033186466

The Autism Research Institute (ARI) is a nonprofit organization that funds and conducts research mainly regarding autism treatment, however also sponsors studies into the causes of autism. ARI focuses their research onto ventures that if successful could be quickly implemented in a clinical setting. ARI gave more than $1.5 million towards research grants in the past 3 years. They also fund a tissue bank for the NICHD through the University of Maryland which helps look at digestive functioning in affected and unaffected individuals.

It should be noted that ARI does fund a study conducted by the New York Department of Health. Also notable is that ARI is currently funding a study in Minnesota conducted by the Chris Bentley Fraser Center.

State Research Programs

Overall, research and interviews revealed that most states neither funded nor had employees conducting research into the causes or risk factors for ASD. Most of the state officials interviewed reported that while they weren't one hundred percent positive that their state didn't fund autism research, they didn't think that they did. Several of the states interviewed stated that they don't currently support research however they think that would be a great idea. Many states focus more on access to services rather than etiologic research. Three states were identified that supported research, either by funding or having state employees conduct research into the causes and risk factors of ASD: New Jersey, New York and California. Their research efforts are expanded upon below.

New Jersey
http://www.state.nj.us/health/autism/

The state of New Jersey funds ASD research through the Governor's Council for Medical Research and Treatment of Autism. The Governor's Council for Medical Research and Treatment of Autism was created in 1999 by Governor McGreevey. Originally it was centered out of the University of Medicine and Dentistry of New Jersey, however in 2007 Governor Corzine moved the council to the New Jersey Department of Health. The research efforts funded by this council are funded by a one dollar surcharge on all motor vehicle violations. This one dollar surcharge results in nearly $4 million annually that goes straight to autism research, education and treatment.

The Governor's Council for Medical Research and Treatment of Autism currently has fourteen members. Members of the council include academic officials, healthcare and autism organization representatives, appointees by the senate, the commissioner of health, a member of the general public, someone with autism, and family members of those with autism.

The council currently mainly funds studies through universities in the state of New Jersey. However the legislations is worded as follows:[32]

> "Council shall make awards of grants and contracts to public and nonprofit private entities to pay all or part of the cost planning, establishing, improving and providing basic operating support for a center of excellence for Autism in the state where basic and applied biomedical research, diagnosis and treatment for autism shall take place"

Areas of research the council is currently funding:

- Basic science research related to ASD
- Clinical research related to ASD
- Clinical enhancement programs to improve access to services

New York
http://www3.opwdd.ny.gov/hp/nyacts/

New York currently has an initiative called NY Initiative for Adults and Children on the Autism Spectrum (NYACTS). NYACTS has five categories of goals: to increase research, to put this research to good use and improve practices, to service as a bridge uniting public, private and nonprofit efforts, to improve services and support for people with autism and to five quality information to families of people with autism.

New York has an Office for People with Developmental Disabilities that has an Institute for Basic Research (IBR) that now studies, genetic and environmental causes of ASD, brain morphology and ASD, and biomarkers for the early detection of ASD. 28% of the budget for IBR is dedicated to autism research and around 25% of IBR staff is currently working on a project related to autism. In 2007 IBR also created a treatment lab that's sole mission is to improve treatment and evaluation.

IBR is currently trying to improve relationships between private and public research institutions to accelerate research, to further applied research and apply this research to practice, and to evaluate service delivery to individuals with developmental disabilities.

It should be noted that most of the studies that come out of the IBR are a joint venture of the state funding from the Office for People with Developmental Disabilities and various national and nonprofit organizations. Some examples of these organizations are listed below:

- March of Dimes
- Autism Speaks
- National Nature Science Foundation
- Michael Smith Foundation for Health Research
- NIH
- National Alliance for Autism Research

California
http://www.ehib.org/topic.jsp?topic_key=33

In California CADDRE is a part of the Environmental Health Investigation Branch, which is part of the California Department of Health. The Environmental Health Investigation Branch conducts research, funded by the California Department of Health and CDC in partnership with various other organizations such as: Kaiser Foundation Research Institute, National Institute of Mental health, and Autism Speaks. Employees of the California Department of Health are part of the investigation team for various studies into the etiology of ASD. Other members of these teams are contracted researchers.

California state legislature requested that the University of California's Medical Investigation of Neurodevelopmental Disorders (M.I.N.D.) Institute conduct a pilot study to look at factors might be associated with an increase in the number of autism cases.

Indiana Resource Center for Autism (IRCA)
http://www.iidc.indiana.edu/index.php?pageId=32/

The Indiana Resource Center for Autism (IRCA) was created in the 1980s by state legislature. The IRCA is part of Indiana University's Institute on Disability and Community. The mandate that created the IRCA mandated that it conduct research, develop and disseminate information, provide training and individual consultations. Research is from the center is centered on strategies to enhance the quality of life of people with ASD. Every three years the IRCA does needs assessment of families of those with ASD. IRCA isn't currently doing etiology research. IRCA also maintains a registry of individuals with ASD. The Indiana registry system is explained later in this report. THE IRCA has an approximate annual budget of approximately $1 million and is funded by the state of Indiana, federal grants and contracts.

Southwest Autism Research and Resource Center (Arizona)
http://autismcenter.org/

The Southwest Autism Research and Resource Center (SARRC) was established in 1997 by 2 mothers of children with ASD and their doctor. The SARRC advocates the need for ASD research and educates family on evidence-based medicine. The SARRC is a non-profit organization and is currently working on research of genetic vulnerability, a study of Fluoxetine in autism, several case control studies of children of varying ages, and several treatment studies. The SARRC has a large budget of $5 million a year which is mostly attributed to donations, however, the SARRC also receives $500,000 a year from Arizona state legislature for training in their state. The SARRC also has various research grants.

Future Plans to do Research

Even though right now the number of state departments actively doing research is limited, several states have plans to do research in the future. Below is a sample of states plans to do research:

- In Texas, the Texas Autism Research and Resource Center 5 year plan, several of their goals relate to autism research. Texas funded a Feasibility and Cost Scenarios study for the planned Autism Research and Resource Center. Four of their goals regarding the Autism Research and Resource Center are specific to autism research and are as follows:
    - Coordination and dissemination of evidence based research across multiple Texas Universities
    - Autism related research
    - Hosting of research symposia and other information sharing meetings
    - Developing and maintaining a web based repository of autism research and interventions

- In the Missouri Autism Research Agenda from 2003 Missouri stated that they aimed to create a statewide database of autism research for universities, although this goal has yet to be acted on.
- The Massachusetts Autism Research Agenda from 2003 Missouri stated that they aimed to create a statewide database of autism research for universities, although this goal has logy.
- In Oregon in 2011 the Oregon Commission on ASD tried to establish committee to study the rise in autism but no further action was taken SB565.

Through research, no states with very specific plans for future research were found, if states mentioned it in their 5 or 10 year plans or legislation at all, they only mentioned very general goals rather than specific actions.

Appendix 2: CDC Autism and Developmental Disabilities Monitoring (ADDM) Network

The Centers for Disease Control Autism and Developmental Disabilities Monitoring (ADDM) network is a program to determine the prevalence of ASD in in the U.S. The goals of the ADDM Network are to provide data regarding prevalence, describe children with ASD, compare ASD population from different areas of the country and understand the impact ASD has. A brief description of each of the 14 programs currently run by the CDC is outlined below.

Alabama

- Run by the University of Alabama Birmingham as an agent for the Alabama department of health
- In 2008 included 32 counties in the state
- 36,566 eight year olds in area studied in 2008
- Spoke to someone that said that the number of counties will be reduced in further studies because of lack of access to special education records
- Believe that they have the lowest prevalence of the study at 1 in 210 because they were unable to ascertain some special education records to identify cases

Arizona

- Investigated by the University of Arizona
- In 2008 included part of one county, Metropolitan Phoenix
- 32,601 eight year olds in area studied in 2008
- Southwest Autism Research and Resource Center

Arkansas

- Investigated by University of Arkansas
- In 2008 included 1 county, metropolitan Little Rock
- 4,940 eight year olds in area studied in 2008

Colorado

- Investigated by Colorado Department of Public Health and Environment and JFK Partners at the University of Colorado Denver
- In 2008 included 1 county, metropolitan Denver
- 7,715 eight year olds in area studied in 2008

Florida

- Investigated by the University of Miami
- In 2008 included 1 county
- 29,336 eight year olds in area studied in 2008

Georgia

- Investigated by CDC

- In 2008 included 5 counties, metropolitan Atlanta
- 50,427 eight year olds in area studied in 2008

Maryland

- Investigated by John Hopkins University
- In 2008 included 6 counties
- 27,022 eight year olds in area studied in 2008

Missouri

- Investigated by Washington University
- In 2008 included 5 counties
- 25,668 eight year olds in area studied in 2008

New Jersey

- Investigated by New Jersey Medical School and New Jersey Departments of Education and Health
- In 2008 included 1 county, metropolitan Newark
- 7,082 eight year olds in area studied in 2008

North Carolina

- Investigated by University of North Carolina Chapel Hill
- In 2008 included 11 counties
- 36,913 eight year olds in area studied in 2008

Pennsylvania

- Investigated by University of Pennsylvania School of Nursing and the Children's Hospital of Philadelphia
- In 2008 included 1 county
- 18,440 eight year olds in area studied in 2008

South Carolina

- Investigated by Medical University of South Carolina
- In 2008 included 23 counties
- 23,769 eight year olds in area studied in 2008

Utah

- Investigated by Utah Department of Health and University of Utah
- In 2008 included part of 1 county
- 2,123 eight year olds in area studied in 2008

Wisconsin

- Investigated by University of Wisconsin and the Wisconsin Department of Health
- In 2008 included 10 counties
- 34,451 eight year olds in area studied in 2008

Appendix 3: Categories and Billing Codes

Federal special education disability categories used in the ADDM Network to identify educational records for screening and potential data abstraction:

1. Mental Retardation
2. Traumatic Brain Injury
3. Specific Learning Disabilities
4. Emotional Disturbance
5. Autism
6. Speech or Language Impairments
7. Deafness
8. Hearing Impairment
9. Visual Impairment (including blindness)
10. Deaf-Blindness
11. Orthopedic Impairments
12. Other Health Impairments
13. Multiple Disabilities

International Classification of Diseases, Ninth Revision Billing Codes Used in the ADDM Network to Identify Health Records for screening and data abstraction

Codes	Disease Classification
299.00	Autistic disorder
299.01	Autistic disorder
299.10	Childhood disintegrative disorder
299.11	Childhood disintegrative disorder
299.80	Other specified pervasive developmental disorders
299.81	Other specified pervasive developmental disorders
299.90	Unspecified pervasive developmental disorder
299.91	Unspecified pervasive developmental disorder
315.30	Developmental speech or language disorder
315.31	Expressive language disorder
315.32	Mixed receptive expressive language disorder
315.40	Developmental coordination disorder
315.50	Mixed development disorder
315.80	Other specified delays in development
315.90	Unspecified delay in development
317.00	Mild mental retardation
318.00	Moderate mental retardation
318.10	Severe mental retardation
318.20	Profound mental retardation
319.00	Unspecified mental retardation
330.80	Other specified cerebral degenerations in childhood (Rett's)
348.30	Encephalopathy, no elsewhere classified
348.80	Other conditions of brain
348.90	Unspecified condition of brain
759.50	Tuberous sclerosis
759.83	Fragile X syndrome
771.00	Congenital rubella
783.42	Delayed milestones
V79.20	Screening, Mental retardation
V79.30	Screening, Developmental handicaps in early childhood
V79.80	Screening, Other specified mental disorders and developmental handicaps
V79.90	Screening, Unspecified mental disorder and developmental handicap

Appendix 4: Sensitivity and Predictive Value Positive

The table below shows how errors in surveillance ASD case status are identified and how the surveillance system attributes of sensitivity and predictive value positive are estimated. The columns of the table classify whether a case in the system really had ASD or not. The rows of the table show how the cases in the surveillance system were classified in terms of their final ASD case status; either a case met or did not meet the ASD surveillance case definition. Finally, the four individual cells in the table show how individuals were actually identified by the surveillance system. In particular, the cells labeled (B) and (C) show where errors occurred, while the cells labeled (A) and (D) show where cases were correctly classified.

Table: True ASD status

Identified by the system	**Has ASD**	**Does not have ASD**
Meets ASD surveillance case definition	(A) "True positives" – Cases in this cell really have ASD and correctly met ASD surveillance case definition	(B) "False positives" – Cases in this cell do not have ASD but were incorrectly identified as meeting the ASD surveillance case definition
Does not meet ASD surveillance case definition	(C) "False negatives" – Cases in this cell really have ASD but were incorrectly identified as not meeting the ASD surveillance case definition	(D) "True negatives" – Cases in this cell do not have ASD and were correctly classified as not meeting the ASD surveillance case definition.

Sensitivity = A / [A + C] = proportion of true ASD cases who were identified as meeting the ASD surveillance case definition

- The sensitivity of a surveillance system will be less than the maximum value of 100% whenever cases with ASD are classified as not meeting the surveillance system's ASD case definition. These missed cases are referred to as "false negatives."

Predictive value positive = A / [A + B] = proportion of cases identified as meeting the ASD surveillance case definition who truly have ASD

- The predictive value positive of a surveillance system will be less than the maximum value of 100% whenever there are cases who do not have ASD are identified as meeting the ASD surveillance case definition. The cases are referred to as "false positives" because they should not have been counted as ASD cases.

Source: Centers for Disease Control and Prevention (2001). Updated guidelines for evaluating public health surveillance systems – Recommendations for the guidelines working group. Morbidity & Mortality Weekly – Recommendations and Reports, 50(13), 1-31.

Appendix 5: ASD Registries in States Requiring Mandatory Reporting of Cases Diagnosed with ASD

State	Description	Case Ascertainment & Population Covered in State	ASD Case Definition	Enforcement
Delaware*	The Autism Surveillance and Registration Program, established in 2005 • Purpose: surveillance, referral to prevention/intervention • It is part of the state's population-based birth defects surveillance program. It is housed in the Delaware Department of Health and Social Services, Division of Public Health • Initial attempts at implementing mandatory ASD reporting prior to 2010 failed because of a lack of compliance with reporting and penalties were not enforced. • A pilot project launched in 2010-2011 to implement active case ascertainment. Cases were confirmed by a psychiatrist who reviewed ICD-9 diagnostic codes. Currently have data but have not determined next steps for data use. • Recent legislation passed that combined the state's birth defect registry with the ASD registry for children ages 0-5 years	• Passive method (2005-2009): Physicians, surgeons, dentists, podiatrists, or other healthcare practitioners who diagnose an individual 18 years or younger with an ASD are required to report information to the registry. This form must be submitted annually to track changes and maintain accurate information. Compliance was a problem using this method (2005-2009). • Active method (2010-2011): Ascertained data on cases aged 7 years with ICD-9 codes for ASD • Present method (2013 -) – no information obtained	DSM-IV-TR and ICD-9	Possible fines up to $100 per violation

Cont'd: ASD Registries in States Requiring Mandatory Reporting of Cases Diagnosed with ASD

State	Description	Case Ascertainment & Population Covered in State	ASD Case Definition	Enforcement
Indiana*	Indiana Birth Defects and Problem Registry • Purpose: Surveillance, research, referral to services • It is part of the state's population-based birth defects surveillance program. • Funding from the state • The data from the registry is used to determine the number of children with birth defects and problems as well as for planning intervention and prevention strategies. • Appears to be representative of the state's population and its numbers are consistent with recent national numbers, but compliance is a problem.	• Passive case ascertainment through mandatory reporting. Those who diagnose birth problems are required to report them to the registry. ASD and Pervasive Developmental Disorders are considered birth problems. • Only autistic disorder is covered. Would like to expand system to collect data on other ASD subtypes • Cases are between the ages of 0 until 5 years of age	ICD-9	No information provided
New Hampshire	New Hampshire Autism Registry, established in 2008. • Purpose: service needs • Housed in the New Hampshire Department of Health and Human Services • State Council on Autism Disorders use the statistics to inform policy recommendations but numbers are not representative of the ASD population in the state • There is no dedicated funding for the registry and the numbers are not representative of ASD in the state • There are no new plans for surveillance and the focus has switched to service needs for the ASD population.	• Mandatory reporting by physicians, psychologists, and any other licensed or certified health care provider who can diagnose ASD • Only collect data on diagnoses made in the state • Cases are between 0 to 18 years of age	DSM-IV-TR	No penalty for not complying mentioned in legislation

Cont'd: ASD Registries in States Requiring Mandatory Reporting of Cases Diagnosed with ASD

State	Description	Case Ascertainment & Population Covered in State	ASD Case Definition	Enforcement
New Jersey*	New Jersey Registry for Autism, established in 2007, went electronic in 2009 • Purpose: Surveillance, research, referall to services, referral to prevention/intervention • Housed in the New Jersey Department of Health and Senior Services- Special Child Health Registry • There are approximately 11,000 children in the database • A key component of the system is referral to case management and services • Still in development, but moving towards accurate representation of population • Difficult to reach out to all therapists, psychiatrists, etc. Hospitals and large providers are easier. Unable to access records diagnosed in other states (Pennsylvania and New York). Missing milder cases and late diagnoses handled by the school system. Would like to access school records.	• An active/passive system – passive case ascertainment with active ascertainment for data completeness and quality audits. • Mandatory reporting by physicians who diagnose, healthcare providers who are diagnosing cases based on the DSM-IV. Those providing services must also report. Parents can decide to not have identifying information included in the system • Case reports take about 10-15 minutes to fill out • Children and adults under the age of 22 are included; there are approximately 11,000 children in registry	DSM-IV-TR	No penalty for not complying mentioned in legislation
Utah	Utah employed the Utah Registry of Autism & Developmental Disabilities (URADD) that collects information about the number of individuals in Utah who have ASD and other developmental disabilities. Utah Registry of Autism and Developmental Disabilities (URADD) was created in 2002 by a four year $350,000 grant from the CDC. The CDC grant has expired and currently URADD's budget has been reduced. As a result, the state's ADDM Network figures more prominently in estimating prevalence.	• Mandatory for diagnosticians if family request a form, but voluntary participation of families	DSM-IV-TR	

Cont'd: ASD Registries in States Requiring Mandatory Reporting of Cases Diagnosed with ASD

State	Description	Case Ascertainment & Population Covered in State	ASD Case Definition	Enforcement
Washington*	Purpose: surveillance, referral to services There is not statewide surveillance on ASD because the activity is not funded to perform ASD surveillance; there are laws to report but no funding or staff. There are difficulties identifying cases because children are older than 1 year of age at diagnosis and are not diagnosed in hospitals, which is a primary source of data for birth defects surveillance.	• Passive case ascertainment. • The Washington State Rules for ASD reporting define eligible cases as between 0 and 10 years of age with autistic disorder only.	ICD-9, ICD-10	
West Virginia*	West Virginia was previously part of the CDC ADDM Network surveillance program, which ended because the state could not hire an epidemiologist to work in the program. Active case ascertainment is more effective but rural counties were also more time consuming to complete record reviews while in ADDM. ASD has been a mandated reportable condition since 2004.The state currently employs the West Virginia Autism Spectrum Disorders Registry established in 2004, and operated by West Virginia Autism Training Center. Bureau of Public Health though Department of Health and Human Services. There is no enforcement of fines for not reporting. • Problems with compliance; no enforcement of fines for not reporting cases. Estimate that 30-40% of kids are being missed • School psychologists are not reporting, especially in the rural areas. School system is not diagnosing because they don't want to hire autism teachers • Held campaigns about reporting cases. Providers felt forms were too long to complete.	• Reporting is mandatory for neurologists, pediatricians, family physicians, psychiatrists, clinical psychologists • Includes children and adults regardless of age	DSM-IV-TR	Penalty of no more than a $500 fine per violation

* Information for these states was augmented with brief telephone interviews with staff.

Appendix 6: Strengths and Limitations of Public Health Surveillance Systems for ASD: ADDM Network Versus Mandatory Reporting

System Attribute	ADDM Network	Mandatory Reporting
Objectives	Implement a uniform case methodology to estimate ASD prevalence. Under the ADDM Network protocol, children identified as having ASD, but not having a previous ASD diagnosis, are **not** referred to for services.	Emphasis on estimating burden in state and guiding decision making at the state and local levels. Referral to services is a priority and states also support research activities.
Case ascertainment	Active	Passive
Case definition	Includes ASD cases with an existing ASD diagnosis or ASD special education program eligibility, and cases without a previous ASD diagnosis who had evidence of ASD symptoms documented in their records. ASD case status is confirmed by trained clinician reviewers	Includes ASD cases with an existing ASD diagnosis. Cases with an ASD special education program eligibility is desired in some states.
Data source(s)	Health records and special education records from public school districts when approval is obtained.	Defined in statute and typically includes health records. Some states are examining access to data from the public school system.
Catchment region/population covered	Selected set of contiguous counties representing at least 20,000 8-year old children based on recent US census data	Statewide
Age range for population	8-year old children. Some ADDM Network sites are examining methods to estimate prevalence among 4-year old children.	Age range is flexible
Representativeness	Not likely in Minnesota because of the limited size of the catchment region and the geographic variations in the state	Represents Minnesota if case ascertainment is complete and consistent across the state
Sensitivity/Predictive Value Positive	Limited information available	Limited information available

System Attribute	ADDM Network	Mandatory Reporting
Completeness of case ascertainment	Limited information available. Gaps in surveillance are known, because data are not collected from facilities that serve a small number of cases, private schools, children who are home-schooled, and public school districts that do not consent to participate, parents who refuse to allow access to their child's public school records	Documented incomplete ascertainment for passive systems. Incomplete reporting is a problem without enforcement authority
Time and resources needed	Demanding in terms of the time and resources required to establish the system and collect data. A greater burden on the surveillance system staff, but facility personnel time is required to identify records for screening and abstraction, as well as to help resolve missing, conflicting, or incomplete data on individual cases. Requires that the records for all abstracted cases are reviewed manually.	Demanding on facility personnel who complete and submit case reports. Developments in information technology may automate some processes and lighten the load for facilities and providers. Developing expert system to automate decision making may be able to significantly reduce the proportion of case records that require manual review.
QA/QC	Intensive initial and ongoing training	Standards depend on the state's program but training will be needed for ensuring complete, valid, and comprehensive data
Comparability with other states	Methods in theory are uniform but a wide range of prevalence estimates is still possible because of variations in methods and diagnoses.	Varies
Funding sources	Cooperative agreement with the CDC. Average award in the last funding cycle was $400K annually. In-kind contribution from the sites may be necessary.	Depends on state funding levels
Timeliness of results	3-4 year delay in data for a given surveillance year.	No information available
Legislation/authority to access data	Depends on the state, but can include state statute.	Provided for in state statute.

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