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## Children with Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) include five developmental disorders: autistic disorder, Asperger's syndrome, Rett's disorder, childhood disintegrative disorder and pervasive developmental disorder, not otherwise specified (PDD NOS). The hallmark characteristic common to each of these disorders is impairment in one's ability to interact socially; however, differences exist in terms of symptom severity and time of onset. Children who are diagnosed with an ASD demonstrate a wide range of intellectual abilities and linguistic skills, which can range from below to above average intellect and children who do not speak at all to those who are able to communicate using complex, grammatically correct speech (1, 2, 3).

In 1943, Dr. Leo Kanner referred to the withdrawn behavior of several children he studied as autism. A year later, Dr. Hans Asperger identified a similar condition that is now called Asperger syndrome (4).

Common characteristics of children diagnosed with autistic disorder include developmental delays or impairments in use of nonverbal behaviors (e.g., facial expression, gestures) to regulate social interaction. Children may not develop peer relationships appropriate to their developmental level or may lack spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., a lack of showing, bringing, or pointing out objects of interest). With respect to communication skills, children diagnosed with autistic disorder show a delay in or total lack of development of spoken language or marked impairment in the ability to initiate or sustain a conversation with others. Other common characteristics of children diagnosed with autistic disorder include repetitive use of language or restricted repetitive and stereotyped patterns of behavior, interests, and activities (e.g., inflexible adherence to routines, repetitive motor mannerisms).

Similar to children with an autistic disorder, children diagnosed with Asperger's syndrome display marked impairment in their ability to use non-verbal behaviors or develop peer relationships. Also, children diagnosed with Asperger's syndrome may use repetitive motor mannerisms. However, children diagnosed with Asperger's syndrome tend to show no clinically significant delays in language or cognitive development (1).

Children diagnosed with Rett's disorder and childhood disintegrative disorder tend to initially do not display delayed development, then appear to regress in communication skills and social

interaction (1). Children diagnosed with a pervasive developmental disorder, not otherwise specified, also display impairment in the development of social interactions or communication skills and display stereotyped behaviors. However, this diagnostic category includes “atypical autism” presentations that do not meet the criteria for autistic disorder (1).

## Factors Associated with ASDs

The exact cause or causes of ASDs have not been fully established; however, there is an increasing body of evidence that points to genetic anomalies as causes of ASDs. For example, researchers identified 27 genetic regions where missing or extra copies of DNA segments were found in genes of children with ASDs that were not present in children without ASDs. Autism susceptibility genes related to the development of brain circuitry in early childhood have also been identified (5) and geneticists have been able to isolate the likely region of an autism gene which contributes to autism, particularly among males (6,7).

Differences in brain structure and functioning also appear to be related to increased risk of ASDs. For example, we have learned toddlers with autism have an increased likelihood of an enlarged amygdala when compared to their peers and this amygdala dysfunction is related to their failure to attend to the eye region of faces, diminishing their ability to gain social cues from people they observe (8). Toddlers with autism also tend to display a lack of activity in the mirror-neuron system, which is associated with our ability to understand actions, intentions and emotions of another individual (9). The differences in brain structure observed in children with ASDs are also evident in adults. For example, researchers investigating the relationship between abnormal brain connectivity and social impairment found adults with the greatest degree of social impairment exhibited the most abnormal pattern of connectivity among a network of brain regions involved in facial processing (10). Additionally, adults with autism tend to have a heightened level of activity in the amygdala, which is the region of the brain associated with fight-or-flight response. This level of activity is associated with one’s level of social impairment where higher degrees of hyperarousal were observed among individuals with more severe social impairment (11).

Some contend the genetic and biological features observed in children and adults with ASD may be linked to environmental causes. In particular, concerns regarding infant vaccines as possible causes of ASDs have focused research attention on the Measles-Mumps-Rubella (MMR) vaccine and thimerosal, a mercury-based preservative previously used in child vaccines (12). However, a comprehensive review of biological, clinical and epidemiological studies indicates there is no evidence that childhood vaccines are associated with autism (13 NAS Safety). Despite our new knowledge about childhood vaccines, more needs to be done to increase public awareness as indicated by survey results that indicate about one in four individuals believed ASDs were caused by childhood vaccines (14).

It is expected that the National Children’s Study will contribute substantially to our understanding of the causes of ASDs. This study is designed to examine the effects of environmental influences on the health and development of over 100,000 children across the United States. Environmental factors are broadly defined to include natural and man-made factors as well as contributions of social and genetic factors. Children in this study will be observed from before birth until age 21. Although the focus of this study is not limited to causes

of ASDs, information gathered from studying children at different phases of development will greatly contribute to our knowledge about how environmental and genetic factors interact and contribute to ASDs (15).

## Challenge and Importance of Early Diagnosis

To date, no physiological tests are available to assist with ASD diagnoses. Instead, certain behavioral characteristics are used to establish a diagnosis. This diagnostic approach has inherent challenges associated with it that can influence the accuracy and timeliness of diagnoses. For instance, in the case of autistic disorders, the onset of symptoms tends to occur during the first three years of life and we have come to realize early, reliable diagnoses are dependent upon careful monitoring of developmental markers. Yet, the challenge posed here is that many of the characteristics used to establish an early ASD diagnosis, such as language, reasoning and social skills, are just beginning to develop and professionals must decide whether the observed characteristics are within the normal range of developmental variations. Parents tend to have an intuitive sense regarding the appropriateness of their children's development so this awareness coupled with pediatric inquiries during children's well-baby visits can improve the likelihood children are diagnosed early and linked to necessary interventions. Typically, assessments can be made reliably when a child is 18 to 36 months old.

Children diagnosed with Asperger's syndrome tend to function at a higher level than children diagnosed with an autistic disorder, which can influence the age at which they are accurately diagnosed. Since development of language and cognitive skills is rarely delayed in children with Asperger's syndrome, children can go undiagnosed until they are five years of age, hindering their early access to interventions (2).

*Learn the Signs—Act Early* is a public awareness campaign developed by the CDC to increase the likelihood diagnoses are made much earlier. The primary goal of this campaign is to help parents incorporate social and emotional milestones along with the more traditional physical milestones when observing their children's development. These milestones include early markers that are developed well before acquisition of language skills. Examples of milestones include smiling, pointing, and social play. The campaign is also intended to increase communication between parents and health care providers with the ultimate aim of early detection and intervention. This campaign can be particularly valuable in offsetting racial and ethnic disparities related to early diagnoses (16, 17).

## Rate of ASD at the National and State Level

Findings from a Centers for Disease Control and Prevention (CDC) surveillance study of 14 health facilities across the US indicated an ASD prevalence rate of one in 152 children for children aged 8 years (18). Information from screenings and record reviews were gathered and, when available, data from psychoeducational evaluations for special education services were also included. Clinicians reviewed the data records and made determinations regarding children's ASD status.

Results of the National Study on Children’s Health (NSCH) indicate about one child in every 110 children nationwide (0.9%) is diagnosed with an ASD (19). The NSCH is a telephone survey of households where parents are asked if a healthcare provider ever told them their child (ages 2 through 17 years) has an ASD. NSCH data for New York State indicate a slightly lower rate than nationally. In New York State, approximately 0.7 percent of parents report a healthcare provider has told them their child may have an ASD. This reflects approximately 28,000 children statewide (19).

Differences in the CDC study and NSCH survey can be due, in part, to the data collection methods used and age groups of children studied.

Another data source for examining New York State children with ASDs is the number of children ages 4 through 21 receiving special education services through their school districts. Similar to the CDC study and NSCH survey, the school based information reflects children who have been identified as having an ASD. However, these data tend to undercount children with ASD since they reflect the subset of children who are served within a special education setting. Information about this group of children is provided in the next section.

### Children Identified with ASD Receiving Special Education Services

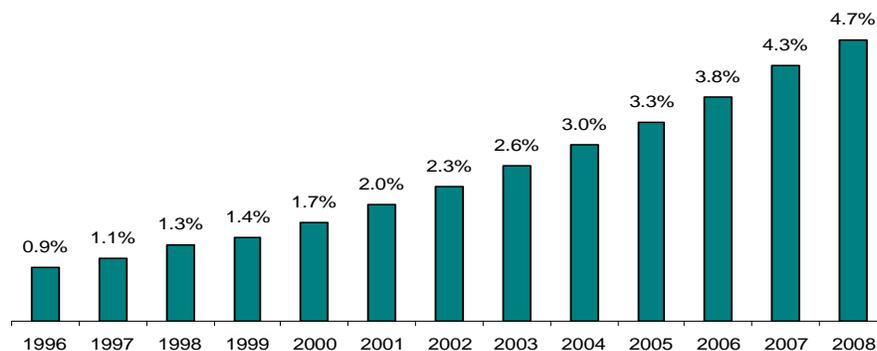
A school census taken each year is used to determine the number of children receiving special education who are classified by various federal disability categories. As of October 2008, 19,132 children ages 4 through 21 years in New York State who were receiving special education services were identified as having an ASD. A review of school census figures over time indicates about a five-fold increase in the percent of special education children identified with ASD (Figure 1).

A number of factors are possible contributors to the observed increase, including the Social Security Administration’s (SSA) broadened definition of disability as well as changes in Individuals with Disabilities Education Act (IDEA) reporting. In both instances, the changes provided incentives to classify children with ASDs (20).

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Figure 1. Students receiving special education services who are identified with ASD

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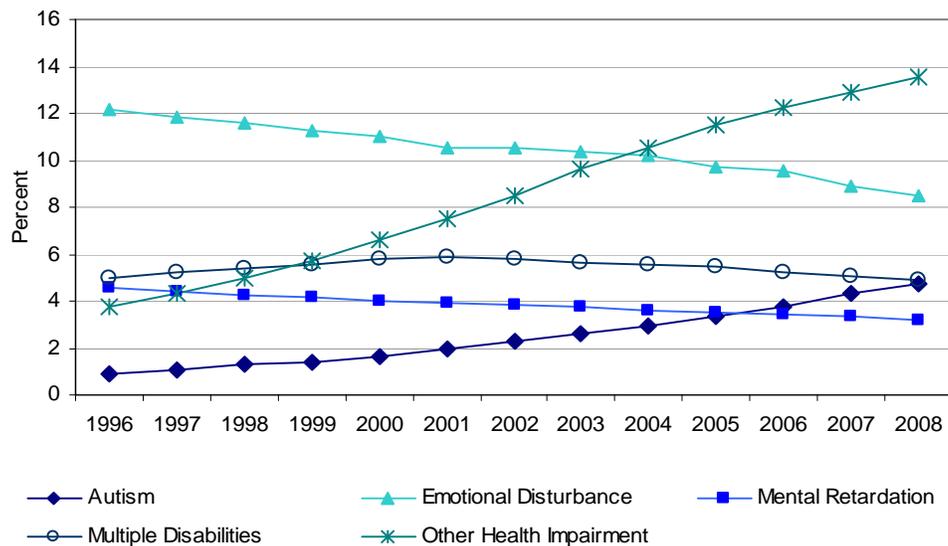
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Data Source: New York State Education Department, Vocational and Educational Services for Individuals with Disabilities

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It has been suggested that the changes made by SSA and IDEA triggered changes in practice that resulted in diagnostic substitutions where children currently identified as having ASDs would have been identified as having a different developmental disability in previous years (20). For example, a child who may have been classified with mental retardation would now be classified as autistic. Figure 2 presents the percent of children receiving special education services who are classified in five broad categories. The rate of children classified with ASDs shows a considerable change over time and this is coupled with a marked decline in the rate of children classified with emotional disturbances. This portrayal does not provide the necessary precision to determine if diagnostic substitution is occurring; however, it serves as a description of the service needs of children in school settings and provides a sense of the extent schools have had to accommodate increased demand for services. It is important to note that during this time period a rise of children identified with “other disability” is parallel to the rise observed among children with an ASD.

Figure 2. Students receiving special education services by classification category



Data Source: New York State Education Department, Vocational and Educational Services for Individuals with Disabilities

The percent of children receiving special education services who are classified as having an ASD varies considerably by county from a low of 1.85 percent in Niagara to 11.21 percent in Schoharie. Table 2 highlights the percent of special education students identified with an ASD by each county. Although not all children with ASD receive special education services, this provides a basic sense of service demands experienced by schools within a given county.

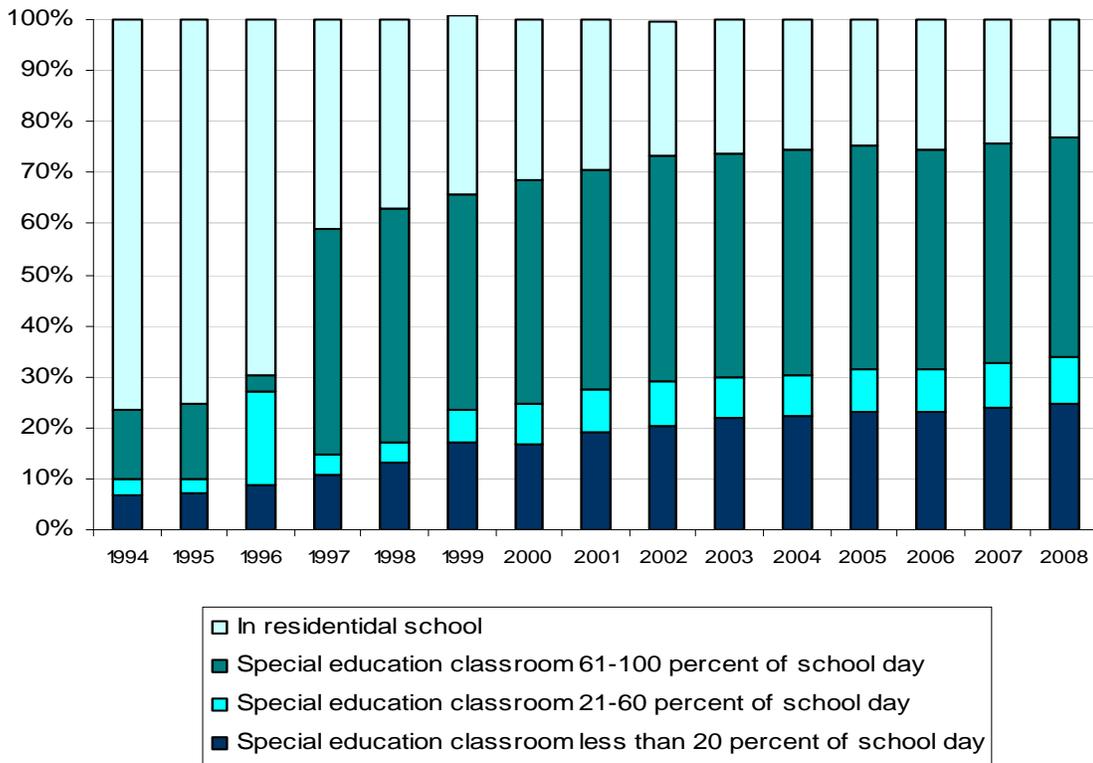
Table 2. Percent of children receiving special education services classified with an ASD by county

County	Special Education Students Identified with Autism (N=)	Special Education Students Identified with Autism (%)	County	Special Education Students Identified with Autism (N=)	Special Education Students Identified with Autism (%)	County	Special Education Students Identified with Autism (N=)	Special Education Students Identified with Autism (%)
Albany	447	7.44	Hamilton	5	10.64	Rensselaer	170	4.73
Allegany	48	4.47	Herkimer	51	3.52	Rockland	339	5.63
Broome	292	6.36	Jefferson	110	4.35	St Lawrence	96	4.15
Cattaraugus	59	2.84	Lewis	14	2.33	Saratoga	271	6.24
Cayuga	60	4.36	Livingston	45	4.62	Schenectady	129	3.86
Chautauqua	90	3.46	Madison	60	4.14	Schoharie	76	11.21
Chemung	102	5.76	Monroe	847	5.37	Schuyler	11	4.51
Chenango	76	5.85	Montgomery	34	2.74	Seneca	37	4.91
Clinton	90	4.21	Nassau	1641	5.95	Steuben	88	3.56
Columbia	69	5.28	NYC Public	6833	4.34	Suffolk	2108	6.22
Cortland	37	3.54	Niagara	84	1.85	Sullivan	75	5.32
Delaware	41	4.06	Oneida	190	3.67	Tioga	32	2.99
Dutchess	353	5.04	Onondaga	650	5.77	Tompkins	100	4.88
Erie	593	2.87	Ontario	94	4.26	Ulster	228	6.04
Essex	19	3.04	Orange	441	4.89	Warren	85	5.83
Franklin	33	2.85	Orleans	27	3.16	Washington	49	3.43
Fulton	69	4.75	Oswego	173	5.44	Wayne	77	3.57
Genesee	38	3.27	Otsego	37	3.93	Westchester	988	5.31
Greene	52	5.26	Putnam	130	5.29	Wyoming	16	2.66
						Yates	19	4.28

Data Source: New York State Education Department, Vocational and Educational Services for Individuals with Disabilities

The increased classification of children with ASD over time coincides with an increased effort to provide education services in the least restrictive setting. Figure 3 reflects this as we see a smaller percentage of children with ASD served in residential schools. In 1994 approximately eight in ten children with ASD were referred for residential services (77%) and this declined to about two in ten children placed out of home in 2008. Factors that contributed to the observed decline are an increased emphasis on family support services that allow children to remain within their homes; diagnosis of children with greater variability in functioning levels; and expanded community-based services. The special education classroom depicted in Figure 3 may be located in either a BOCES or public school district.

Figure 3. Placements of special education students with ASD



Data Source: New York State Education Department, Vocational and Educational Services for Individuals with Disabilities

## Summary

Autism spectrum disorders, as the name implies, include a wide range of symptoms and levels of symptom severity. This variability poses considerable challenges in making accurate, timely diagnoses. However, it is clear that early identification can result in improved outcomes, including improvement in language and social skills as well as a reduction in inappropriate behaviors. To help improve early diagnoses, the New York State Department of Health has supported the development of clinical practice guidelines on autism pervasive developmental disabilities and plans to update these guidelines through a recently awarded federal grant<sup>1</sup>. Furthermore, DOH is working with the healthcare community to increase the number of

<sup>1</sup> Clinical Practice Guidelines on Autism/Pervasive Developmental Disorders: Assessment and Interventions for Young Children 0-3 years is available online at: [www.nyhealth.gov/community/infants\\_children/early\\_intervention/disorders/autism/](http://www.nyhealth.gov/community/infants_children/early_intervention/disorders/autism/)

pediatricians and primary care providers who perform screenings among children ages 18 through 24 months.

The rising number of children diagnosed with ASDs also calls for improved surveillance systems that will allow communities to develop a more accurate assessment of children who require services, allowing them to build a local infrastructure that supports children with ASDs and their families.

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