

**TESTIMONY ON SB 2268
INTERIM HUMAN SERVICES COMMITTEE**

August 2, 2011

**By Robert Rutten, Special Education Regional Coordinator
Department of Public Instruction**

Chairman Wieland and members of the Interim Human Services Committee:

I am from the special education office at the North Dakota Department of Public Instruction. Since the 2009 Legislative Assembly passed SB 2174 creating the Autism Spectrum Disorder Task Force, I've represented our agency on that work group. I've been asked to provide some information for your committee from the perspective of education.

Our state education agency is responsible for the general supervision of the **Individuals with Disabilities Education Act**, more commonly referred to as the IDEA, which is our nation's federal law for special education. It's important that all members of the committee have an awareness of some basic principles of this law:

1. Both students who have disabilities and their parents have certain rights and safeguards under this federal law.
2. Public education for students with disabilities must be at no cost to their families; it must be free.
3. The education must be appropriate to meet the unique needs of each eligible individual student who has a disability.
4. Special education services must be provided in the least restrictive environment (LRE) for the child. This is typically defined as the student's neighborhood school. This placement must be determined by a group of

people which includes the child's parents and representatives from the local public school district.

As a point of clarification, the current regulations for the IDEA dating from 2006 use the term *autism*. There is a growing national sense that the term will be broadened to *autism spectrum disorder*, or ASD, to more properly describe the range of variations which this disorder can have.

Autism—As defined by the Individuals with Disabilities Education Act (IDEA) CFR.300.8 (c) (1) (i)

Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movement, resistance to environment change or change in daily routines, and unusual responses to sensory experiences. The term does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance.

The North Dakota Department of Human Services is responsible for the IDEA services for infants and toddlers and their families in our state up to age three. The Department of Public Instruction is responsible for the IDEA special education services for children and youth with disabilities from age 3 through 21. Because of this shared administration of the IDEA services in North Dakota, our two agencies jointly created state guidelines for identifying, serving, and educating children and youth with autism.

To help committee members become more familiar with autism and some key concepts and terms regarding ASD here is some information from our guidelines.

- Autism is a life-long, nonprogressive developmental disability.

- Autism is a disability characterized by impairments in social interaction, communication, and the capacity for imaginative and symbolic thinking resulting in exaggerated and stereotyped interests, behaviors, and activities. It is presumed to be present from birth and is always apparent before the age of three. At this time the specific cause of autism is not fully understood.
- Autism affects an individual's ability to communicate, understand language, play, and interact with others. The severity of impairment in each of these domains varies along a continuum and the particular signs of impairment may be very diverse. Thus, those with autism may appear quite different from each other with respect to sensory stimuli, the regulation of attention, behavioral and emotional self-control, activity level, attachment to others, resistance to change, and cognitive functioning.

Fact . . .

*Autism is neither
an illness nor a
disease and is not
contagious.*

The *Diagnostic and Statistical Manual-IV* (DSM-IV) is used by physicians and mental health professionals, as a guide to diagnosing disorders. In the current edition, five disorders are identified under the category of Pervasive Developmental Disorders (PDD). Agencies and professionals in fields, other than early intervention and education, use these definitions to formulate a diagnostic approach to services. To understand how the disorders differ and how they are similar, it is useful to look at the descriptions for the full criteria of each disorder.

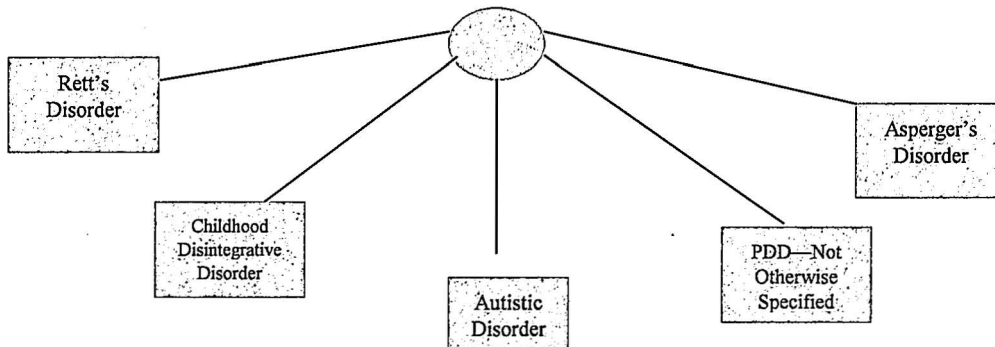
1. ***Autistic Disorder*** sometimes referred to as early infantile autism or childhood autism, is four times more common in boys than in girls.

Individuals with Autistic Disorder have a moderate to severe range of communication, socialization, and behavior problems. Many with autism also have an intellectual disability.

2. ***Rett's Disorder*** is diagnosed primarily in females. In children with Rett's Disorder, development proceeds in an apparently normal fashion over the first six to 18 months, at which point parents notice a change in their child's behavior and some regression or loss of abilities, especially in gross motor skills such as walking and moving. This is followed by an obvious loss in abilities such as speech, reasoning, and hand use. The repetition of certain meaningless gestures or movements is an important clue to diagnosing Rett's Disorders.
3. ***Childhood Disintegrative Disorder*** an extremely rare disorder, is clearly apparent regression in multiple areas of functioning (such as the ability to move, bladder and bowel control, and social and language skills) following a period of at least two years of apparently normal development.
4. ***Asperger's Disorder*** is a developmental disorders characterized by a lack of social skills, difficulty with social relationships, poor coordination and concentration, and a restricted range of interests but normal intelligence and adequate language skills in the areas of vocabulary and grammar. However, the individual may have difficulty understanding the subtleties used in conversation, such as irony and humor. Asperger's Disorder appears to have a somewhat later onset than Autistic Disorder, or at least it is recognized later.
5. ***Pervasive Developmental Disorder—Not Otherwise Specified (NOS)*** is used when there is a severe and pervasive impairment in the development of social interaction or verbal and nonverbal communication skills or

when stereotyped behavior, interests, and activities are present but the criteria are not met for a specific disorder.

Pervasive Developmental Disorder - *PDD refers to a category of disorders and is also used as a diagnostic label.*

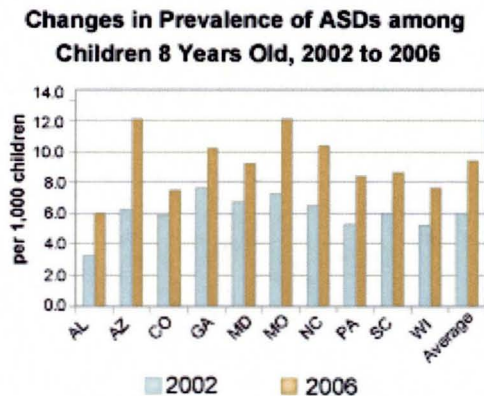


Each year our office makes an annual count of the number of eligible students with disabilities ages 3 through 21 who are receiving special education and related services in North Dakota public schools. In our most recent statewide *Child Count* on December 1, 2010 it was determined that there were 13, 170 such students.

Of that total number, 586 were reported as having a primary disability of autism. Similar to what has occurred across the United States, the number of children identified with autism has risen rapidly in the past decade. In 1999, only 112 children were identified as having autism as a primary disability. The 586 students with autism now identified represent 4.4% of the identified special education population in North Dakota schools.

It's important to keep in mind that this increase in the number of children identified with an autism spectrum disorder is not unique to our state. Across the United States and in other countries around the world, many more young people

are receiving a diagnosis of an autism spectrum disorder. The United States Centers for Disease Control and Prevention report that studies in Asia, Europe, and North America have identified individuals with an ASD with an approximate prevalence of 0.6% to over 1%. The following table illustrates the changes in prevalence of ASDs among children 8 years old, 2002 to 2006.



Approximately 13% of children have a disability, ranging from mild disabilities such as speech and language impairments to serious developmental disabilities, such as intellectual disabilities, cerebral palsy, and autism.

Centers for Disease Control and Prevention

There are several points that might seem obvious members of the committee but merit pointing out.

The range of abilities among young people who have an ASD can vary hugely. One child with an ASD may require extensive special education and related services to address behavior, communication, cognitive and social development. Another child may require far less structured services. Another child may require little or no special education services whatsoever.

To address these diverse needs schools need to have access to knowledgeable special education teachers, speech-language pathologists, behavioral experts, and paraprofessionals. They also require access to appropriate materials and assistive technology. We are fortunate to have special education

professional preparation programs available for North Dakota educators at both the University of North Dakota and Minot State University to help provide pre-service and in-service training specifically for ASD, on campus and online. As practices become more fully developed across our state and nation there is an increased recognition that it's too often the behavior of a student with ASD that interferes with his/her access to instruction. More training is needed for teachers and paraprofessionals to not only understand these challenging behavioral issues, but to work systematically to shape appropriate behavior that will allow them to focus on the content of a class lesson.

Throughout the meetings of the ND ASD Task Force an issue that continued to surface was service coordination. Transitions between programs can be difficult for children and their families. However, the coordination across home, school, medical, and social services is vitally important. If some technique is working effectively in a child's home there needs to be an understanding of that success and a possible application to the child's school day as well. The reverse is also true; strategies that work well at school may need to be continued in a child's home.

The identification of a child with an ASD can be an overwhelming experience for a family. The life of the family can become largely focused on the child with ASD. Oftentimes this can be a monumental challenge for the entire system of care surrounding the child and family. Because schools are where children and youth spend much of their waking hours, schools are a proper focal point for much of the support for these young people. However, it's typical that that most students are only in school for 6-7 hours 5 days a week, and often much less for younger children. The system of support for these students and their families needs to extend beyond the school day.

As I'm sure you already understand, ASD presents a broad set of challenges

and is greater than an education issue alone. As our universities increasingly gear up to provide more comprehensive training on ASD for teachers and our schools provide more innovative assistive technology for students, and use more research-based strategies to improve educational outcomes for students with ASD, underlying questions demand our attention. Perhaps the most basic questions of all are what's causing this worldwide surge in ASD? And is there any preventive action to address possible causal factors? Is the level of research adequate to truly understand this phenomenon? The education system is joined with families, the medical system, the scientific community, the social services system, and the system of government to respond equitably and responsibly. The school doors are open. Much can be done to mitigate the effects of an ASD to help students succeed in school, to graduate from high school, to receive positive post-school training and successful outcomes, and to achieve a measure of independence. These goals remain worth pursuing for each student with an Autism Spectrum Disorder in the schools of our state, for their families, and our larger society as well.

In the spring of 2009 the Department of Public Instruction conducted a detailed analysis of the demographic characteristics of students with autism in North Dakota public schools. The data presented in this study include information about the ages, distribution, location, and school districts of students with autism and represents a point-in-time view of the demographic characteristics. The report is included for the benefit of committee members as you study our state's system of support for this special population of North Dakota citizens.

Chairman and members of the Committee, this concludes my testimony. I would be happy to answer any questions the committee may have.



SPECIAL EDUCATION IN NORTH DAKOTA

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Autism Spectrum Disorders in North Dakota Public Schools

April 2, 2009

Autism Spectrum Disorders in North Dakota Public Schools

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Data as presented in this report are extracted from the statewide special education case management system (TIEnet). All data presented in this report are accurate as of this date and reflect a point-in-time view of the demographic characteristics of students with autism and students with other eligible disability categories in ND public schools.

April 2, 2009

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Autism Spectrum Disorder in North Dakota Public Schools

Background

The prevalence rate of children identified with an Autism Spectrum Disorder (ASD) has increased dramatically over the last 10-20 years. In 1992, approximately 15,302 children in the United States between the ages of 6 and 21 were identified as having Autism. In 2004, approximately 165,662 children in this same age range, commonly referred to as "school aged," were identified with the disorder (U.S. Department of Education). This exponential increase in reported rate has placed an extraordinary strain on schools to provide programs and interventions that meet the unique needs of individuals identified as possessing a disability on the spectrum; i.e., Rett's Disorder, Childhood Disintegrative Disorder, and Asperger's Syndrome. (For convenience sake referred to in this report simply as "Autism").

Autism is the most common of the Pervasive Developmental Disorders, affecting an estimated 1 in 250 births (Centers for Disease Control and Prevention, 2003). "CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network released data in 2007 that found about 1 in 150 8-year-old children in multiple areas of the United States had an ASD." (Centers for Disease Control and Prevention, 2007) This means that as many as 1.5 million Americans today are believed to have some form of Autism. And that number is on the rise. Based on statistics from the U.S. Department of Education and other governmental agencies, Autism is growing at a rate of 10-17 percent per year. The overall incidence of Autism is consistent around the globe, but is four times more prevalent among boys than girls. Autism knows no racial, ethnic, or social boundaries, and family income, lifestyle, and educational levels do not affect the chance of Autism's occurrence.

Recognized as a developmental disability, Autism affects verbal and non-verbal communication as well as social interactions. These deficit areas adversely affect a child's educational and social performance and is generally evident before age three. Other characteristics typically associated with Autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in routine and unusual responses to sensory experiences. The symptoms and characteristics of Autism can present themselves in a wide variety of combinations, from mild to severe. Although Autism is defined by a certain set of characteristics, children and adults can exhibit any combination in any degree of severity. Two children, both with the same diagnosis, can act very differently from one another and have varying skills and needs.

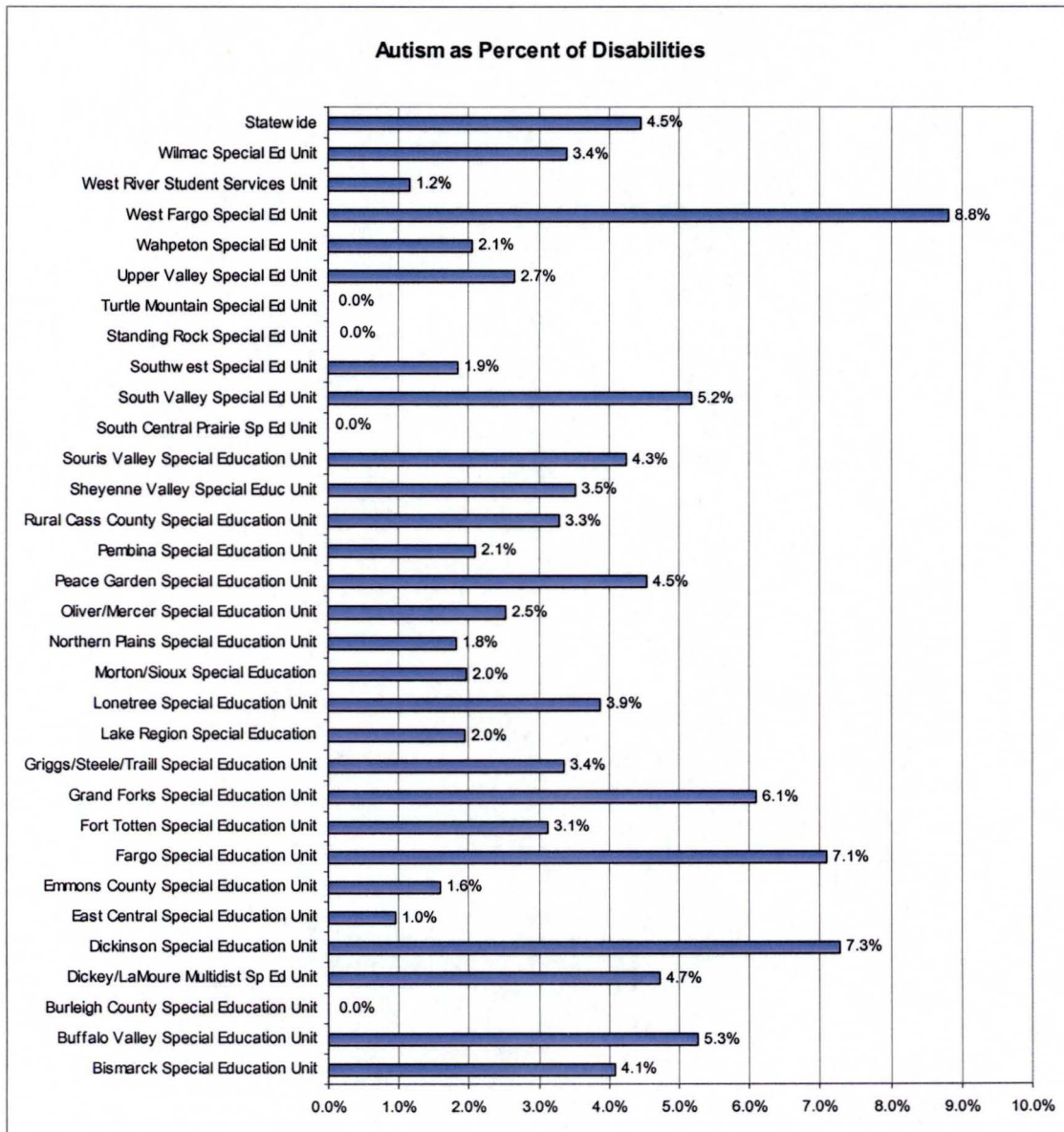
Autism in North Dakota Public Schools

Like most of the nation, North Dakota is on the fast track to mitigate a disorder which has concerned policy makers and practitioners with its apparent rapid growth rate. Before additional resources can be allocated to meeting the unique needs of these children, it is necessary to take a measure of the problem, to answer the question, "What is the scope of the challenge of Autism in the academic environment?" Although the qualitative component of this question is beyond the scope of this initial report, the implied quantitative component which is implied is particularly germane.

Utilizing the Department of Public Instruction (DPI) TIEnet data management and reporting system, a highly accurate picture of the numbers of children being served in the public school system across the state can be obtained. This picture provides a point-in-time snapshot of the demographic characteristics of these children and where they are receiving their education. It must be recognized that, if the last 10-20 years are any indication, this snapshot does not represent a static event and is constantly changing.

Autism Spectrum Disorder in North Dakota Public Schools

However children with Autism are identified, they frequently receive at least part of their education as a "special education student." As a special education student they are entitled to an individually designed educational opportunity. Within North Dakota, geographically placed administrative units are responsible for overseeing and ensuring that these children receive a free appropriate public education under federal and state law.

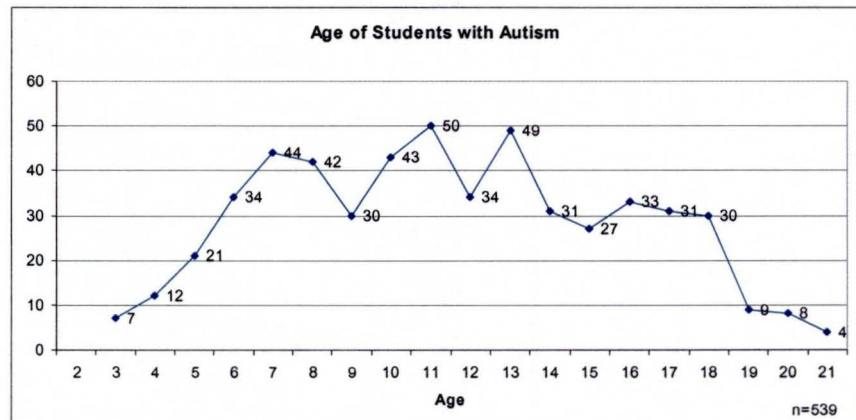


Within North Dakota, 31 of these special education administrative units oversee related services to 12,059 students. Of these, 539 have Autism as their primary disability. Seven of these units serve special education student with an Autism diagnosis in excess of the state average (4.5%); West Fargo (8.8%), Dickinson (7.3%), Fargo (7.1%), Grand Forks (6.1%), Buffalo Valley (5.3%), South Valley (5.2%), and Dickey/LaMoure (4.7%). Four special education units did not have any students with Autism identified as their primary disability; Turtle Mountain, Standing Rock, South Central Prairie, and Burleigh County. These 539 students with Autism are being served in 84 separate school districts. In addition, one child has noted as his district of residence, "State Responsible," which is commonly referred to as "ward of the state." (See Appendix A: Districts of Residence for Students with Autism.)

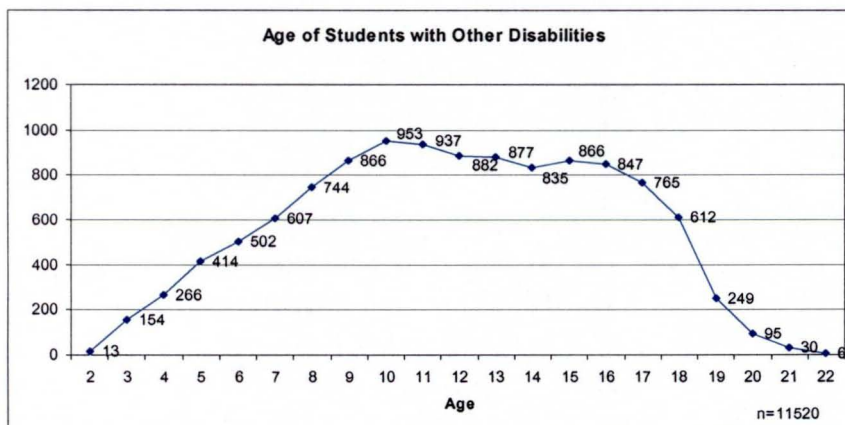
Autism Spectrum Disorder in North Dakota Public Schools

Age is a factor which can tell us a lot about both the incidence and prevalence of individuals being served. Within special education, it can tell us at what age students are accessing services as well as their age of departure from services. Typically such consideration yields more questions and it is the intent of the current study to directly address these issues; it is the intent though to broach them for future consideration.

At present, students with Autism as their primary disability, range in age from three years to 21 years of age. These 539 students possess a median age of 11 years 4 months. Although spread throughout the distribution, the largest proportion of students (50) were 11 years of age.



When looking at the age distribution of other students with disabilities served through the special education units, a very similar pattern is realized. These 11,520 students ranged in age from two years to 22 years of age and possessed a median age of 11 years 8 months. Like the preceding age chart of students with Autism, students with other disabilities were also spread-out, but the largest proportion (953) were 10 years of age.

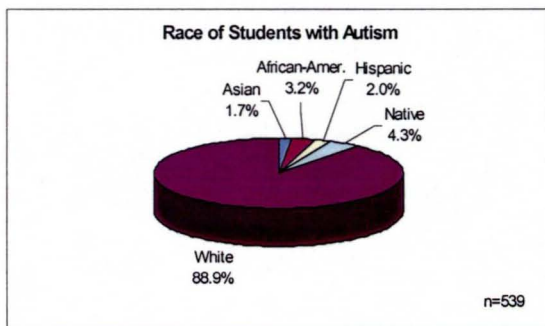
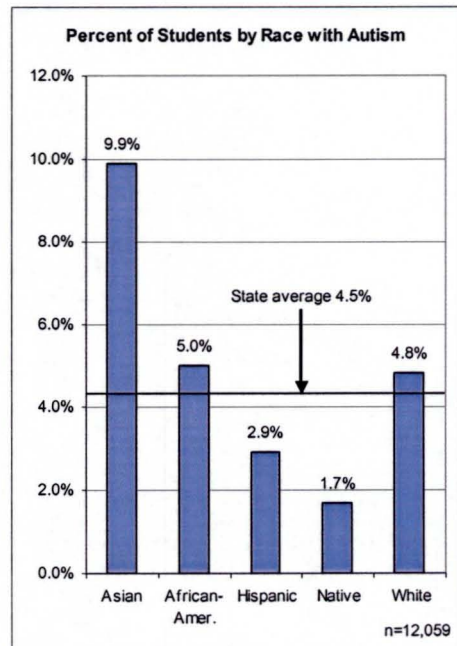


Although one could argue that the age distribution of students with Autism is bi-, if not tri-, modal, it is also interesting that both distributions display a dip in age at 12 years and 14 years. Since larger numbers tend to cancel out such "noise," this dip is more apparent in the Autism age distribution since there are a fewer number of students.

Autism Spectrum Disorder in North Dakota Public Schools

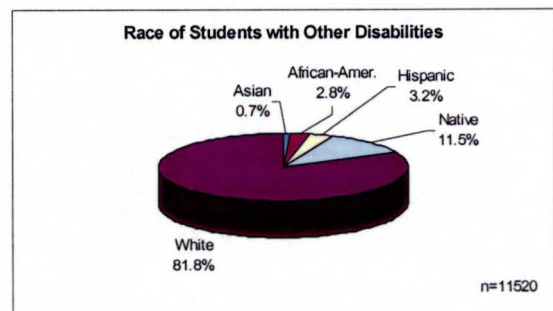
Of the 12,059 students with a diagnosed disability who are being served in special education, 4.5% possess Autism as their primary diagnosis (n=539). When looking at the racial characteristics of students with Autism being served in North Dakota public schools, it becomes obvious that there is a degree of disproportionality. For example, of the 91 students who are Asian and are being served by special education, 9.9% have a diagnosis of Autism as their primary disability. Of students with disabilities who are of African-American descent, 5% possess Autism as a primary diagnosis, and 4.5% of white student possess a similar diagnosis (n's of 340 and 9904 respectively).

Of course not all groups are above the state average (a mathematical impossibility), and only 2.9% of the 375 Hispanic students are being served under category of "Autism." Native-Americans with 1349 students have proportionally the fewest number of students with an Autism diagnosis (1.7%).



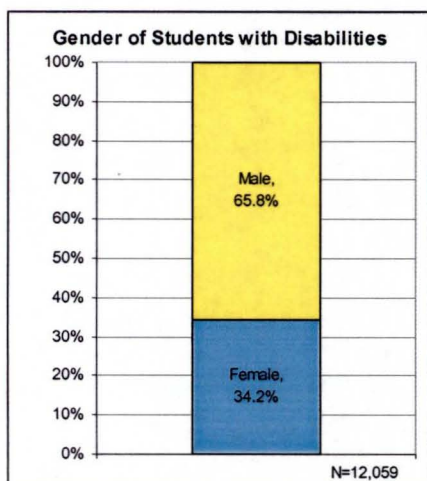
When looking at the racial profile of students with Autism who are being served as special education students (n=539), it becomes immediately apparent that the majority (88.9%) are white. The remaining four racial groups account for approximately 11%, with Native-Americans accounting for 4.3%, African-Americans 3.2%, Hispanics 2%, and Asians 1.7%.

It is worthwhile to take a look at the racial distribution of students with disabilities being served in North Dakota public schools who do not possess an Autism diagnosis (N=11,520). The relative ordering of the racial groups is very similar to that displayed by students with Autism, except for African-American and Hispanic students which have reversed position.



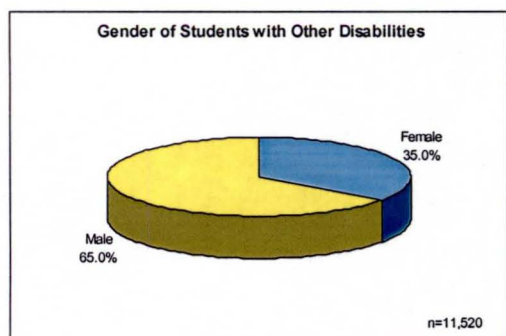
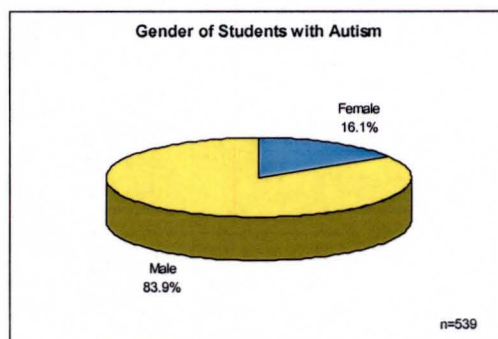
Comparing the racial proportions of students with Autism as a primary disability to those with other disabilities indicates that three groups are over-represented; white, African-American, and Asians.

Autism Spectrum Disorder in North Dakota Public Schools



When looking across all students with disabilities being served in the North Dakota public school system, it is found that male students out-number female students by a factor of almost two-to-one. Male students make up 65.8% of the population of individuals with identified disabilities in the public school system and females make up the remaining 34.2%.

Whereas males make up 65.8% of the overall student population with disabilities, they comprise 83.4% of the students with autism subpopulation. Conversely, females which make up 34.2% of the student with disabilities population are under-represented in the Autism subpopulation (16.1%).

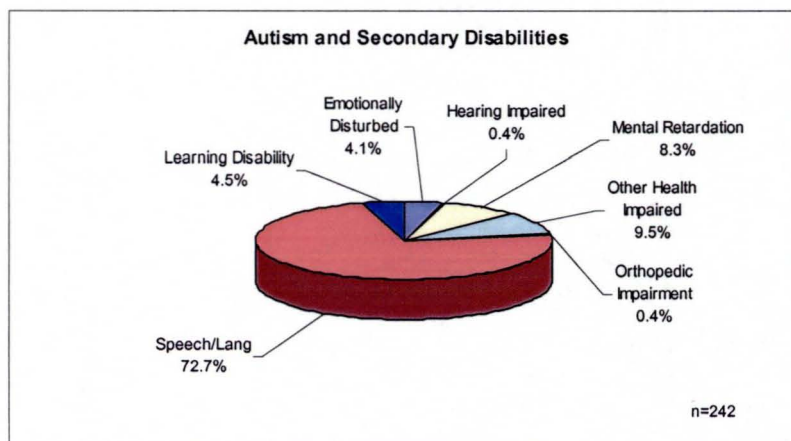
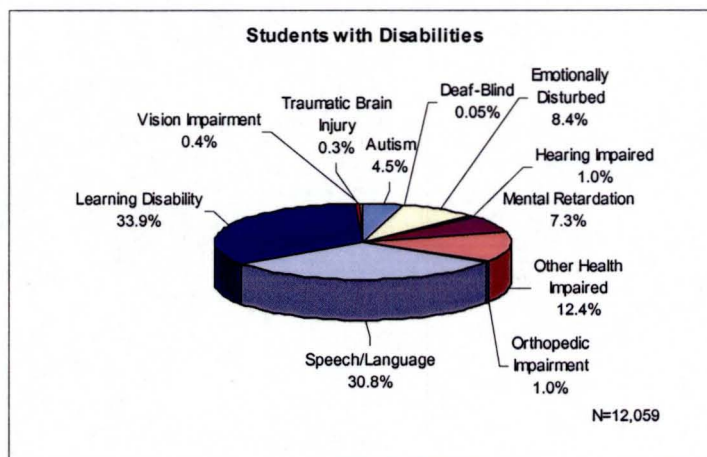


Not surprisingly, the gender distribution of students with other disabilities being served in the North Dakota public school system (65% male and 35% female), because of its greater numbers, is very similar to the distribution of all students with disabilities (65.8% male and 34.2% female).

Autism Spectrum Disorder in North Dakota Public Schools

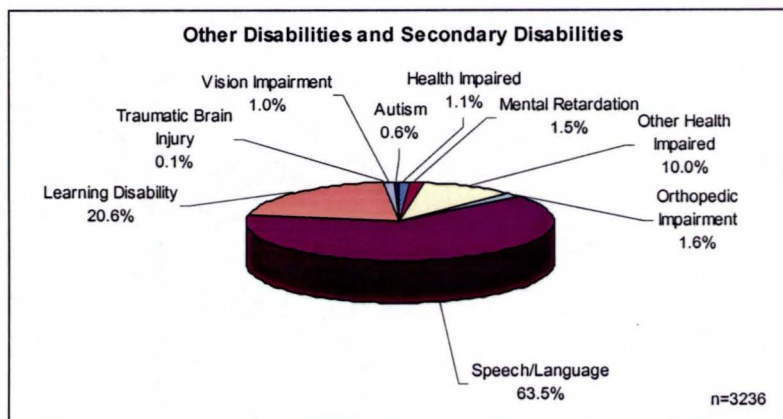
As noted earlier in this report, 4.5% of students receiving special education services in North Dakota Public Schools receive such services with an Autism diagnosis (593). The remaining 96.5% of students receiving special education services receive such services with different qualifying conditions (11,520).

Students with learning disabilities (33.9%) and those with speech/language disorders (30.8%) account for almost two out of every three students served in special education in North Dakota public schools. The remaining disability groups range from 0.05% for students classified as "Deaf/Blind," to 12.4% for students who possess Other Health Impairments. As noted earlier, students with Autism comprise 4.5% of the students with disabilities population.



Of the 539 students with Autism in North Dakota Public Schools, 44.9% possess an identified secondary disability (n=242). Close to three-quarters of these secondary disabilities are in the area of Speech and Language (72.7%). Six additional disabilities range from 0.4% (Hearing Impairments and also Orthopedic Impairments) to 9.5% (Other health Impaired).

Aside from secondary disabilities which students with Autism as their primary disability may possess, 26.8% of other students with disabilities also possess a secondary disability (n=3226). Again, Speech and Language accounted for the largest proportion (63.5%) and the remaining range from 0.1% (Traumatic Brain Injury) to 20.6% (Learning Disabilities). It is interesting to note that 0.6% identified Autism as their secondary disability (n=19).



Appendix A:

Districts of Residence for Students with Autism

Autism Spectrum Disorder in North Dakota Public Schools

District of Residence for Students with Autism

District of Residence	Number of Students
Apple Creek 39	2
Barnes Co North 7	3
Beach 3	2
Beulah School District	4
Bismarck 1	55
Bottineau 1	4
Bowman Co 1	1
Carrington 49	1
Cavalier 6	2
Central Cass 17	1
Central Valley 3	1
Dakota Prairie 1	1
Devils Lake 1	8
Dickinson 1	24
Drake School District	1
Dunseith 1	1
Edgeley 3	1
Elgin-New Leipzig 49	1
Ellendale 40	2
Enderlin Area 24	3
Fargo 1	85
Fessenden-Bowdon 25	2
Ft Ransom 6	1
Ft Totten 30	1
Garrison 51	1
Glenburn 26	1
Grafton 3	6
Grand Forks 1	64
Griggs County Central 18	1
Hankinson 8	2
Harvey School District	1
Hatton 7	1
Hazen 3	1
Hillsboro 9	2
Jamestown 1	11
Kindred 2	5
LaMoure 8	2
Langdon Area 23	1
Larimore 44	2
Lidgerwood 28	1
Linton School District	1
Lisbon School District	6
Litchville-Marion 46	2

District of Residence	Number of Students
Mandan 1	15
Manvel 125	1
Max School District	1
May-Port CG 14	2
McKenzie Co 1	1
Medina 3	5
Midkota 7	1
Milnor 2	2
Minot 1	57
Minto School District	1
Mohall-Lansford-Sherwood 1	2
Montefiore 1	1
Mt Pleasant 4	1
Nedrose 4	1
New 8	1
New Salem 7	1
New Town 1	4
North Border 100	1
North Central 28	1
North Star 10	1
Northern Cass 97	1
Richland 44	2
Rugby 5	4
Sargent Central 6	2
Sawyer School District	1
Selfridge 8	1
South Prairie 70	3
St Thomas 43	1
Stanley 2	2
Surrey School District	2
TGU School District	1
Thompson 61	5
Turtle Lake-Mercer 72	1
United 7	2
Valley City 2	3
Wahpeton 37	4
Washburn 4	1
West Fargo 6	69
Westhope 17	1
Williston 1	13
Wyndmere 42	1
State Responsible	1

N=539