

Autism in Tennessee: Part 1 - An Introduction to Issues and Data Collection Methods

Contact: Joseph Woodson, Associate Legislative Research Analyst
(615) 401-7874 / Joseph.Woodson@tn.gov

October 2009
Updated February 2010

Introduction

Autism Spectrum Disorders (ASDs) are a group of developmental disabilities that affect social interaction, communication, and behavior. No single underlying cause has been identified, and symptoms range from mild to severe impairments. ASDs have increasingly become a topic in public policy discussions, primarily because of the steady increase of children identified on the autism spectrum. Nationally and in Tennessee, the number of children and youth ages 3 through 21¹ receiving special education services related to autism tripled between 2001 and 2007. Autism issues are complex and affect many policy areas including healthcare, education, and cross-agency service delivery models.

Report Scope and Objectives

This report is the first in a series in response to a legislative inquiry about public services for infants, children, and youth with autism in Tennessee. (See Appendix A.) This series will consider causation and options for medical treatment only to the extent that they are significant for policies affecting public services for children.

The series has been divided into public policy areas directly connected to autism services (i.e., data collection, education, and healthcare services). The objectives of this report in the series include:

- An overview of autism as a disability and associated laws, and
- A review of autism data collection and prevalence estimates.

Subsequent reports within the series will review public education and healthcare services.

This report includes numerous terms that are commonly referred to by acronym. Appendix B is a glossary of acronyms used in the report.

Methodology

Information, findings, and considerations for policy are based on:

- A review of the major Tennessee and federal laws affecting autism and disability services;
- A review of national and state-specific research on autism spectrum disorders;
- Interviews with staff from the Tennessee Department of Health (TDOH) and the Tennessee Department of Education (TDOE), Division of Special Education;
- Interviews with officials from other states providing autism services and data collection;
- Interviews with staff from Tennessee's University Centers of Excellence in Developmental Disabilities (the Vanderbilt Kennedy Center for Human Development and the Boling Center for Developmental Disabilities) and autism advocacy groups (the Autism Society of America and Easter Seals); and
- Interviews with officials from the Centers for Disease Control's (CDC's) Autism and Developmental Disability Monitoring Network.

See Appendix C for a complete list of persons contacted.

See Appendix D for a brief history of autism research in Tennessee.

What is autism?

Under federal and Tennessee law, autism is classified as a developmental disability that significantly affects verbal and nonverbal communication, social interaction, and educational performance. It is often associated with “engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.”²

The medical community classifies ASDs as *pervasive developmental disorders*. Complex and numerous, pervasive developmental disorders include mild to severe ASDs, specifically *Asperger’s syndrome* and *autistic disorder*. A child displaying symptoms of these disorders but not fitting within the specific criteria will receive a diagnosis of *pervasive developmental disorder – not otherwise specified* (PDD-NOS). Rarer and more extreme diagnoses on the spectrum of

pervasive developmental disorders include *childhood disintegrative disorder (CDD)* and *Rett’s syndrome*. Throughout the report, “autism” refers to any pervasive developmental disorder unless otherwise specified.

There is no single medical exam for autism. Instead, doctors perform behavioral assessments to identify symptoms that indicate autism. Some autism disorders may be identified as early as the first few months after birth (for autistic disorder and Rett’s syndrome) to any time before the age of three. Typically, research has indicated that a diagnosis at age two can be reliable. However, according to the CDC, despite evidence that ASDs can be identified at 18 months or younger, “many children do not receive a final diagnosis until much older.”³ There are a number of behavioral characteristics, symptoms and signs that indicate pervasive developmental disorders. (See Exhibit 1.)

Definitions

T.C.A. Title 33 – Mental Health and Developmental Disabilities

Developmental Disability: A condition based on having either a severe chronic disability or mental retardation. (T.C.A. §33-1-101(10))

Autism is counted as a *severe chronic disability*. (The Tennessee Department of Mental Health and Developmental Disabilities website is available at <http://tennessee.gov/mental/DlandR/DIRindex.html>)

T.C.A. Title 49 - Education

Child with disabilities: A child identified as requiring special education, including a child with autism. (T.C.A. §49-10-102(1)(A) and (B))

Exhibit 1: Characteristics of Pervasive Developmental Disorders

Characteristic	Autistic Disorder	Asperger’s Disorder	PDD-NOS	Childhood Disintegrated Disorder	Rett’s Syndrome
Social impairment	X	X	X	X ^b	X
Language and communication disorder	X		X ^a	X ^b	X
Repetitive interests and activities	X	X	X ^a	X ^b	
Average intelligence		X			
Onset prior to 36 months	X				X
Period of normal development followed by loss of skills in several areas				X	X
Relative impairment	Variable	Milder	Milder	More severe	More severe
Relative prevalence	Higher	Intermediate	Higher	Lower	Lower

Notes: ^a At least one of these two characteristics must be present

^b At least two of these three characteristics must be present

Source: Wendy Stone, *Does My Child Have Autism?*, San Francisco, Jossey-Bass, 2006, pp. 5-11.

Boys are four times more likely than girls⁴ to have autism and white children are more likely than other racial ethnicities;⁵ the reasons are unknown. Among children with autism, the severity of symptoms ranges widely, but may include:

- **Language and Communication:** Some children are nonverbal, while others have minimal language development delays.
- **Social Impairments:** Some children have extreme difficulty interacting socially, while others have moderate social skills. Adapting to social environments is difficult for children with autism. Likewise, children with autism often have difficulty adapting to transitions between social environments and changes in daily schedule.
- **Activities and Interests:** Some children exhibit peculiar mannerisms and interests or obsession in particular areas, as well as repetitive, nonfunctional, atypical behaviors called *stereotypies*. Common stereotypies include hand flapping, finger movements, rocking, or twirling.
- **Comorbid Conditions:** Some children have diagnosed conditions in addition to autism, such as intellectual disabilities, seizure disorders, gastrointestinal symptoms, sleep difficulties, attention deficits, and psychiatric disorders.

What causes autism?

Scientists have not identified a specific cause of autism; however it is likely that genetics and environmental factors play a role. Some studies indicate that many autism cases display abnormal levels of neurotransmitters (such as serotonin) in the brain. This has led to theories that autism may be caused by a disruption of brain development during fetal incubation.

A theory that poor parenting is a factor has been disproved. Other speculations once tied childhood vaccines that use thimerosal – a preservative containing mercury – to autism; however the CDC and the Institute of Medicine (IOM) have studied and rejected this claim. Furthermore, the U.S. Court of Federal Claims ruled against this claim in 2009.

What do federal laws require states to do for children diagnosed with autism?

Several federal laws — including the Americans with Disabilities Act, the Rehabilitation Act of 1973, and the Individuals with Disabilities Education Act — require states to address the needs of people with disabilities, including autism. These laws, in conjunction with state laws, outline state responsibilities and services for children and adults with disabilities.

Rehabilitation Act of 1973, Section 504 & Americans with Disabilities Act (ADA), Title II

The Rehabilitation Act of 1973 and the ADA guarantee equal opportunity for individuals with disabilities in federally funded healthcare, education, and transportation programs and agencies at all levels.

Individuals with Disabilities Education Act (IDEA)

IDEA requires state and local governments to provide special education, early intervention, and related services to children with disabilities, including autism.

IDEA services include Free and Appropriate Public Education (FAPE), the Individualized Education Program (IEP), Child Find, due process rights, Early Intervention, and Family Support services. Under IDEA, children and youth ages 3 through 21 may receive special education services, while infants and toddlers from birth to age 3 may receive early intervention and related services.

IDEA requires states to annually report the number of students receiving IDEA services to the U.S. Department of Education. The information must be categorized by type of disability and age, and analyzed by appropriate provision of services. Autism first became a mandatory federal reporting disability category in the 1992-93 school year for ages 3 through 21 (Part B), but it is not mandatory to report early intervention data (Part C) by specific disabilities. See pages 7-9 for more information on IDEA data collection.

Additional federal laws (including the Social Security Act, Elementary and Secondary Education Act, and No Child Left Behind) that generally apply to all children may affect disability services; however, this report series focuses on laws specific to the provision of

services for children with autism. These services will be explained in more detail in companion reports throughout the series.

Which Tennessee laws specifically address autism?

Since most Tennessee state laws concerning autism services affect all children with developmental disabilities, any policy change to those laws – unless specified otherwise – may also affect all developmental disability services.

Tennessee law directly addresses services for those with autism in the following instances:

- *T.C.A. §49-10-102(1)(B)*: defines a “child with disabilities” to include autism.
- *T.C.A §56-7-2367*: requires insurance companies providing coverage for neurological disorders to provide treatment for autism up to age 12, and prohibits denial of eligibility based on autism diagnoses.

From which entities do Tennessee residents receive autism services?

Children identified as having autism may be eligible for a variety of public services based on individual diagnosis, needs, and age. Numerous agencies and programs are responsible for administering and providing services. Tennessee law designates authority and responsibility to at least six state departments to meet the requirements of the federal acts. Exhibit 2 describes major entities providing services by age eligibility.⁶

In some areas of the state, regional, district, and local entities also provide services. In addition, families often rely on services provided by not-for-profit autism and disability advocacy groups (e.g., Autism Society of America, Autism Speaks, and Easter Seals) and University Centers for Excellence in Developmental Disabilities.

Some state-level groups advocate for the interests of those with developmental disabilities, including the Tennessee Council on Developmental Disabilities and the Advisory Council for the Education of Students with Disabilities. The Disability Pathfinder, a collaborative effort of the Tennessee Council on Developmental

Disabilities and the Vanderbilt Kennedy Center, is a free online referral system for families of and children with disabilities, including autism.

What attempts have been made in Tennessee to coordinate services at the state level?

Because a broad range of symptoms characterize autism, many agencies provide services. (See Exhibit 2.) However, no single agency is responsible for overall service coordination. Over the past decade, attempts have been made to coordinate Tennessee’s departments and services for individuals with developmental disabilities.

IDEA State Interagency Agreements

IDEA requires states to develop interagency agreements, which outline financial and administrative responsibilities of state departments for provision of special education and early intervention services under federal law.⁷ Tennessee’s Interagency Agreement was developed in 2000 and most recently updated in July 2009. According to the Division of Special Education and the Governor’s Office of Children’s Care Coordination (GOCCC), the 2009 Interagency Agreement includes no major changes with the exception of an interagency dispute resolution process. This process includes a “Children’s Cabinet” to rule on disagreements about funding or provision of services between agencies.

2000 Title 33 Revision

In 2000, the Tennessee General Assembly revised the state’s mental health code (*T.C.A. Title 33*) based on recommendations of a Title 33 Revision Commission, with the purpose of finding ways to more efficiently plan services for individuals with developmental disabilities. As a result of the Commission’s recommendations, the General Assembly designated the Department of Mental Health and Mental Retardation as the authority on developmental disabilities services and changed its name to the Department of Mental Health and Developmental Disabilities (DMHDD). Governor Sundquist transferred the Division of Mental Retardation Services (DMRS) to the Department of Finance and Administration by Executive Order in 1996. These revisions established DMHDD as the state authority on developmental disabilities (including

Exhibit 2: Major Entities Providing Autism Services by Age Eligibility

Entity/Program	Age Eligibility^a	Services Provided
Department of Mental Health and Developmental Disabilities (DMHDD)	All	Authority to guide the planning process for developmental disability services.
Department of Children Services (DCS)	Birth to 18	Assistance and information to those caring for children with autism in or at risk of entering state custody, or eligible for adoption.
Department of Health (TDOH), Children Special Services Program (CSS)	Birth to 21	CSS is not an entitlement program, but services are provided based on resource availability. CSS is a third party payer of last resort for a variety of medically necessary or support expenses. Service coordination may be provided for children with diagnosed medical needs, including autism.
Department of Education, Division of Special Education		
<i>Tennessee Early Intervention System (TEIS), Office of Early Childhood Programs</i>	Birth to 3	Services include an Individualized Family Service Plan (IFSP), Service Coordination, and transition to LEA for special education services if eligible.
<i>Office of Early Childhood Programs</i>	3 through 5	Guidance and oversight of LEA provision of special education and related services, including transition from TEIS.
<i>Division of Special Education</i>	3 through the school year child turns 21	Guidance and oversight of LEA provision of special education and related services, including transition to adulthood.
Department of Human Services (DHS)		
<i>Vocational Rehabilitation Services</i>	As early as possible, but no later than 12-18 months prior to exit from school when appropriate.	Services may include eligibility assessment, counseling, services guidance and referral, technical assistance, post-employment services, and any other job-related services.
<i>Tennessee Tech Access Program (TTAP)</i>	All	A statewide program developed to increase access to assistive technology (e.g., alternative communication devices). TTAP includes four major programs: Funding Assistance, Device Demonstration, Device Loan, and Device Reutilization.
<i>Eligibility Determination</i>	All	DHS determines eligibility for Medicaid.
Department of Finance & Administration (F&A)		
<i>TennCare</i>	Birth to 21, possibly all ages within certain eligibility criteria.	Provision and coordination of some services deemed <i>medically necessary</i> for individuals meeting certain eligibility.
<i>TENNderCARE</i>	Birth to 21	This is Tennessee’s Early Periodic Screening Diagnosis and Treatment (EPSDT) Program, which ensures those who have TennCare receive early health care services.
<i>Division of Intellectual Disability Services (DIDS), Family Support Program (FSP)</i> <i>Formerly the Division of Mental Retardation Services (DMRS)</i>	Birth to 22 (“school age and younger”) There is a waiting list for services as of 2009.	The FSP may provide funds to families for needed supports such as home modifications, respite care, family counseling, and summer camp. Additionally, family support councils are represented at state, regional, and local levels.

Note: ^a Some listed programs have further eligibility criteria; for example, TennCare and CSS have income requirements, while TDOE programs also have diagnostic and educational evaluation requirements.

Source: OREA Compilation of Tennessee laws, regulations, agency websites, and reports.

autism) and made persons with developmental disabilities other than mental retardation eligible for services subject to appropriations. The revision to Title 33 also created a Statewide DMHDD Planning and Policy Council, a Developmental Disabilities Planning and Policy Council, and Regional Developmental Disabilities Planning and Policy Councils. These Councils assist DMHDD in planning prevention, early intervention, treatment, and habilitation services for persons with mental illness, serious emotional disturbance, and developmental disabilities. However, DMHDD has reported that other than initial funding for service planning and supports for this population, funding to provide services and supports to persons with developmental disabilities other than intellectual disabilities has not been appropriated. Furthermore:

The DD [developmental disabilities] Planning and Policy Council, along with the DMHDD Planning and Policy Council and the Developmental Disabilities Task Force have recommended that responsibility for service provision for persons with developmental disabilities be transferred to the Division of Mental Retardation Services in the Department of Finance and Administration. They continue to work on this issue with the DD Task Force implementing a grassroots campaign to promote the transfer.⁸

Since these revisions some members of the General Assembly have proposed legislation to further study and reorganize the structure and administrative location of these services; however, these have not become law. Also, the legislature renamed DMRS the Division of Intellectual Disabilities Services in 2009 to change “attitudes and perceptions about people with intellectual disabilities.”⁹

How prevalent is autism nationally and in Tennessee?

The number of children and youth receiving autism-related special education services tripled between 2001 and 2007, from approximately 94,000 to 297,739 nationally, and from 1,293 to 4,019 in Tennessee. This increase has prompted the federal and some state governments to attempt to estimate the prevalence of autism. Prevalence is a measure of the proportion of a population which has a disease or medical condition at

a specified time. Three main sources collect information about children and young adults with autism: CDC data; IDEA reports; and state-specific data collection on developmental disabilities. However, these sources collect different types of information with different purposes and methods, so each should be used with caution when trying to determine prevalence.

According to the CDC, approximately 1 in every 110 eight-year-old children has autism. This statistic was updated from the CDC’s original “1 in 150” statistic. These statistics are the first national population-based estimates of autism prevalence and are widely accepted as the most reliable numbers.¹⁰ The federal *Children’s Health Act of 2000* authorized the CDC to monitor autism prevalence. The “1 in 110” statistic comes from research conducted in several sites across the U.S. funded by the CDC’s Autism and Developmental Disabilities Monitoring (ADDM) Network. The ADDM Network offers grants to public or nonprofit entities — typically universities and state-level agencies — for data collection services. Since inception, the ADDM Network grants have been awarded to 16 sites in 17 states.¹¹ As of 2009, there are 10 active ADDM Network Sites covering 11 states.¹² The ADDM Network also works in collaboration with the Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE), to conduct surveillance of children with autism to estimate prevalence. Data is collected across all sites using a standard methodology. The ADDM Network studies were released in two phases. Phase one (1 in 150) was released in 2002, and phase two (1 in 110) was released in 2009.

Although commonly accepted as the most reliable estimate of autism prevalence, the data from the ADDM Network studies has limitations:

- *The CDC estimate of 1 in 110 results from data collected at 14 ADDM Network surveillance sites. According to the CDC, “Because participating sites were selected through a competitive federal award process and not specifically to be representative of the entire U.S. population, ADDM Network results cannot be used as a basis for estimating the national prevalence of ASDs.”*¹³

Each ADDM Network site surveys the eight-year-old population of geographic areas with a minimum birth rate of 25,000 within the age group; areas with extremely high birth rates are avoided to minimize expenditures. Rates differ by site. Most sites in phase one ranged from 5.2 to 7.6 per 1,000 (overall mean 6.6), while Alabama is lower (at 3.3) and New Jersey is higher (at 10.6). Most sites in phase two ranged from 7.6 to 10.4 per 1,000, while Florida is lower (at 4.2) and Arizona and Missouri are higher (at 12.1).¹⁴

- *Federal privacy laws have hindered CDC data collection in some ADDM Network sites.* Interpretations of the Family Educational Rights and Privacy Act (FERPA) and Health Insurance Portability and Accountability Act (HIPAA) have inhibited some agencies from obtaining child data records, which interferes with ADDM Network methodology. FERPA interpretations in Alabama, Missouri, Pennsylvania, and Wisconsin limited CDC access to records and resulted in a lower reported prevalence in the 2002 ADDM study: “[l]ack of participation by education sources caused four sites (Arizona, Colorado, New Jersey, and North Carolina) to redefine their surveillance areas after data collection had started.”¹⁵ Due to HIPAA restrictions, one or more healthcare facilities did not participate in eight states: Alabama, Arizona, Colorado, Georgia, Missouri, New Jersey, Pennsylvania, and Wisconsin.¹⁶

Although Tennessee does not participate in the ADDM Network or collect autism prevalence data, interviews with Tennessee Special Education Data Services and TDOH officials indicate that privacy rights would not obstruct similar data collection in Tennessee.

IDEA data identifies the number of children receiving special education services by disability category; it does not determine disability prevalence. IDEA data showed that 4,019 Tennessee students with autism were receiving special education services in 2007. The purpose of IDEA data collection,

however, is not to estimate the prevalence of different types of disabilities in the population as a whole, but to report the number of students ages 3 through 21 receiving special education services by age and disability category to ensure state and local accountability for funding purposes. Some children in Tennessee schools with a medical diagnosis of autism may not require special education services, and would not be included in Tennessee’s IDEA data reports.

States’ IDEA data on autism generally reports lower numbers than the CDC national prevalence studies, which include health, education, and other data. According to OREA analysis of available statistics from TDOE’s 2007 *Child Count* report and 2007 *Annual Statistics Report*, approximately 1 in every 220 grade 3 students in Tennessee has been reported to receive special education for autism primarily, a lower proportion than the CDC’s national estimate of 1 in 110 8-year-olds. OREA analysis of the Tennessee data also results in an autism prevalence rate of 1 in every 271 students ages 6 through 21. (See Appendix E for calculations.)

States have been required to include autism as a disability reporting category in their annual IDEA reports to the U.S. Department of Education since the 1992-93 school year. States also report the number of infants and toddlers ages birth to age 3 receiving early intervention services, but are not required to report this data by specific disability category. For children exhibiting comorbid conditions, IDEA *Child Count* reports include only primary disability classifications. For example, a child with a primary diagnosis of mental retardation and a secondary diagnosis of autism is categorized under mental retardation but is not included in IDEA autism data. IDEA data alone is insufficient for determining availability of autism resources, causes of autism, or prevalence of autism in Tennessee.

The number of children classified as having autism and receiving special education services is increasing. State IDEA reports show that the number of Tennessee children classified as having autism is growing faster than the numbers in any other disability category by a wide margin, showing an average annual percentage increase of 20.8 percent. Following at a

distant second and third respectively are developmental delays (6.45 percent) and other health impairments (4.81 percent), which include a number of specific conditions. Exhibit 3 shows how many children received special education services in Tennessee by disability category and year, and how those numbers have changed between 2001 and 2007.

According to the TDOE 2006-07 *Annual Statistical Report*, of the 136 school systems, nine of the largest systems report providing over 100 students with educational services for autism, and 112 systems provide services for less than 30 students each. Appendix F contains a complete listing of school systems with the number of children receiving special education services for autism.

National IDEA data shows that 297,739 students nationwide received publicly funded special education services for autism in 2007, ranking autism as the seventh-most commonly classified disability in this data set. (See Exhibit 4 for detailed numbers.)

Exhibit 4: Top Seven IDEA Disability Reporting Categories in 2007, Ages 3-21

Specific learning disabilities	2,633,740
Speech or language impairments	1,482,540
Other health impairments ^a	647,745
Mental retardation	510,710
Emotional disturbance	443,663
Developmental delays ^b	358,450
Autism	297,739

Notes: ^a Other health impairments include limited strength, vitality, or alertness due to chronic or acute health problems such as asthma, attention deficit disorder, or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, sickle cell anemia, and Tourette syndrome.

^b "Developmental delays" covers only children ages 3-9.

Source: OREA analysis of federal law; National IDEA Child Count Data 2006-07, Data Accountability Center, Table 1-7. Children and students served under IDEA, Part B, in the U.S. and outlying areas, by age and disability category, Fall 2007, https://www.ideadata.org/TABLES31ST/AR_1-7.xls (accessed Aug. 4, 2009); U.S. Department of Education, *The Digest of Education Statistics*, March 2008, p. 77, http://nces.ed.gov/pubs2008/2008022_2a.pdf (accessed Aug. 4, 2009).

Exhibit 3: Number of Children in Tennessee Receiving Special Education by Disability Category, Ages 3-21

	2001	2002	2003	2004	2005	2006	2007	Average Annual Rate Change
Autism	1,293	1,606	1,958	2,390	2,794	3,362	4,019	20.83%
Developmental Delay	4,857	5,214	5,513	5,819	6,143	6,781	7,060	6.45%
Other Health Impairments	9,194	10,153	10,558	11,395	11,548	11,868	12,154	4.81%
Deaf-Blindness	5	4	3	7	5	3	3	3.29%
Traumatic Brain Injury	269	272	274	280	274	289	309	2.38%
Multiple Disabilities	1,926	1,912	1,862	1,992	1,916	1,947	2,098	1.53%
Emotional Disturbance	3,652	3,805	3,773	3,894	3,778	3,833	3,702	0.27%
Speech or Language Impairments	33,808	32,071	31,888	32,293	32,494	32,937	33,897	0.08%
Hearing Impairments	1,520	1,543	1,449	1,412	1,476	1,500	1,507	-0.08%
Visual Impairments	830	806	756	658	800	746	783	-0.38%
Specific Learning Disabilities	53,232	52,644	49,907	48,303	46,579	45,878	45,171	-2.69%
Orthopedic Impairments	1,178	1,123	1,063	1,033	989	952	894	-4.49%
Mental Retardation	14,481	14,236	13,623	13,167	11,326	10,167	9,328	-6.97%
Total	126,245	125,389	122,627	122,643	120,122	120,263	120,925	-0.38%

Source: OREA analysis of TDOE December 1 Child Count data reports, 2001-2007.

Although effective for monitoring state provision of special education and related services, IDEA data alone is not appropriate for estimating autism prevalence. Furthermore, the CDC recommends more extensive data collection than IDEA requires.

Accompanying the increase in the number of students receiving special education services with a primary diagnosis of autism is a decrease over the past several years in the number of those students classified with mental retardation and specific learning disabilities. A review of national IDEA data found that:

The average administrative prevalence [i.e., totals computed from education data] of autism among children increased from 0.6 to 3.1 per 1000 from 1994 to 2003....During the same period, the prevalence of mental retardation and learning disabilities declined by 2.8 and 8.3 per 1000, respectively. Higher autism prevalence was significantly associated with corresponding declines in the prevalence of mental retardation and learning disabilities.¹⁷

Tennessee data from 2001 through 2007 indicates similar trends, as indicated in Exhibit 5.

National and Tennessee IDEA data show a steady increase of children receiving special education for autism with each age cohort from age 3 to 10; rates of increase begin to level off in the 11- and 12-year-old age cohorts. One researcher concludes that a higher frequency of autism in younger cohorts does not necessarily mean autism is increasing at the rate indicated by IDEA data. The actual number of children with autism might not be increasing, but autism might be diagnosed more frequently:

There are indications that the increasing awareness of autism in the medical and educational communities may have led to a gradual shift in diagnosis to include less disabled individuals who would not previously have been described as autistic or would have received a different diagnosis.¹⁸

In Tennessee, 1.66 percent of children receiving early intervention services were diagnosed with autism. The Tennessee Early Intervention Data System (TEIDS) is a real-time, web-based system

Exhibit 5: Change in Number of Children Receiving Special Education Services by Disability Category, 2001-2007, Ages 6-21

Disability	Change
Autism	+ 2,374
Specific Learning Disability	- 7,969
Mental Retardation	- 5,150

Source: OREA analysis of TDOE December 1 Child Count data reports, 2001-2007.

operated by the Tennessee Early Intervention System (TEIS) that contains IDEA Part C data and is not federally required to be reported by specific learning disability categories. The Office of Early Childhood Programs further explains that “the reporting tools were primarily developed to answer federal reporting issues,” thus, the number of children in TEIS with autism is not regularly reported. However, TEIS performed an internal statewide snapshot survey in May 2008, and reported that approximately 1.66 percent of children receiving TEIS services were diagnosed with autism.¹⁹ According to the Office of Early Childhood Programs, TDOE is working to ensure an efficient transfer of TEIS data to IDEA data on special education.

Some other Tennessee agencies collect data on the number of people with autism receiving specific services. The Division of Intellectual Disability Services (DIDS) in Finance and Administration also collects data on the number of people with autism receiving services under their Family Support Program. The number of individuals receiving these services spans all ages and disabilities. These totals are considerably smaller than the TDOE number of individuals receiving educational services for autism. DIDS reports 452 individuals: 414 children and youth ages birth through 21 and 38 individuals ages 22 and older. Other Tennessee agencies, e.g., the Bureau of TennCare, may also collect data on the number of people receiving specific services for autism.²⁰

What additional tools do other states use to collect autism data?

Over the past decade, some states have created autism registries to enhance statewide data collection and develop a better understanding of the need for autism-related services. Exhibit 6 briefly describes

some registries, including year of inception, administrative authority, reporting requirements, and eligibility for these registries.²¹

Stakeholders involved with autism and other health condition registries have identified the following reporting factors as challenges for autism registries:

- participation requirements;
- eligibility; and
- information collected.

Participation Requirements

Reporting is permissive for some state autism registries, such as Utah and Virginia. However, because voluntary reporting relies solely on information provided by family or medical professionals, it may not be useful in determining accurate autism prevalence

data. Thus, mandatory reporting for registries is more likely to result in the most accurate prevalence data.

Most statewide autism registries do not have a penalty for failure to report. Delaware is an exception; failure to report may result in a fine up \$100 for each violation.

Registry Eligibility

The state registries listed in Exhibit 6 distinguish between each of the five diagnoses classified within pervasive developmental disorders. However, states vary in whether they collect age-delineated data and whether they add data to their registries retroactively. Three states require new and potential re-diagnoses to be reported to the registry, but do not require reporting of cases diagnosed prior to the creation of the registry. On the other hand, New Jersey and Utah registries

Exhibit 6: Selected State Autism Registries

State Program Name	Year of Inception and Administrative Authority	Reporting Participation Requirements	Registry Eligibility
Delaware <i>Autism Surveillance and Registration Program</i>	2005 Department of Health and Social Services, Division of Public Health	Mandatory Any healthcare practitioners must report ASD diagnoses within age requirements.	Children under and diagnosed prior to age 18
New Hampshire <i>Autism Spectrums Disorder Registry</i>	2008 Department of Health and Human Services	Mandatory Healthcare and other providers must record and report ASD diagnoses (no age specified).	New Cases as of 2008 – age not specified
New Jersey <i>Autism Spectrums Disorder Registry</i>	2009 Department of Health and Senior Services, Special Child Health Registry	Mandatory Physicians must record and report ASD diagnoses within age requirements and healthcare providers must report those already receiving services.	Birth through age 21 Has taken initiatives to include already diagnosed children.
Utah <i>Utah Registry of Autism and Developmental Disabilities (URADD)</i>	2003 Collaboration of Department of Health and University of Utah School of Medicine’s Department of Psychiatry	Mandatory upon URADD request, Voluntary participation of families Autism diagnostic or service providers must report within 30 days of diagnosis upon request.	Children birth to 18 Has taken initiatives to include already diagnosed children.
West Virginia <i>West Virginia Autism Spectrum Disorders Registry</i>	2004 Bureau of Public Health, Department of Health and Human Services	Mandatory All diagnosticians or other persons investigating or treating autism (e.g., school administrators, pathologists) must report.	New Cases as of 2004 – age not specified

Source: OREA summary of state registry websites; and interview and materials provided by the New Jersey Autism Registry.

include children diagnosed prior to the creation of the registry. Utah's registry (similar to and under guidance of the CDC ADDM Network) operates as a surveillance program to assess all diagnoses within specific geographic areas and uses the data to estimate statewide prevalence. New Jersey's program requires medical professionals already providing autism services to report patients to the registry. According to a New Jersey official, including children with autism diagnosed prior to registry inception allows the state to more quickly and efficiently estimate the number of children with autism. Data collection for states without these initiatives may take longer and result in less inclusive numbers.

Information Collected

The type, amount, and level of detail of information collected vary by registry. Most states collect general information such as date of birth, gender, race, ethnicity, and diagnostician information (e.g., provider's specialty, contact information). New Jersey and West Virginia collect more extensive case information including comorbid conditions, pregnancy-related issues, current medications, and diagnostic instruments used. Of the five states listed in Exhibit 6, all but New Hampshire collect information on the age at which symptoms were first noticed, as well as the age of actual diagnosis. Such information can aid in evaluating a state's capacity for early diagnosis and intervention – both keystones in autism services and thus child development.

Certain identifying information (i.e., a name and/or identification number associated with each child) is necessary to ensure data is not duplicated within the registry, yet more detailed information may better inform policymakers in analyzing, planning, and developing services for those with autism, according to registry officials. Child privacy protection laws like FERPA and HIPAA reportedly may affect a registry's ability to collect child-specific information and/or share data between authorities (i.e., education and private healthcare facilities). However, federal law permits states to share interagency data for certain purposes, including research; state law could permit private health agencies to submit child-specific data to a registry.

State registries that collect contact information of those diagnosed may be able to utilize the registry system for case management and more time-efficient connection of parents to services. For example, New Jersey intends to identify specific families, children, and geographic areas in need of case management services using its autism registry data. Tennessee's Traumatic Brain Injury Registry contacts reported individuals through written notice to improve awareness and access to services.

What medical condition registries does Tennessee currently keep and how are they beneficial?

Although Tennessee does not have an autism registry, the state keeps registries for some medical conditions including traumatic brain injury, birth defects, and cancer. According to Tennessee registry officials, registries are beneficial in the following ways:

- Collecting accurate statewide prevalence and/or incidence data;
- Developing information for policymakers, diagnosticians, and healthcare providers on effectiveness of services;
- Identifying areas and individuals in need of services; and
- Providing more efficient referral services for patients and families.

Such registries can also improve grant application processes, which often require an applicant state to provide accurate data. Registries may provide more comprehensive data than IDEA reporting requires. For example, Tennessee's IDEA 2006 data reported 268 cases of traumatic brain injury for children and youth ages 6 through 21 in December 2006, while 947 new cases for ages 6-24 were reported to the registry between July and December that same year.²²

Each registry is administered by TDOH and reporting of diagnoses is mandatory for respective medical professionals. The registry programs were created to collect statewide data and develop an understanding of the conditions; some are able to locate and identify individuals and geographic areas in need of services. Exhibit 7 shows the inception date, reporting process, and budget for the registries.²³

Exhibit 7: OREA Review of Some Tennessee Registries for Medical Conditions

Program and Condition	Date Created and Current Status	Reporting Participation of Medical Professionals	Constituent Service(s) Referral	Annual Budget (Provided by Program Directors)
Tennessee Birth Defects Registry (TBDR)	2000 T.C.A. § 68-5-506 Ongoing	Mandatory TN Hospital Discharge Data System is linked with Birth, Death and Fetal Death Certificate Data Systems and individual medical record reviews at hospitals by Public Health Nurse Consultants.	Yes Referral to services provided upon request of parent or legal guardian.	FY09 \$382,200 Primarily salary plus benefits for two statistical analysts and two public Health Nurse Consultants.
Traumatic Brain Injury (TBI) Registry	1993 T.C.A. § 68-55-201, et seq. Ongoing	Mandatory Cases may be reported by mail or electronically and must be submitted either monthly or quarterly.	Yes The TBI Program contacts constituents in writing once after reported.	FY08 \$82,600 Primarily salary plus benefits of a Statistical Analyst II using a PC.
Tennessee Cancer Registry (TCR)	1983 T.C.A. § 68-1-1001, et seq. Ongoing	Mandatory Electronic and paper reporting must be submitted six months after diagnosis. Software is provided by the CDC.	No The TN Comprehensive Cancer Control Coalition performs cancer prevention and control activities statewide.	FY09 \$978,600 (working budget) Funding split approximately evenly through state appropriations and federal Grants.

Source: OREA summary of state laws and interviews with Tennessee Department of Health officials.

According to one TDOH official, the development of an additional registry within the department would require additional funding. Tennessee may be able to obtain funding for statewide autism data collection and analysis through federal grants, including the CDC ADDM Monitoring Network. However, the state has not applied for such grants or received funding for autism data collection as of 2009.

Considerations for Policy Discussion
Informed policy discussions may require more comprehensive autism data than is currently available. Policymakers may wish to consider the following points related to this issue:

- Federal and state laws require TDOE’s Division of Special Education to collect data on children with autism receiving education services. However, this data does not measure prevalence and is analyzed exclusively for provision of mandated special education and related services.

- Federal and state laws do not require service-provision data on children from birth to age 3 to be categorized by specific disabilities. Therefore, autism-specific state data on service provision is lacking for this age group. Such data could provide specific information on statewide capacity for early identification of and intervention for autism.
- While IDEA data alone is not appropriate for estimating statewide autism prevalence, it may be useful for generating autism prevalence when combined with other data sources, such as medical diagnostic information. However, if Tennessee chooses to collect and coordinate autism data from health and educational resources, a designated entity would need to be legally authorized for this task.
- Some states have developed Autism Registries to develop prevalence estimates, evaluate services, and inform constituents of available resources.

- Tennessee does not receive grants for collecting data exclusively on autism.
- Most Tennessee laws affecting autism services affect all children with developmental disabilities; therefore, any policy change to those laws – unless specified otherwise – would alter all developmental disability services.

Endnotes

- ¹ Tennessee law defines *child with disabilities* to include those who turn 22 years of age between the beginning of the school year in August and the conclusion of the school year in June. Those students continue to receive services for the remainder of that school year. See *Tennessee Code Annotated* 49-10-102(a).
- ² Office of Special Education and Rehabilitative Services, U.S. Department of Education, Title 34 Code of Federal Regulations §300.7(c)(1)(i), 2009 edition.
- ³ Centers for Disease Control, Autism Information Center Website, “Screening and Diagnosis,” <http://www.cdc.gov/ncbddd/autism/screening.html> (accessed July 10, 2009).
- ⁴ Wendy Stone, *Does My Child Have Autism?*, San Francisco, Jossey-Bass, 2006, p. 60.
- ⁵ David S. Mandell, Lisa D. Wiggins, Laura Arnstein Carpenter, et al., *American Journal of Public Health*, “Research and Practice: Racial/Ethnic Disparities in the Identification of Children With Autism Spectrum Disorders,” abstract, March 2009, Vol. 99, No. 3.
- ⁶ Karen Edwards and Mary Rolando, Department of Mental Health and Developmental Disabilities, *Preliminary Plan for Tennessee Developmental Disabilities Services*, Jan. 2003. Tennessee Department of Mental Health and Developmental Disabilities, “Resources for Autism Spectrum Disorders,” http://www.tennessee.gov/mental/DIandR/Autism_resources.html, (accessed Sept. 2, 2008); Tennessee Council on Developmental Disabilities and the Vanderbilt Kennedy University Center for Excellence in Developmental Disabilities, “Tennessee Disability Pathfinder, Disability Resources Library,” <http://kc.vanderbilt.edu/tennesseepathfinder/resources/> (accessed Aug. 12, 2009); Tennessee Department of Education, “Interagency Agreement among Tennessee Department of Education; Tennessee Department of Children’s Services; Tennessee Department of Finance and Administration, Bureau of TennCare and Division of Mental Retardation Services; Tennessee Department of Health, Tennessee Department of Human Services, Tennessee Department of Mental Health and Developmental Disabilities and Tennessee Department of Correction,” July 1, 2009; Rules of State Board of Education, Chapter 0520-1-10, “Tennessee’s Early Intervention System,” <http://www.state.tn.us/sos/rules/0520/0520-01/0520-01-10.pdf> (accessed July 31, 2009); Rules of State Board of Education, Chapter 0520-1-09, “Special Education Programs and Services,” <http://www.tennessee.gov/education/speced/doc/330905202921308.pdf> (accessed July 31, 2009); Tennessee Department of Human Services, “The Tennessee Technology Access Program,” no date, <http://www.state.tn.us/humanserv/rehab/ttap.html> (accessed Aug. 3, 2009); TennCare, “TENnderCARE,” no date, <http://www.state.tn.us/tenncare/tenndercare/index.html> (accessed July 28, 2009).
- ⁷ The entities included in the Interagency Agreement are the Tennessee Departments of Education; Children’s Services; Finance and Administration (Bureau of TennCare and Division of Mental Retardation Services); Health; Human Services; and Mental Health and Developmental Disabilities.
- ⁸ Tennessee Department of Mental Health and Developmental Disabilities and the DMHDD Planning and Policy Council, *FY 2007 Joint Annual Report*, July 1, 2006 – June 30, 2007, pp. 7-8.
- ⁹ Department of Finance and Administration, Division of Intellectual Disabilities Services, “A Message From Deputy Commissioner Stephen H. Norris,” <http://www.tn.gov/dids/newsroom/announcements/NameChange.html> (accessed July 28, 2009).
- ¹⁰ Melody Stevens, Anita Washington, Catherine Rice, et al., Centers for Disease Control, Autism and Developmental Disabilities Monitoring Network, *Prevalence of the Autism Spectrum Disorders (ASDs) in Multiple Areas of the United States, 2000 and 2002*, 2002, p. 10, <http://www.cdc.gov/ncbddd/autism/documents/AutismCommunityReport.pdf> (accessed Sept. 10, 2009); Centers for Disease Control (CDC) and Prevention, Autism and Developmental Disabilities Monitoring Network, *Prevalence of the Autism Spectrum Disorders (ASDs) in Multiple Areas of the United States, 2004 and 2006*, p. 10, 2009, <http://www.cdc.gov/ncbddd/autism/states/ADDMCommunityReport2009.pdf> (accessed Jan. 15, 2010).
- ¹¹ Alabama, Arizona, Arkansas, California, Colorado, Delaware, Florida, Georgia, Illinois, Maryland, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Utah, West Virginia, and Wisconsin; Georgia is funded by the CDC, being the 18th state covered.
- ¹² Ten states with current ADDM Network sites: Alabama, Arizona, Colorado, Florida, Maryland, Missouri, North Carolina, Pennsylvania, South Carolina, Wisconsin, plus CDC in Georgia.
- ¹³ Kim Van Naarden Braun, Ph.D., et al., *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, <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5601a3.htm> (accessed Sept. 10, 2009).

- ¹⁴ Melody Stevens, et al., *Prevalence of Autism Spectrum Disorders*; Centers for Disease Control (CDC) and Prevention, Autism and Developmental Disabilities Monitoring Network, *Prevalence of the Autism Spectrum Disorders (ASDs) in Multiple Areas of the United States, 2004 and 2006*.
- ¹⁵ Kim Van Naarden Braun, Kim, Ph.D., et al., *Evaluation of a Methodology for a Collaborative Multiple Source Surveillance Network for Autism Spectrum Disorders*, Feb. 9, 2007, <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5601a3.htm> (accessed Oct. 8, 2009).
- ¹⁶ The project's acceptability was lower among education sources; four sites were unable to gain access to education facilities or had minimal access (Alabama, Missouri, Pennsylvania, and Wisconsin). At six sites (Arizona, Arkansas, Colorado, Maryland, New Jersey, and North Carolina) certain schools or entire districts in their surveillance area elected not to participate. In four sites (Georgia, South Carolina, Utah, and West Virginia) school participation was complete. Lack of participation by education sources caused four sites (Arizona, Colorado, New Jersey, and North Carolina) to redefine their surveillance areas after data collection had started.
- ¹⁷ Autism became a mandatory reporting category in the 1992-93 school year; autism data analysis began in 1994. Shattuck, "The Contribution of Diagnostic Substitution to the Growing Administrative Prevalence of Autism in U.S. Special Education," p. 1028.
- ¹⁸ James R. Laidler, "U.S. Department of Education Data on 'Autism' Are Not Reliable for Tracking Autism Prevalence," in *Pediatrics: Official Journal of the American Academy of Pediatrics*, Vol. 116, pp. e120-e124, 2005, <http://pediatrics.aappublications.org/cgi/content/full/116/1/e120> (accessed Oct. 8, 2009), p. e123.
- ¹⁹ "This is not a cumulative number of every child served throughout the year, but a number on a given day. These 74 children included children with diagnoses on the Autism Spectrum. This is 74 children out of the 4,460 children TEIS was serving on this snapshot date." Jamie Kilpatrick, Director, Office of Early Childhood Programs, e-mail, Nov. 24, 2008.
- ²⁰ Jan Coatney, State Coordinator for the Family Support Program, Tennessee Department of Finance and Administration, Division of Intellectual Disabilities Services, interview and materials, Sept. 24, 2009; Debbie Shahla, Director of Planning, Tennessee Department of Mental Health and Developmental Disabilities, e-mail and materials, Sept. 23, 2009.
- ²¹ Sandra Howell, New Jersey Department of Health and Human Services, Early Identification and Monitoring Program, interview and materials, Dec. 12, 2008; Jean Doster, Program Director for the Traumatic Brain Injury Program, Tennessee Department of Health, interview, April 1, 2009; State of Delaware, Department of Health and Social Services, Division of Public Health, "Autism Surveillance and Registration Program," <http://www.dhss.delaware.gov/dph/chca/dphnsp7.html> (accessed Sept. 10, 2009); State of New Hampshire, Department of Health and Human Services, "Autism Spectrum Disorders Registry," <http://www.dhhs.state.nh.us/DHHS/BDS/autism.htm> (accessed Sept. 10, 2009); Nancy Scotto Rosato and Sandra Howell, Special Child Health and Early Intervention Services, Early Identification and Monitoring Program, New Jersey Department of Health and Senior Services, *Reporting of Autism in the New Jersey Special Child Health Registry Prior to the Implementation of the 2007 Mandatory Reporting Law*, May 2009, http://www.nj.gov/health/fhs/eis/documents/report_on_autism.pdf (accessed Sept. 10, 2009); Marshall University College of Education and Human Services, "The West Virginia Autism Spectrum Disorders Registry (WVASDR)," <http://www.marshall.edu/coe/atc/wvasdr.htm> (accessed Sept. 10, 2009); "Utah Registry of Autism and Developmental Disabilities (URADD)," <http://health.utah.gov/autism/> (accessed June 5, 2009).
- ²² Tennessee Department of Education, "Dec. 1 Child Counts," 2006, http://tennessee.gov/education/speced/data_reports.shtml (accessed Sept. 10, 2009); Tennessee Department of Health, Policy, Planning and Assessment, Division of Health Statistics, "Tennessee Traumatic Brain Injury July – Dec. 2006," http://health.state.tn.us/statistics/PdfFiles/TBI_JulDec06.pdf (accessed Sept. 10, 2009).
- ²³ Tennessee Department of Health, "Traumatic Brain Injury Program," <http://health.state.tn.us/TBI/index.htm#registry> (accessed Sept. 10, 2009); Department of Health, Bureau of Health Informatics, Office of Health Statistics and Research, *Traumatic Brain Injury Registry: Patients Treated in Tennessee with at Least One Head Injury and Discharged in 2000*, Nov. 2001, p.2, <http://health.state.tn.us/statistics/PdfFiles/TBI2000.pdf> (accessed Sept. 10, 2009); Jean Doster, Program Director for the Traumatic Brain Injury Program, Tennessee Department of Health, interview and e-mail, April 1, 2009; Martin Whiteside, Director of the Tennessee Cancer Registry, Tennessee Department of Health, interview and e-mail, April 2, 2009; David Law, Director of Research, formerly Director of the Tennessee Birth Defects Registry, Office of Policy Planning and Assessment, Department of Health, interview, June 4, 2009; Lori Ferranti, Director of Policy, Planning, and Assessment, Department of Health, interview and e-mail, Sept. 30, 2009.

Bibliography

American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM-IV-TR)*. Washington, DC: American Psychiatric Publishing, 2000.

Braun, Kim Van Naarden, Sydney Pettygrove, Julie Daniels, Lisa Miller, Joyce Nicholas, Jon Baio, Laura Shieve, Russell S. Kirby, Anita Washington, Sally Brocksen, Hossein Rahbar, and Catherine Rice. "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." *CDC Morbidity and Mortality Weekly Report Surveillance Summaries* 56 (Feb. 9, 2007): 29-40. <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5601a3.htm>

"The Children's Health Act of 2000," Public Law 106-310, Section 102, Oct. 17, 2000.

http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=106_cong_public_laws&docid=f:publ310.106

- Data Accountability Center, Individuals with Disabilities Education Act (IDEA) Data, Data Tables for OSEP State Reported Data, Part B Child Count (2007), Table 1-7. http://www.ideadata.org/arc_toc9.asp#partbCC
- Data Accountability Center, *Part C Data Collection History*, Rockville, MD: Data Accountability Center, May 2009, Revised. <https://www.ideadata.org/docs/Cdatahistory.pdf>
- Edwards, Karen and Mary Rolando, *Preliminary Plan for Tennessee Developmental Disabilities Services*, Tennessee Department of Mental Health and Developmental Disabilities, January 2003.
- "Individuals with Disabilities Education Improvement Act of 2004," Public Law 108-466, Section 602(3)(A)(i).
- Johnson, Chris Plauché, Scott M. Myers, and the Council on Children With Disabilities. "Identification and Evaluation of Children With Autism Spectrum Disorders." *Pediatrics* 120 (Nov. 2007) 1191-1193. <http://www.providencelearningcentres.com/files/EarlyIdentificationAutism-Pediatrics.pdf>
- Laidler, James R. "U.S. Department of Education Data on 'Autism' Are Not Reliable for Tracking Autism Prevalence." *Pediatrics* 116 (July 2005) e120-e124. <http://pediatrics.aappublications.org/cgi/content/full/116/1/e120>
- National Institute of Mental Health. *Autism Spectrum Disorders*. Bethesda, MD: National Institutes of Health, 2004. <http://www.nimh.nih.gov/health/publications/autism/nimhautismspectrum.pdf>
- Shattuck, Paul T. "The Contribution of Diagnostic Substitution to the Growing Administrative Prevalence of Autism in U.S. Special Education." *Pediatrics* 117 (April 2006) 1028-1037. <http://pediatrics.aappublications.org/cgi/reprint/117/4/1028>
- Stevens, Melody, Anita Washington, Catherine Rice, Walter Jenner, Jennifer Ottolino, Kristen Clancey, and Julia Whitney. *Prevalence of the Autism Spectrum Disorders (ASDs) in Multiple Areas of the United States, 2000 and 2002*. Atlanta, GA: Centers for Disease Control, 2002. <http://www.cdc.gov/ncbddd/autism/documents/AutismCommunityReport.pdf>
- Stone, Wendy. *Does My Child Have Autism?* San Francisco: Jossey-Bass, 2006.
- Tennessee Council on Developmental Disabilities. *Report of the Developmental Disabilities Task Force: Fulfilling the Promise*. June 30, 2007. <http://fulfillthepromise.org/report.pdf>
- Tennessee Department of Education, Data Services and Reports, Statewide Special Education Data Reports, Dec. 1 Child Counts, 2006. http://tennessee.gov/education/speced/data_reports.shtml
- Tennessee Department of Education. "Interagency Agreement among Tennessee Department of Education; Tennessee Department of Children's Services; Tennessee Department of Finance and Administration, Bureau of TennCare and Division of Mental Retardation Services; Tennessee Department of Health, Tennessee Department of Human Services, Tennessee Department of Mental Health and Developmental Disabilities and Tennessee Department of Correction." July 1, 2009. <http://www.tennessee.gov/education/speced/doc/7109IDEAIntAgency.pdf>
- Tennessee Department of Mental Health and Developmental Disabilities, Disability Information and Referral, Resources for Autism Spectrum Disorders. http://www.tennessee.gov/mental/DIandR/Autism_resources.html
- Tennessee Public Acts*, 101st General Assembly, 2000, Public Chapter 947, § 1, "An act relative to persons with mental illness, serious emotional disturbance, mental retardation, and developmental disabilities."
- U.S. Department of Education, Office of Special Education Programs, *IDEA, Part B Data Collection History*, Rockville, MD: Westat, October 2007. <https://www.ideadata.org/docs/bdatahistory.pdf>
- U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, Autism Information Center: State Activities. <http://www.cdc.gov/ncbddd/autism/states/index.htm#addm>
- U.S. Department of Health and Human Services, Centers for Disease Control, Mercury and Vaccines (Thimerosal). <http://www.cdc.gov/vaccinesafety/updates/thimerosal.htm>

JAMIE WOODSON
STATE SENATOR
6TH SENATORIAL DISTRICT – KNOX COUNTY

LEGISLATIVE OFFICE
309 WAR MEMORIAL BUILDING
NASHVILLE, TN 37243
(615) 741-1648
1-800-449-8366 Ext. 11648
FAX: (615) 253-0270

E-MAIL
sen.jamie.woodson@legislature.state.tn.us

Senate Chamber State of Tennessee

NASHVILLE

CHAIRMAN
EDUCATION COMMITTEE

CO-CHAIRMAN
SELECT OVERSIGHT COMMITTEE ON
EDUCATION

SECRETARY
JUDICIARY COMMITTEE

MEMBER
TRANSPORTATION COMMITTEE
FISCAL REVIEW COMMITTEE
SELECT COMMITTEE ON TENNESSEE
EDUCATION LOTTERY CORPORATION

REPUBLICAN CAUCUS SECRETARY

May 2, 2008

Comptroller John Morgan
State Capitol, 1st Floor
Nashville, TN 37243

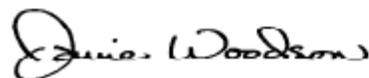
Dear Comptroller Morgan:

We would like to request a report be prepared on the children in Tennessee with autism. Please have your office look at the resources available to these children as well as the obstacles that they and their families face. Specifically, please address the following questions:

- What are the ways that children are presently identified who have autism, both by schools and by other providers?
- What services are presently available for children with autism?
- What services do other states provide that Tennessee does not?
- What is the present methodology for estimating the number of children with autism in Tennessee? Are there other methods that should be considered?
- Is the Early Intervention Services program effectively helping identify autistic children at an early age? What other methods might be employed?

We appreciate your taking the time to look into this issue. If you have any questions regarding this request, please feel free to give us a call.

Sincerely,



Jamie Woodson

Sincerely,



Randy McNally

APPENDIX B: LIST OF ACRONYMS

AAP: American Academy of Pediatrics	IEP: Individualized Education Program
ADA: Americans with Disabilities Act	IFSP: Individualized Family Support Plan
ADDM Network: Autism and Developmental Disabilities Monitoring (ADDM) Network	IOM: Institute of Medicine
ADM: Average Daily Membership	L TSAE: Federal region IVA Learn the Signs. Act Early. (L TSAE) Summit
ASD: Autism spectrum disorders	NCBDDD: National Center on Birth Defects and Developmental Disabilities
BCDD: Boling Center for Developmental Disabilities (BCDD) at the University of Tennessee Health Science Center	NIH: National Institute of Health
CDC: Centers for Disease Control	NINDS: National Institute of Neurological Disorders and Stroke
CDD: childhood disintegrative disorder	OSEP: United States Office of Special Education Programs, Department of Education
CSS: Children Special Services Program	PDD-NOS: pervasive developmental disorder – not otherwise specified
DCS: Tennessee Department of Children Services	SLD: Specific learning disability
DHS: Tennessee Department of Human Services	TBDR: Tennessee Birth Defects Registry
DIDS: Division of Intellectual Disability Services, formerly the Division of Mental Retardation Services (DMRS)	TBI: Traumatic Brain Injury
DMHDD: Tennessee Department of Mental Health and Developmental Disabilities	TCR: Tennessee Cancer Registry
DMRS: see DIDS	TDOE: Tennessee Department of Education
EPSDT: Tennessee’s Early Periodic Screening Diagnosis and Treatment	TDOH: Tennessee Department of Health
F&A: Tennessee of Department Finance and Administration	TEIDS: Tennessee Early Intervention Data System
FAPE: Free and Appropriate Public Education	TEIS: Tennessee Early Intervention System
FERPA: Family Educational Rights and Privacy Act	TRIAD: Treatment and Research Institute for Autism Spectrum Disorders (TRIAD) at the Vanderbilt Kennedy Center for Human Development
FSP: Family Support Program	UCEDD: University Centers for Excellence in Developmental Disabilities
HIPAA: Health Insurance Portability and Accountability Act	URADD: Utah Registry of Autism and Developmental Disabilities
IDEA: Individuals with Disabilities Education Act	

APPENDIX C: PERSONS CONTACTED

Jon Baio, Epidemiologist
National Center on Birth Defects and Developmental
Disabilities, Centers for Disease Control and Prevention

Tom Catron, Director (former)
Governor's Office of Children's Care Coordination

Jan Coatney, State Coordinator
Family Support Program, Division of Intellectual
Disabilities Services, Tennessee Department of Finance
and Administration

Linda Copas, Director
Behavioral and Autism Services, Division of Special
Education, Tennessee Department of Education

Jean Doster, Program Director
Traumatic Brain Injury Program, Tennessee Department of
Health

Denny Dukes, Associate Director
Children's Mental Health Services Research Center,
University of Tennessee Knoxville

Bob Duncan, Director
Governor's Office of Children's Care Coordination

Patti van Eys, Assistant Professor
Department of Psychological Science, Vanderbilt
University

Joe Fisher, Assistant Commissioner
Division of Special Education, Tennessee Department of
Education

Linda B. Hartbarger, Part C Coordinator
Office of Early Childhood, Division of Special Education,
Tennessee Department of Education

Sandra Howell
Early Identification and Monitoring Program, New Jersey
Department of Health and Human Services

Jamie Kilpatrick, Director
Office of Early Childhood, Division of Special Education,
Tennessee Department of Education

David Law, Director
Tennessee Birth Defects Registry, Office of Policy
Planning and Assessment, Tennessee Department of
Health

Pat Levitt, Director (former)
Vanderbilt Kennedy Center for Research on Human
Development

Terry Long, Director
Office of Data Services, Division of Special Education,
Tennessee Department of Education

James M. McCarten, Attorney
White & Reasor, PLC

Joe McGlaughlin
Co-Author of the Autism Services Proposal of 2002

Nan McKerley, Director
Administration Services/LEA Allocations and Budget,
Division of Special Education, Tennessee Department of
Education

Elise McMillan, Co-Director
Vanderbilt Kennedy University Center for Excellence in
Developmental Disabilities

Melissa McPheeters, Director of Research
Governor's Office of Children's Care Coordination

Nanette Mitchell
Journal Clerk for Chief Clerk of the Tennessee State
Senate

Jena Napier, Children's Care Coordinator
Governor's Office of Children's Care Coordination

Mary Rolando, Policy Analyst
Governor's Office of Children's Care Coordination

Kathi Rowe, Director
Program Management, Division of Special Education,
Tennessee Department of Education

Ann Sanders, Associate Director
Assessment, Division of Special Education, Tennessee
Department of Education

Debbie Shahla, Director of Planning
Tennessee Department of Mental Health and
Developmental Disabilities

John Shouse, Board of Directors
Autism Society of America

Steve Sparks, Director
State Reporting and Professional Development, Division of
Special Education, Tennessee Department of Education

Wendy Stone, Director
TRIAD, Vanderbilt Kennedy Center

Martin Whiteside, Director
Tennessee Cancer Registry, Tennessee Department of
Health

Marthagem Whitlock, Executive Director
Division of Policy and Legislation, Tennessee Department
of Mental Health and Developmental Disabilities

Bill Wilson, Attorney
Division of Special Education, Tennessee Department of
Education

Ruth Wiseman, Public Awareness Coordinator
Office of Early Childhood, Division of Special Education,
Tennessee Department of Education

APPENDIX D: A BRIEF HISTORY OF AUTISM RESEARCH AND REVIEWS IN TENNESSEE

Prior to this series, autism has been studied and reviewed in Tennessee through a variety of methods.

Autism Services Proposal of 2002

As required by Senate Joint Resolution 567 of the 102nd General Assembly, an interagency study was conducted by approximately 60 stakeholders throughout the state. The result was a written proposal released in December 2002. The Resolution also required the proposal be presented and studied by a joint committee. According to the State Senate Chief Clerk's Office, there is no record of a joint committee having been called for this purpose.

University Centers for Excellence in Developmental Disabilities

Tennessee is home to two national University Centers for Excellence in Developmental Disabilities: the Treatment and Research Institute for Autism Spectrum Disorders (TRIAD) at the Vanderbilt Kennedy Center for Human Development and the Boling Center for Developmental Disabilities at the University of Tennessee Health Science Center. Both programs actively perform research, outreach, and training on autism.

Tennessee *Learn the Signs. Act Early.* Summit

In January 2009, Tennessee – through the university centers – hosted the federal Region IVA *Learn the Signs — Act Early* (LTSAE) Summit. Initially launched in 2004 by the Centers for Disease Control and the National Center on Birth Defects and Developmental Disabilities, the LTSAE campaign aims to broaden the outreach and understanding of autism and provision of services for families and stakeholders. At the 2009 Summit, federal region IVA stakeholders from Kentucky, North Carolina, South Carolina, and Tennessee met and developed state plans to improve statewide autism services. As of May 2009, the Tennessee Act Early Team continues semi-monthly meetings to discuss plans for service improvement and community awareness. This summit focused on early intervention and related services.

APPENDIX E: BRINGING AVAILABLE TENNESSEE DATA TO PARITY WITH THE CDC'S ADDM NETWORK ESTIMATES

The CDC's ADDM Network created an ASD population-based prevalence estimate by surveying 8-year-old children in the targeted survey year in the participating sites. Based on this methodology, the CDC estimates that 1 in 110 8-year-old children has autism.

Bringing Tennessee data to parity with the CDC's ratio is challenging due to Tennessee's lack of population-based autism data. Therefore, OREA selected the Tennessee Department of Education's *2007 Annual Statistical Report* average daily membership (ADM) of grade 3 (presumable 8-year-olds) as the 8-year-olds' population base, and the Office of Special Education Data Services' 2007 child count number of 8-years-olds receiving special education services for autism. Based on these calculations, OREA estimates that at least 1 in 220 8-year-old children in Tennessee schools has autism.

Tennessee 8-year-olds:

ADM 8-year-olds: **72,257**
Autism in 8-year-olds: **329**

Brought to Parity:

Population Base: **220**
8-year-olds: **1**

Total Numbers:

In 2007, the Tennessee Department of Education *Annual Statistical Report* indicates total average daily membership at 943,149. For 2007, the Office of Special Education Data Services reports 3,477 students ages 6 through 21 receiving special education services related to autism. This would bring the total ratio of children with autism to:

Tennessee Students:

Total ADM Grades K-12: **943,149**
Students with Autism ages 6-21: **3,477**

Brought to Parity:

Population Base: **271**
8-year-olds: **1**

Data Sources:

- Tennessee Department of Education, *2007 Annual Statistical Report*, Table 7-A - Average Daily Membership Grades Kindergarten through Twelve 2006-2007, http://www.tennessee.gov/education/asr/06_07/doc/table7a.pdf.
- Tennessee Department of Education, Division of Special Education, IDEA December 1 Child Count, 2007.
- Centers for Disease Control (CDC) and Prevention, Autism and Developmental Disabilities Monitoring Network, *Prevalence of the Autism Spectrum Disorders (ASDs) in Multiple Areas of the United States, 2004 and 2006, 2009*, <http://www.cdc.gov/ncbddd/autism/states/ADDMCommunityReport2009.pdf>.

APPENDIX F: NUMBER OF CHILDREN AGES 3 THROUGH 21 RECEIVING SPECIAL EDUCATION SERVICES FOR AUTISM BY SCHOOL DISTRICT

School District	
ANDERSON COUNTY	31
CLINTON	**
OAK RIDGE	19
BEDFORD COUNTY	22
BENTON COUNTY	9
BLED SOE COUNTY	6
BLOUNT COUNTY	34
ALCOA	7
MARYVILLE	49
BRADLEY COUNTY	12
CLEVELAND	35
CAMPBELL COUNTY	8
CANNON COUNTY	6
CARROLL COUNTY	N/A
*HOLLOW ROCK-BR	**
*HUNTINGDON	0
*MCKENZIE	**
*S. CARROLL	**
*W. CARROLL	6
CARTER COUNTY	7
ELIZABETHTON	**
CHEATHAM COUNTY	17
CHESTER COUNTY	10
CLAIBORNE COUNTY	18
CLAY COUNTY	**
COCKE COUNTY	19
NEWPORT	**
COFFEE COUNTY	20
MANCHESTER	**
TULLAHOMA	20
CROCKETT COUNTY	**
ALAMO	**
BELLS	**
CUMBERLAND COUNTY	17
DAVIDSON COUNTY	427
DECATUR COUNTY	8
DEKALB COUNTY	7
DICKSON COUNTY	41
DYER COUNTY	**
DYERSBURG	9
FAYETTE COUNTY	8
FENTRESS COUNTY	**
FRANKLIN COUNTY	17
GIBSON COUNTY	N/A
HUMBOLDT	**
*MILAN	7
*TRENTON	**

GREENEVILLE	6
GRUNDY COUNTY	7
HAMBLÉN COUNTY	35
HAMILTON COUNTY	203
HANCOCK COUNTY	**
HARDEMAN COUNTY	9
HARDIN COUNTY	**
HAWKINS COUNTY	29
ROGERSVILLE	**
HAYWOOD COUNTY	9
HENDERSON COUNTY	7
LEXINGTON	**
HENRY COUNTY	10
*PARIS	**
HICKMAN COUNTY	20
HOUSTON COUNTY	**
HUMPHREYS COUNTY	11
JACKSON COUNTY	**
JEFFERSON COUNTY	22
JOHNSON COUNTY	**
KNOX COUNTY	412
LAKE COUNTY	6
LAUDERDALE COUNTY	8
LAWRENCE COUNTY	15
LEWIS COUNTY	6
LINCOLN COUNTY	15
FAYETTEVILLE	**
LOUDON COUNTY	13
LENOIR CITY	**
MCMINN COUNTY	15
ATHENS	12
ETOWAH	**
MCNAIRY COUNTY	11
MACON COUNTY	8
MADISON COUNTY	57
MARION COUNTY	13
*RICHARD CITY	**
MARSHALL COUNTY	8
MAURY COUNTY	71
MEIGS COUNTY	**
MONROE COUNTY	12
SWEETWATER	**
MONTGOMERY COUNTY	193
MOORE COUNTY	**
MORGAN COUNTY	10
OBION COUNTY	7
UNION CITY	**
OVERTON COUNTY	6

DAYTON	**
ROANE COUNTY	20
ROBERTSON COUNTY	29
RUTHERFORD COUNTY	116
MURFREESBORO	36
SCOTT COUNTY	**
*ONEIDA	**
SEQUATCHIE COUNTY	7
SEVIER COUNTY	43
SHELBY COUNTY	203
MEMPHIS	262
SMITH COUNTY	7
STEWART COUNTY	7
SULLIVAN COUNTY	14
BRISTOL	20
KINGSPORT	28
SUMNER COUNTY	139
TIPTON COUNTY	34
TROUSDALE COUNTY	6
UNICOI COUNTY	9
UNION COUNTY	10
VAN BUREN COUNTY	**
WARREN COUNTY	24
WASHINGTON COUNTY	17
JOHNSON CITY	23
WAYNE COUNTY	7
WEAKLEY COUNTY	14
WHITE COUNTY	12
WILLIAMSON COUNTY	172
*FRANKLIN	35
WILSON COUNTY	36
*LEBANON	18
TOTAL***	3,744

Notes:

*Special School District

**To protect student confidentiality, Tennessee suppresses any student count below 6 students when providing information to the general public.

***Total includes counts in suppressed cells.



PHIL BREDESEN
GOVERNOR

STATE OF TENNESSEE
DEPARTMENT OF EDUCATION
6th FLOOR, ANDREW JOHNSON TOWER
710 JAMES ROBERTSON PARKWAY
NASHVILLE, TN 37243-0375

TIMOTHY K. WEBB, Ed.D.
COMMISSIONER

September 25, 2009

Director Phillip Doss
Offices of Research and Education Accountability
Comptroller of the Treasury
James K. Polk Building, Suite 1700
Nashville TN 37243-0268

Dear Director Doss:

The purpose of this letter is to provide the Tennessee Department of Education's (TDOE) response to the Tennessee Comptroller of the Treasury, Offices of Research and Education Accountability (OREA) report entitled *Autism in Tennessee: An Introduction to Issues and Data Collection Methods* (9/16/2009 draft). This report accurately represents information collected from interviews and contacts with TDOE personnel.

TDOE supports the pursuit of legal authority and grant funding for the establishment of a statewide autism registry with constituent referral services and/or for establishing a designated, legally authorized entity to collect and coordinate autism data from health and educational resources. TDOE will use the information in the report as support for enhancements needed in the Tennessee Early Intervention Data System to collect more detailed disability category and medical information for children ages birth through three identified with developmental disabilities.

TDOE appreciates the efforts of the OREA in thoroughly researching and writing this report on autism data collection in Tennessee. We look forward to the completion of the other reports in this series on autism and are hopeful that the report recommendations lead to actions to coordinate and enhance services to people, birth through adult, with Autism Spectrum Disorders in our state.

Sincerely,

A handwritten signature in cursive script that reads "Timothy K. Webb".

Timothy Webb
Commissioner
Department of Education

APPENDIX H: RESPONSE LETTER FROM COMMISSIONER OF MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES



**STATE OF TENNESSEE
DEPARTMENT OF MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES
CORDELL HULL BUILDING, THIRD FLOOR
425 FIFTH AVENUE, NORTH
NASHVILLE, TENNESSEE 37243**

PHIL BREDESEN
GOVERNOR

VIRGINIA TROTTER BETTS, MSN, JD, RN, FAAN
COMMISSIONER

October 7, 2009

Phillip Doss, Director
Office of Education Accountability
Comptroller of the Treasury
505 Deaderick Street, Suite 1700
Nashville, TN 37243

Dear Mr. Doss:

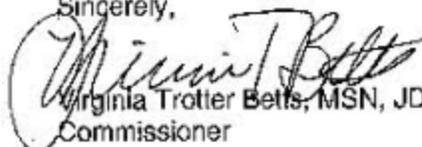
Thank you for giving DMHDD the opportunity to review and comment on the report "Autism in Tennessee: An Introduction to Issues and Data Collection Methods," and for incorporating our suggested revisions in the report. This report is a good first step in identifying issues related to data collection methods for autism spectrum disorders in Tennessee. The methodology used in developing the report was based on a logical approach, and the report reflects the scope and objectives set forth by the Legislature.

Although there are different sources that collect autism data in Tennessee, currently, there is no means to capture all data needed to accurately assess prevalence. As used in some states to collect autism data and mentioned in the report, a registry would be an excellent means to collect data that would be comprehensive, but such a registry would need to be mandatory in order to be effective.

As the report concludes, autism is a highly prevalent disorder and is considered to be a great public health challenge.

Again, thank you for the opportunity to review the report. I look forward to reviewing the subsequent reports relating to public education and healthcare services. Hopefully, with accurate data, the needs of persons with autism spectrum disorders in Tennessee can be addressed in a more systematic manner.

Sincerely,


Virginia Trotter Betts, MSN, JD, RN, FAAN
Commissioner

VTB: ds

Comptroller of the Treasury, Office of Education Accountability. Authorization Number 307376, 75 copies, October 2009. This public document was promulgated at a cost of \$0.99 per copy.



OFFICES OF RESEARCH AND EDUCATION ACCOUNTABILITY
Phillip Doss, Director
Suite 1700, James K. Polk Building ■ 505 Deaderick Street
Nashville, Tennessee 37243 ■ (615) 401-7911
www.tn.gov/comptroller/orea

