

A Comparison of State Autism Registries: New Jersey and Beyond

The rise in the prevalence of Autism Spectrum Disorderⁱ (ASD) rates over the last 15 years (ADDM, 2014, 2016; Newschaffer, et. al., 2005; Shattuck, 2005) has spurred a number of national endeavors by the Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), and other organizations to better understand why the rate has increased, what causes autism, and what services are needed. Although the CDC's Autism and Developmental Disabilities Monitoring (ADDM) network study has provided "national" prevalence information based on a select number of sites, there continues to be a wide range of rates, and differing race and ethnicity results across the study sites. For example, CDC's 2012 ADDM study yielded an overall ASD rate of 1 in 68 children rate, but the individual site rates vary considerably from New Jersey's 1 in 41 to 1 in 92 for both Wisconsin and Colorado (CDC, 2016). These differences may be attributed to true rate differences as well as differences in access to children's records. For instance, the 2012 ADDM combined rate for those study sites that reviewed both health and special education records was 1 in 58 (1.7%) compared to the combined rate of 1 in 93 (1.1%) for those sites that only had access to school records. In New Jersey where the access to both school and health records was the same for all four counties included in the study, there appeared to be significant rate differences across and within the sites. Three study sites (Essex, Union, and Hudson counties) are mostly urban, densely populated, and located in the north-eastern side of the state. The fourth study site (Ocean County) is more rural, less densely populated, and located in the southern (along the shore) part of the state. Based on the 2007 results, Dr. Walter Zahorodny (Principal Investigator for the CDC's NJ site) found that the ASD prevalence was related to district wealth, with wealthier census tracts having higher rates of autism, perhaps due to differential access to pediatric and developmental services (Thomas, et.al, 2012). Although differences continue, many states have implemented task forces, councils, and other initiatives to address the overall rise of autism, and are looking within their own state to develop ways to plan for the increase of needed services. Collecting the necessary information to supply policy makers with reliable information to plan for and provide the appropriate services in the right areas is the challenge.

While all states mandate the reporting of specific congenital birth abnormalities and non-congenital diagnoses so that they can track the prevalence and better plan for services, only a few states mandate the reporting of autism or other developmental disorders. There are a few national registries such as the National Autism Registry (Kennedy Krieger Institute) and the Simons Foundation that rely on families self-registering their children so that researchers have more information about the varying symptoms and needs of these children. According to an article

published by the Simons Foundation, Dr. David Mandell describes registries as an important tool that communities can use to plan for services (Hughes, 2009). While the self-selection bias of voluntary registries does hamper their ability to reliably generalize their findings to the entire population, they are instrumental in establishing significant risk factors, potential causal factors, and cellular-level research results. State-based or population based registries, however, are designed to provide generalizable information for health planners and policy makers who need to effectively provide services. And while prevalence research studies can provide important information about the overall rate of autism based on a study sample, mandated population-based registries can provide information about the variations across and within the states, variations and patterns of the disorder, and potentially have the added benefit of providing those individuals with autism specific information and services. This report describes and compares eight states that currently mandate autism as a reportable condition, and how each state defines the population to be registered, collects the information, and uses the data.

Key Challenges and Registry Design Factors

Individuals with ASD vary in symptom presentation, functional abilities, and can have a complex cluster of co-occurring conditions. Some may have verbal or language skills, while others do not. Some may have significant medical comorbidities such as seizure disorders, while others do not. These variations can dramatically impact the type of services, professionals, therapies and treatments needed, as well as the associated costs. Policy planners need to anticipate, plan and provide for these heterogeneous populations, as well as help families who are often overwhelmed and unsure how to navigate through all of the available resources and systems. To this end, policy makers need accurate information regarding the needs of the population so that they can create and ensure that the appropriate resources are available. Thereby, the need for information will shape the registry's goals, and in turn, shape how it is designed and operated. Three main goals of state registries are:

1. Plan for policy and services.
2. Monitor the prevalence of a disorder.
3. Link individuals to services and resources.

However, collecting information about individuals with ASD has its own set of challenges. Therefore, states will have to clearly define their goals in order to address the following questions when establishing an autism registry:

- Who must *BE* registered?
- Who must report?
- What information is collected?
- Will names and other identifying information *BE* collected?

Who must *BE* registered?

Deciding on who is required to be registered is not an easy answer. First, States who are considering mandating autism as a registerable condition must carefully weigh how they define the condition. Currently, ASD is defined by the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5). With numerous editions over the past 60 years, the DSM provides clinicians the criteria to diagnose and treat specific mental disorders. In terms of autism, the criteria and names have recently changed from a set of five distinct disordersⁱⁱ under the umbrella disorder of Pervasive Developmental Disorders to the Autism Spectrum Disorder that uses two three-point scales to evaluate, and meet four criteria to diagnose. Therefore, States must consider how changes in the DSM might affect their reporting requirements.

Requiring only newly diagnosed individuals (incidence) or including those who were previously diagnosed (prevalence) to the mandate is also an issue that States must consider. If only newly diagnosed children are required, fewer registrations will be generated as reporters will only register those individuals whom they have diagnosed after the mandate. Thus, this will exclude all those who were diagnosed prior to the mandate. If previously diagnosed individuals are required to be registered, more registrations will be submitted, but reporters would need clear guidance on how far back in their case records they are required to go. For example, a developmental specialist who only sees children for a one-time evaluation would need to know how far back in time they must go to register. If the goal of the registry is to plan for services, the incidence could be extrapolated to estimate prevalence, but since the rates have changed over time this is not simple or precise. If the goal is to link individuals with services, then including individuals who were previously diagnosed will ensure that they are not missed.

Age is also used as a determining factor for who should be registered. Since there is a distinct difference between mandating the registering of children and adults, states must consider what the purpose of the registry is in determining if there is an age criterion. In New Jersey, the Autism Registry rules mandate children through their 21st year. This criterion was selected because the Registry is located in the Division of Family Health Services which provides case management

services to children until they reach their 22nd birth date. Other states such as Rhode Island selected the age of five as a “cut-off.” The CDC selected eight years old for their ADDM study with the assumption that most children should be diagnosed by the age of eight. The selected age cut-off is important because the median age of diagnosis is between four and five, and if the cut-off is too low, children diagnosed after the cut-off will not be registered. Registering adults is even more complex and can include significantly more legal issues because of the question of legal guardianship. However, if the purpose of the registry is to plan for adult services such as health care, housing and employment, then knowing the number of children can speak to future needs of adults, but not the current level of need for the adult population.

Who must report to the Registry?

Potential reporters could include health care providers, parents, and educators. In terms of a mandated registry, the agency or department that houses the registry must consider who they have regulatory authority over to require the registration. They may also consider who can reliably diagnose or provide the diagnostic information about the child. Since most states mandate medical diagnosis under their health regulations, they can only mandate reporters who they have authority over such as licensed or certified health care providers and health care facilities. Additionally, which health care providers to include is also a question. In New Jersey, health care providers who are licensed and educated to diagnose autism or provide the follow up medical home care for children with ASD are required to register. This means that specialists who typically diagnose autism such as pediatric developmental specialists, neurologists, psychiatrists, and psychologists are required to register as well as primary care providers who provide medical home services such as general pediatricians and family medicine physicians. By mandating both diagnosticians and primary care/medical home professionals, the newly and previously diagnosed children would be registered.

Whether families or the individuals themselves are allowed to register is also a consideration. Many families advocate and are able to document the diagnosis, but many families are not able to provide the documentation about the diagnosis or reliably recall the specific diagnosis details. While voluntary registries rely on parent registrations, mandated registries typically rely on professionals to register. In this way, the correct diagnostic codes and descriptions are provided, and could also be audited for validation. Due to the Family Educational Rights and Privacy Act (FERPA), schools and educators cannot be mandated to provide a student's

information without parental consent, so only Departments of Education would have authority over educational records.

What information is collected?

The purpose of the registry and usefulness of the data should determine the type of information collected. Basic demographic information such as age, gender, location, race/ethnicity are useful data that can provide policy makers with an understanding of who needs services and where services are needed. Information about types of diagnoses, functional level and severity, and comorbidities provide information about the level and type of services needed. For instance, the “Age at First Autism Diagnosis” and the “Age of First Symptoms” can be used to assess current screening efforts and the timeliness of their evaluations. Information about other needs such as housing, employment, and support services can also be helpful. For instance, if adults are included in the registry, and the State is interested in the need for employment assistance, then information about the individuals’ functional abilities and independence levels as well as their education and their employment status are useful measures.

While there are many potential uses for data, a major consideration is the reliability of the data. If parents report, they would be able to accurately report the demographic information, but maybe not necessarily have specifics about the diagnosis or condition. If professionals report, they could provide accurate evaluation information, but may not collect demographic data. If professionals report, would they be able to skip the data element or report “unknown” or would they be required to collect the data. Nevertheless, collecting and reporting even a minimal amount of data requires time and effort. The balance between the amount of data collected and the staff time and resource costs need to be considered. The fewer the elements, the easier and less costly to the reporter, but the fewer questions the data can answer. If the collection tool is too long and requires additional data to be collected, the resource cost could be quite large, and therefore, compliance may become an issue. For example, West Virginia originally had a very detailed and comprehensive collection tool, but had low compliance. When they shortened their collection tool, reporting dramatically improved (WVA Staff Interview, 2016).

Will names and other identifying information be collected?

The purpose of the registry will drive the decision to collect names and/or other identifying data. Names and other identifying data elements are needed if the registry plans to contact or refer

children for services. In New Jersey, the Registry links all registered children with county-based case management units. Case managers, who are usually social workers or nurses, provide families with resources and referral information. If the child is under the age of three, they would also be referred to Early Intervention Services. Even if a registry does not plan to refer, having the names of the children ensures that the data can be de-duplicated. Names can also be used to match the registry data to other data sets. The concept of matching data sets has its own concerns about data privacy, but can be useful to ensure that demographic data is accurate, examine patterns of hospitalizations, etc. Matching to birth files, for example, can provide information that reporters may not always collect such as birth weights, gestational age, and race. While not all health care providers collect these elements, they can be helpful in describing the population, examining risk factors, and for further epidemiological analysis of the data. For instance, examining birth location can provide information about whether potential environmental factors are linked with certain disorders. In terms of autism, the CDC's ADDM researchers for New Jersey considered birth place and migration into New Jersey to see if New Jersey's high prevalence rate could be explained by people moving to New Jersey because of the vast number of services available.

There are also reasons for not collecting names. New Hampshire, for example, collects data only on newly diagnosed cases for incidence purposes. Since they do not refer children to services, they do not need the names and/or contact information. They do, however, collect certain identifying information to ensure that children are not duplicated in the registry. Anonymity for children and families is another consideration. Some families may not want their children's names in a state database. Concerns over privacy and future use of the data are often raised when names are collected. States that do collect identifying information, therefore, must decide if parents or the individuals have an option of anonymity.

Comparison of States

The following profiles provide an overall picture of how the eight states that mandate the reporting of individuals with autism have designed their registries. Each state has its own unique system, but these descriptions focus on how they have addressed the issues discussed above. The information was collected from each state's website, on-line reports, and interviews with state staff. New Jersey Registry staff conducted phone interviews with individuals from each state. To ensure the accuracy of the information, each state was provided their summary description and the comparison table for their review and verification. Since programs may be altered, this information reflects each registry as on 2016.

Delaware:

Established in 2005, the purpose of the Delaware Autism Registry was to track prevalence over time, to inform planning policy and services, and facilitate autism research. Focusing mainly on prevalence, cluster identification and risk factors, health care providers were required to submit a form within 30 days of diagnosis or identification of a child with autism. In the first few years of the Registry, the Division of Public Health received fewer than anticipated reports. To address the goal of providing prevalence rates, the methodology was changed from a passive surveillance whereby health providers submit reports, to an active surveillance whereby medical records are abstracted by the contracted Birth Defects Registry team. Using Title V funding to abstract records, the prevalence rate was obtained for the seven-year-old birth cohort. Three subsequent seven-year-old cohorts have been completed and work on a fourth cohort is underway. Funding for the active Registry, however, is uncertain and the state may return to a passive registry if funding becomes unavailable. This method of selecting a birth cohort, and then abstracting their records is similar to the CDC's ADDM study. In Delaware, only medical records are reviewed. In the ADDM study, one of the biggest predictors of rates is access to both medical and educational records, so that states with only health records report significantly lower rates than study sites that had access to both educational and medical records.

Indiana:

Autism Spectrum Disorders (ASDs) are mandated reportable conditions within Indiana's Birth Defects and Problems Registry (IBDPR) at the Indiana State Department of Health (ISDH). Physicians and hospitals are required to report to IBDPR anyone seen and diagnosed with an ASD. Until July 1, 2014, only children up to the age of 5 were required to be reported to the IBDPR; however, in 2014 the rule was amended to require reporting of persons with an ASD at any age. Physician offices actively report ASD cases via an online portal. These cases are considered confirmed when received by the IBDPR. Letters are sent annually to all physicians in the state to remind them of the reporting requirements and any changes that have been made (including the change in age for autism reporting). Hospitals passively report this information through ICD-9 or ICD-10 billing codes. Cases of ASDs passively gathered from hospitals under the age of eight are actively audited by registry auditors, who abstract data from hospital medical records in order to improve the accuracy of the data collected. The rule change in 2014 prompted hospitals to update their reporting filters to include ASD cases of all ages.

Follow-up of reported cases occurs in conjunction with the ISDH Children's Special Health Care Services Program (CSHCS). Follow-up occurs via a phone call to all families who have a child under eight years of age that is reported to the registry. In certain cases, where a family is unable to be reached by phone, a letter containing a list of community resources is sent to that family. Follow-up occurs via the same letter to all children over the age of eight and adults reported to IBDPR.

The information obtained from hospitals and physicians includes date, name, date of birth, the diagnosis (ICD 9 or 10) code and hospital medical record number if applicable. At the state level, the information from both physician reporting and hospital reporting is then matched to other data sources such as vital records. ISDH reports de-identified whole state data to the state legislature annually.

New Hampshire:

In 2008, New Hampshire established and implemented the New Hampshire Autism Registry. New Hampshire designed their Registry to address three specific goals: 1) the number of newly diagnosed cases, 2) the age of diagnosis, and 3) epidemiological issues of geographical differences of incidence and access to care. By capturing these data, policy makers and planners would be able to determine the outcome effects of developmental screening and evaluation services. The New Hampshire Autism Registry does not collect names or contact information of the individuals, so they are unable to refer for services or resources, but sufficient data is collected to de-duplicate multiple registrations for the same individual. The data are used by policy makers to apply for federal funds, and in planning other services such as developmental services, community mental health, and vocational supports. New Hampshire has no age limit on the Registry, but only individuals who are residents at the time of diagnosis are required to be registered. All medical doctors, licensed psychologists and other health care providers who make a definitive diagnosis are required to register. Demographic data such as gender, race/ethnicity, birthplace, and date of birth are collected. Diagnosis type and date are also collected along with the diagnostician's name, degree, and license number.

From November 1, 2008 to June 30, 2012, a total of 438 newly diagnosed cases of autism have been reported. An annual data report is posted on their website, and provides aggregate information about the number of reports per month, the age at diagnosis, race/ethnicity, county of residence, and type of ASD subtype (based on the DSM-IV). The race/ethnic breakdown mirrors the state demographics, and autism is seen in every county. Approximately one-third of children are diagnosed before the age of three and approximately half are diagnosed between the ages of

three and nine. These data are collected to address the questions of early identification, screening and ultimately diagnosis. To date, no prevalence rates have been issued by the Registry. Having only a few years of data, including all ages, and only collecting incidence, calculating prevalence rates is not feasible at this time.

New Jersey:

New Jersey passed its law to mandate the reporting of autism in 2007. Administrative rules were promulgated in September 2009, and autism was added as a mandatory reportable condition to an existing Birth Defects Reporting System. The purpose of the Autism Registry is threefold: 1) link children/families with county-based case management services, 2) provide information for policy and planning, and 3) perform epidemiological analysis to better understand the prevalence of autism across New Jersey. All resident children zero through 21 who have an ASD diagnosis are required to be registered. In terms of who must report, New Jersey chose a broad approach, and requires all licensed health care providers who either diagnose or follow children with autism to report. This ensures that both newly diagnosed and previously diagnosed children are registered. While the Autism Registry is considered a passive registry, New Jersey staff actively audit the accuracy of the registration by conducting on-site reviews of selected records. Each facility is asked to provide a list of records that meet time-period and code criteria. Typically, three months of each audit year are selected, and the records are reviewed by Registry staff to ensure that the facility correctly registered each person who had a confirmed autism diagnosis.

The Registry collects information about the child's birth (weight, gestation, and plurality), race/ethnicity and primary language, date of first ASD diagnosis; age symptoms were first noticed, comorbid conditions, and the number of siblings who have an ASD. The reporting rules tie the definition of autism to the DSM, so under the DSM-IV-TR the five subtypes were collected. With the change to the DSM-5, the severity levels for the two criteria under DSM-5 will be collected. Because the Registry refers children and their families to case management, the names and contact information are needed. This also serves to ensure that children are not duplicated in the registry. With an age spread of 22 years, a child would probably be seen by a multitude of health care providers who could potentially register him or her, so collecting enough identifying information to de-duplicate the registry is important. As important, having the identifying information allows the data to be matched with other data sources for epidemiological research projects.

North Dakota:

In 2013, the North Dakota Legislature passed a law (NDCC chapter 23-01-41) that requires the North Dakota Department of Health to create and manage a database which includes a record of all individuals diagnosed with ASD. The information collected will be used to complete epidemiologic surveys, research and analysis, and to provide services to individuals with an ASD diagnosis. Health care professionals are required to report newly diagnosed individuals into the database within 30 days of diagnosis and previously diagnosed individuals into the database within 30 days of the individual's first patient or client encounter with the reporter. The reporting form is detailed and collects information about symptoms, comorbidities, and medication use. Personal identifiers are collected, but families are not contacted. Only individuals who are North Dakota residents or one of the individual's parents/guardians are a resident of North Dakota will be reported. In their first year, staff coordinated statewide stakeholder meetings, created administrative rules, and developed an electronic reporting system. The decision to use the term "Database" rather than "Registry" was made after engaging with family stakeholders and advocacy groups.

Rhode Island:

Rhode Island has two types of Autism Registries. First, autism is considered a sentinel condition for their mandated Birth Defects Registry. This Registry is mandated to identify children with birth defects up to the age of five. Providers are able to register using KIDSNET which is Rhode Island's confidential, computerized child health information system. This system includes a wide area of information such as immunization records, metabolic, hearing, and developmental risk assessments for newborns, and lead test results and participation in the Early Intervention and WIC Programs. The system is also designed as a tool for providers who can run reports and print immunization records to meet school requirements. Although regulations were enacted that require health care providers and facilities to report cases, few autism cases have been registered. The low reporting has been attributed to two reasons: 1) not having either an incentive to register or a penalty for not registering, and 2) the low age cut-off of five years. While many children are diagnosed before the age of five, providers may not register at the time of diagnosis, and therefore children older than five are not registered. The second type of autism registry is the Rhode Island Consortium for Autism Research & Treatment (RI-CART) which is a voluntary-research oriented project. RI-CART is funded by the Simons Foundation is housed at Bradley and Women & Infants Hospitals, which are major teaching affiliates of the Warren Alpert Medical School at Brown University. Enrollment in RI-CART includes clinical assessments, record review and collection of bio-specimens. RI-CART in part functions as a traditional research registry, supporting recruitment

into additional research protocols. RI-CART has enrolled 1,100 families through April 2016, and has recently been refunded through April 2019. Initial estimates indicate that RI-CART has enrolled roughly 25% of minors with autism in Rhode Island. A core feature of RI-CART is involvement of families of children with ASD in project leadership and committee structure. The two autism registries, the State Birth Defects Registry and the RI-CART, are separate and different entities.

Utah:

The Utah Registry for Autism and Developmental Disabilities (URADD) was established in 2002 as a joint effort between the Utah Department of Health and the University of Utah Department of Psychiatry. URADD identifies persons with a community-based diagnosis of ASD to track changes in autism prevalence in Utah over time, investigate the epidemiology of autism, inform public policy, and disseminate high quality research findings to Utah citizens. URADD uses a passive surveillance system in which individuals with ASD are identified based on a community medical diagnosis of ASD and/or an autism special education eligibility. Utah Health Code R398-10-4 states that “Upon Department request, qualified professionals and diagnostic or treatment facilities that provide specialized care for ASD and related disorders shall allow the Department or its agents to review medical and educational records of individuals with ASD, mental retardation, and related disorders to clarify duplicate names and to collect demographic characteristics, medical and educational histories, and assessments.” Individuals with ASD and related developmental disabilities are identified by querying the electronic data warehouses of community medical providers that provide ASD-related services. Children found eligible for an autism special education classification are identified through a long-standing collaboration with the Utah State Board of Education. Initially, URADD ascertained ASD in a largely urban three county surveillance area including Davis, Salt Lake, and Utah Counties. ASD surveillance is currently being expanded statewide to allow for comprehensive ASD surveillance throughout Utah. Utah previously participated in the CDC’s Autism and Developmental Disabilities Monitoring (ADDM) Network in surveillance years 2002, 2008, 2010, and 2012. The ADDM project uses a retrospective record review approach to identify children who meet the case definition of ASD based on the American Psychiatric Association’s DSM-IV-TR and DSM-5 criteria. Excellent consistency has been found between ADDM methodology and community identification of individuals with ASD with approximately 90% of persons with ASD identified through the ADDM project having received a previous community-based ASD diagnosis and/or autism special education classification. For more information about URADD, please visit <http://www.utahautismregistry.org/>.

West Virginia

West Virginia was the first state to enact an autism registry. West Virginia participated in the CDC's ADDM study in 2000 and 2002, with the entire state of West Virginia as the study site. The West Virginia Autism Spectrum Disorders Registry (WVASDR) was established in 2002. With the goal of providing incidence data, the WVASDR provided a less expensive and labor intensive way to track the incidence of autism. Since 2004, it requires that only newly diagnosed persons be registered. Persons of all ages including adults who are newly diagnosed are required to be registered. Names and other identifiers are not needed, but information is entered to create a unique identification number so that a person is not entered multiple times in the system. Medical doctors, psychiatrists and licensed psychologists who make the diagnosis are required to complete a registration form. Originally, the form was quite detailed and asked a number of questions regarding the severity and function, behavioral symptoms, comorbidities, and known medications. These items were included to provide detailed descriptions of the population's needs, but few providers completed the forms. The form was revised in September 2013 so that it is easier and quicker to complete. Now only collecting minimal information, the number of registrations being submitted has increased drastically. The WVASDR is housed and operated by the West Virginia Autism Training Center at Marshall University, but staffed by state employees.

Overview

Table 1 provides a state-by-state overview of the key reporting elements. One of the main differences between the states is whether they collect the child's contact information or information that could uniquely identify the child. New Jersey and Indiana both collect the full name of the child and contact information. These states also outreach to parents to offer services and/or resources that they might not have been aware of, and connect the children with services as soon as possible. Three states do not currently outreach to families, but collect identifying information in order to connect with other available data for analysis purposes. States that do not collect identifiable information such as New Hampshire and West Virginia, are not able to make those linkages. While collecting the name and contact information has raised some concerns, doing so is important if the state plans to use the information as a way to offer families services. At a minimum, some form of a unique identifier is needed so that children are not registered multiple times by providers who are not aware of their registration status.

New Jersey and North Dakota are the only states that collect age that symptoms were first noticed by anyone. While autism is usually diagnosed by the age of four, the diagnosis process usually occurs after the child's family and care providers notice a number of symptoms, a regression in ability, or his/her lack of meeting age appropriate milestones. This difference between when the symptoms first appear and when the diagnosis is actually made is important because the earlier the child receives interventions the more beneficial it is for the child. All of the states ask about the health care professional's name, contact information and training.

One of the biggest difference between the states is the age range of those mandated to be registered. Four states (Indiana, New Hampshire, North Dakota, and West Virginia) mandate all ages to be registered. Since New Hampshire collects only newly diagnosed individuals, they may have success in obtaining complete information about adults who have an ASD diagnosis. For Indiana, North Dakota, and West Virginia, obtaining information for adults may be more challenging. Moreover, obtaining information from providers about previously diagnosed individuals not diagnosed by them is a struggle.

While all of these autism registries collect somewhat different types of information, they all provide valuable information to their states to assist policy makers and health care planners in developing appropriate services to serve individuals with autism.

Table 1: Autism Registries: A Review of Eight States

	Delaware	Indiana*	New Hampshire	New Jersey	North Dakota	Rhode Island*	Utah	West Virginia
Data Collected								
Child's Name	X	X	1 st initial of last name	X	X	X	X	1 st initial of last name
Date of birth	X	X	X	X	X	X	X	X
Race and Ethnicity	X	X	X	X	X	X	X	X
Place of birth	X	X	X	X	X	X	X	
Parent date of birth		X		X	X	X		
Date of diagnosis.		X	X	X	X		X	X
Age of 1st symptoms				X	X			
Provider name	X	X	X	X	X	X		X
Provider degree/Specialty			X	X	X			X
Link Families to Resources		X		X				
Mandated Age Range	By Birth Cohort	All Ages	All Ages	0-21	All Ages	0-5	All ages/by birth cohort	All Ages
Collection Method	Active Record Review	Provider Submitted Reports	Provider Submitted Reports	Provider Submitted Reports	Provider Submitted Reports	Provider Submitted Reports	Active Record Review	Provider Submitted Reports

*Some elements (e.g., demographics) are obtained by matching with other database.

References

Autism and Developmental Disabilities Monitoring Network Surveillance Year 2002 Principal Investigators. (2007). Prevalence of Autism Spectrum Disorders-Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2000. MMWR. Vol56 (SS-1) 12-28.

CDC. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010. MMWR 2014; 63 (No. SS 2):1-21.

Community Report from the Autism and Developmental Disabilities Monitoring (ADDM) Network: A Snapshot of Autism Spectrum Disorder among 8-year-old Children in Multiple Communities across the United States in 2012, CDC, 2016.

Hughes, Virginia (2009) Scandinavian Registries Boost Autism Research. <http://sfari.org/news-and-opinion/news/2009/scandinavian-registries-boost-autism-research>.

Newschaffer, Craig, Falb, Matthew, and Gurney, James. (2005). National Autism Prevalence Trends from United States Special Education Data. Pediatrics. Vol 115(03) e277-282.

Shattuck, Paul. (2005). The Contribution of Diagnostic Substitution to the Growing Administrative Prevalence of Autism in US Special Education. Pediatrics. Vol 117 (4) 1028-1037.

Thomas, Pauline, Zahorodny, W., Peng, P., Kim, S., Jani, N., Halperin, W., and M. Brimacombe. (2012). The Association of Autism Diagnosis with Socioeconomic Status. Autism. Vol. 16 (2) 201-213.

State Contacts

Delaware

Kathryn Tullis
Department of Health and Social Services
<http://www.dhss.delaware.gov/dph/chca/dphnsp7.html>

Indiana

Holly Miller, MPH
Indiana Birth Defect and Problems Registry Administrator
hmiller@isdh.in.gov
www.in.gov/isdh/

New Hampshire

Ken Lindberg
New Hampshire Department of Health and Human Services
KLindberg@dhhs.state.nh.us
<http://www.dhhs.nh.gov/dcbcs/bds/registry.htm>

New Jersey

Sandra J. Howell, PhD
Autism Registry Coordinator
Early Identification & Monitoring Program
Special Child Health & Early Intervention Services
Division of Family Health Services
New Jersey Department of Health
PO Box 364
Trenton, NJ 08625
Sandra.howell@doh.nj.gov
http://nj.gov/health/fhs/sch/autism_registry.shtml

North Dakota

Kodi A. Pinks
Autism Database Administrator
Division of Children's Special Health Services
ND Department of Health
600 E. Boulevard Ave., Dept. 301
Bismarck, N.D. 58505-0200
E-mail: kpinks@nd.gov

Rhode Island

Deborah Garneau, MA
Co-Director, Health Equity Institute
Special Needs Director
Director's Office
RI Department of Health
(email) deborah.garneau@health.ri.gov
(t) 401-222-5929
<http://www.health.ri.gov/specialneeds/about/autism/>
<https://www.brown.edu/research/projects/ri-consortium-autism-research-treatment/index.php?q=home>

Utah

Amanda V. Bakian, PhD
Research Assistant Professor
Director, Utah Registry of Autism and Developmental Disabilities
Department of Psychiatry, University of Utah
amanda.bakian@hsc.utah.edu
801-581-5413
<http://utahautismregistry.org/>

West Virginia

Julie O'Malley
Old Main 316
1 John Marshall Drive
Huntington, West Virginia 25755
lynch29@marshall.edu

<http://www.marshall.edu/atc/wvasd-registry/>

ⁱ Autism Spectrum Disorder (ASD) is the name for a group of developmental disorders. In the literature, the words “disorder” and “disorders” are often used interchangeably because of the changes in diagnostic terminology. Prior to ASD, the group of developmental disorders were preferred to as Pervasive Developmental Disorder and included five specific disorders.

ⁱⁱ The DSM-IVr subtypes included Autistic Disorder, Pervasive Developmental Disorder (NOS), Asperger Disorder, Rett Syndrome, and Childhood Disintegrative Disorder.