

TENNESSEE AUTISM PLAN

Stakeholder
recommendations
for a comprehensive
coordinated system of
care for children and
youth with Autism

07

How Families
Understand Autism

10

Tennessee State
Agencies for ASD

46

Moving Ahead

Adopted by the Legislative
Task Force on Autism
Spectrum Disorder in 2015

A close-up photograph of a young boy with short dark hair and glasses, wearing a green button-down shirt. He is looking down intently at a dark surface, likely a table, where there are some colorful blocks (red and yellow) and a black watch on his wrist. The background is blurred, showing other people in a room.

CONTENTS

- 3 Comprehensive, Coordinated System of Care
- 7 How Families Understand Autism
- 8 The State of Autism in Tennessee
- 10 Tennessee State Agencies for ASD
- 14 Autism Summit Team
- 18 Early Identification
- 22 Service Coordination
- 26 Information for Families
- 30 Education
- 36 Healthcare
- 40 Aging and Adulthood
- 46 Moving Ahead
- 48 Appendices
- 55 Acknowledgments

COMPREHENSIVE, COORDINATED SYSTEM OF CARE

This plan was developed as a part of an Autism State Planning Grant #H6M-MC22711A0 from the Maternal and Child Health Bureau (MCHB) of the U.S. Department of Health and Human Services and is directed at building a comprehensive, coordinated system of care to increase accessibility and availability of services for individuals with Autism Spectrum Disorders (ASD).

Through collaboration, Tennessee can develop a strategy focused on addressing the needs of individuals with ASD and can work to coordinate, streamline, and enhance the public-private partnerships necessary to provide adequate resources and services.

A “system of care” is a coordinated network of community-based services and supports that are organized to meet the needs of children and youth with ASD or related developmental disabilities and their families.

A system of care is more of a philosophy than a specific structure, and the Autism Plan approaches the system accordingly. Many entities and agencies play a role in realizing a coordinated, comprehensive system of care. Families and youth work in partnership with public and private organizations to design services and supports that are effective, that build on the strengths of individuals, and that address each person’s cultural and linguistic needs.

A system of care helps children, youth, and families function better at home, in school, in the community, and throughout life.

The Tennessee Autism Summit Team¹ was convened to serve as the planning and advisory council for the Autism State Planning Grant. Building on a foundation of evidence-based and -informed practices and a commitment to developmentally appropriate services and supports, the team developed recommendations for the Tennessee Autism Plan.

Parents, individuals with ASD, health care providers, educators, social service professionals, state agencies, researchers and academics all contributed time and expertise to the recommendations laid out in this plan.

Planning efforts built on the early work of the SJR 567 committee in 2002, as well as three reports authored by the Tennessee Comptroller’s Office of Research and Education Accountability (OREA) between 2009- 2012.² The Tennessee Autism Plan is the culmination of the ideas, discussion, data, and talents of a diverse group of Tennesseans who are dedicated to improving quality of life for individuals with ASD and their families.

In 2015, the the 109th Tennessee General Assembly formed a Legislative Task Force on Autism Spectrum Disorder. This Task Force subsequently voted to adopt the recommendations made in the Tennessee Autism Plan on December 3rd, 2015.







SYSTEM OF CARE PRINCIPLES

Tennessee Public Chapter 1062³ enumerated the principles of a coordinated system of care for children with special needs.

System of Care Principles include:

- A comprehensive array of services addressing physical, emotional, social, and educational needs.
 - Individualized services based on the unique needs and potential of each individual, and guided by an individualized service plan.
 - Services provided in the least restrictive environment.
 - Families as full partners in all aspects of planning and delivering services.
 - Links between agencies and programs with mechanisms for planning, developing, integrating and coordinating services.
 - Promotion of early identification and intervention that enhances the likelihood of positive outcomes.
 - Case management or similar mechanisms provided to each individual to ensure that services are provided in a coordinated and integrated manner that can address changing needs.
 - Smooth transitions from youth to adulthood with the supports and services needed.
 - Services responsive to the cultural and linguistic needs of all individuals.
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A photograph of a man and a woman smiling together at what appears to be a formal event. The man, on the left, is wearing a dark suit, a white shirt, and a striped tie. He has glasses and a mustache. The woman, on the right, has blonde hair and is wearing a teal off-the-shoulder top and a decorative necklace. The background is dark with green and yellow bokeh lights.

"Some people look
past me and don't
take the time to
understand autism.
I've obsessed what
it would be like
to be normal, and
what if I'd known
early I had autism."
~Nicholas Jones



HOW FAMILIES UNDERSTAND AUTISM

Parent representatives at Autism Tennessee like to say: “When you’ve met one child with autism, you’ve met one child with autism.” What they mean is that each individual with this diagnosis is unique, and the way it impacts their life may be very different from another with the same diagnosis. Autism impacts more than the day-to-day of that individual, it impacts his or her family and our larger community. Including individual and family perspectives is key to understanding autism and the diverse needs of those with this diagnosis.

“Autism has affected every aspect of our lives--where we live, worship, where the kids attend school, work situations, social lives, vacations and finances,” Janet Shouse, a mom, describes.

“Autism is a team sport, and there’s no room for bench warmers,” says Tammy Vice, a parent. “There are days when I wonder how many more educational, medical insurance and financial battles I can fight.”

“We have learned that autism is unpredictable, so we try to be prepared for anything,” explains Becky Gore, a parent.

“We have been forced to make new dreams-- few in number and very basic. Our dreams are things that most people take for granted,” explains Sherree Ann Sauer, a grandparent.

Excerpts from the book, “From Heartache to Hope,” by Leisa Hammett and Rebekah Pope.⁴



THE STATE OF AUTISM IN TENNESSEE

Autism is a complex developmental disability that typically appears in early childhood and affects a person's ability to communicate, form relationships and respond appropriately to the environment.

Autism is one of a spectrum of related disorders that carry names such as Asperger's Syndrome, Pervasive Developmental Disorder – Not Otherwise Specified, Rett's Syndrome, and Childhood Disintegrative Disorder. The current convention is to label this array of disorders as Autism Spectrum Disorders (ASD).

ASD is defined by a set of symptoms and behaviors that affect individuals differently, to varying degrees and last throughout the lifespan. No single underlying cause has been identified, and symptoms range from mild to severe impairments. There is no single medi-

cal exam for autism. Instead, behavioral assessments identify symptoms that indicate autism. Some autism disorders may be identified as early as the first few months after birth 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 Centers for Disease Control and Prevention (CDC) despite evidence that ASDs can be identified at 18 months or younger, "many children do not receive a final diagnosis until much older."⁵

The prevalence of ASD in the general population has greatly accelerated in re-

cent years. According to the new report from the CDC National Center on Birth Defects and Developmental Disabilities Autism and Developmental Disabilities Monitoring Network, the prevalence of ASD in children is one in 68, or 14.7 per 1,000 eight year olds. This represents an approximate 30 percent increase between 2008 and 2010.⁶ Many people view these data as indicative of an epidemic of ASD. While there is debate about how much of the increase results from increased recognition versus increased prevalence, there is no disagreement that there are significantly larger numbers who need services to treat and cope with ASD.

DEMOGRAPHICS

While Tennessee lacks an adequate database for information about people with ASD, there is no indication that the rate is statistically different from national data. In response to a legislative inquiry, the Comptroller of the Treasury Offices of Research and Education Accountability (OREA) published an October 2009 report on autism in Tennessee. A significant statistic from that report shows that from 2001 to 2007, the number of children and youth receiving autism-related special education services tripled. Based on special education data, 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 increase of 20.8%.⁷

In 2000, 1,088 or 0.86% of children ages

3-21 who received special education services in Tennessee were classified as having autism. In 2011-2012, 6,752 or 5.44% of children with disabilities ages 3-21 who received special education services had autism.⁸

Statistics alone do not come close to describing the scope of the problems faced by children, families, providers, and the state. Families often report that having a child with ASD/DD has a tremendous impact on the family unit. The impact pervades a family's finances, employment status, recreational activities, community involvement, and other quality of life issues. Families report voluntarily reducing work hours and in some instances resigning from positions in order to provide care for their child.⁹ It is estimated to cost at least \$17,000 more per year to care for a child with ASD compared to a child without ASD. Costs stem

from health care, education, ASD-related therapy, family-coordinated services, and caregiver time. For a child with more severe ASD, costs per year increase to over \$21,000.¹⁰

Children and adolescents with ASD had average medical expenditures that exceeded those without ASD by \$4,110–\$6,200 per year. On average, medical expenditures for children and adolescents with ASD were 4.1–6.2 times greater than for those without ASD. Differences in median expenditures ranged from \$2,240 to \$3,360 per year with median expenditures 8.4–9.5 times greater.¹¹

The transition to adulthood brings its own challenges. Educational and employment opportunities for individuals with ASD are scarce, even when compared to those of individuals with other disabilities.¹² Meeting the diverse and complex needs of children and adults with autism and their families poses a major challenge. Tennessee must work toward development and implementation of systems to ensure that individuals with ASD and other developmental disabilities receive early and timely identification, diagnosis, and intervention services. Because of varied needs, no single state agency can accomplish the systems changes required to meet the growing demand for supports and services.



TENNESSEE STATE AGENCIES FOR ASD

Individuals 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 needed services for this population. Tennessee law designates authority and responsibility to at least six state departments. These include the Department of Mental Health, Department of Intellectual and Developmental Disabilities, Department of Children's Services, Department of Education, Department of Health, Department of Human Services, and the Department of

Finance and Administration. No single agency is responsible for overall service coordination. The Comptroller's reports point out that "Over the past decade, attempts have been made to coordinate Tennessee's departments and services for individuals with developmental disabilities,"¹³ including those with ASD.

DEPARTMENT OF INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (DIDD)

DIDD is responsible for planning and providing services and supports to Tennesseans with intellectual and developmental disabilities. DIDD provides services directly or through contracts with community providers in a variety of settings, almost exclusively through Medicaid home- and community-based waivers, or through institutional settings. Despite its authority to provide services to those with developmental disabilities (DD), DIDD only provides these services to those who have a diagnosis of intellectual disability (ID) and who meet TennCare's level of care eligibility criteria. Over the last decade, the department has moved to serving almost exclusively adults.

Budgetary constraints severely limit the number of people who are able to be served by the department. There is an ID waiting list that is roughly the same size as the number of individuals currently being served. The number of those on the waiting list does not reflect the need or demand for these services. Individuals with DD such as autism without a co-occurring ID (defined for these purposes as having an I.Q. less than 70) are excluded entirely.

The Family Support Program, operated by DIDD, was established by the TN General Assembly in 1992 and has been funded at approximately 7.2 million dollars for the last 15 years. Family Support is a source of assistance to individuals with developmental disabilities (not necessarily with a co-occurring intellectual disability) and their families. With a maximum annual benefit of \$4000, Family Support is not a substitute for comprehensive services. However, the program assists approximately 4,200 families, some of whom have ASD, each year with supportive services.

DEPARTMENT OF HEALTH

The Department of Health is home to a num-



ber of initiatives with the potential to yield positive outcomes for Tennessee's system of care. The Family Health and Wellness Division is home to a variety of programs that assist children and youth with special health care needs (CYSHCN) and their families. The Division provides leadership for maternal and child health efforts, health promotion, and addresses the needs of CYSHCN. The Children's Special Services (CSS) program may provide coverage for comprehensive medical care and other non-medical resources for children with physical disabilities from birth to 21 years of age. Diagnostic and financial eligibility criteria must be met to participate in the program. The CSS program is coordinated through local health departments and provides resources for medical and non-medical services. Service coordination is a component of CSS and may be provided for children with diagnosed medical needs, however, ASD is not a covered diagnosis.

Integrated Community Systems of Services for Children and Youth with Special Health Care Needs is an initiative to develop a family centered network of community-based services to improve access to quality, comprehensive, and coordinated services that are culturally sensitive for CYSHCN and their families in Tennessee, including Autism. A primary goal of this program is to advance the application of family-centered care and Medical Home concepts in healthcare.

The Tennessee Young Child Wellness Council (TYCWC) is a new early childhood state team that is evolving from the former Early Childhood Comprehensive Systems State Action Team and the Early Childhood Advisory Council. The TYCWC aims to lead the necessary system enhancements that support programs or services to mitigate toxic stress, expand developmental screening, and strengthen systems for improved child care quality in infancy and early childhood. TYCWC is an excellent venue for interdisciplinary initiatives.

DEPARTMENT OF MENTAL HEALTH AND SUBSTANCE ABUSE SERVICES (DMHSAS)

The Department of Mental Health Services provides oversight of the statewide system of mental health services for children and youth and their families, and is responsible for statewide planning and program development. The office provides policy guidance, technical assistance and support to child-serving agencies in the development, and implementation and expansion of statewide programs and services for children and youth with or at risk of mental health disorders and their families. This office has experience in the development and implementation of systems of care. It works on an interdisciplinary basis with other groups, most notably the Council on Children's' Mental Health.



DEPARTMENT OF EDUCATION

The mandate for a free appropriate public education¹⁴ makes school the primary source of assistance for children with ASD and other developmental disabilities. The Department of Education is a partner with local school systems where 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 through Tennessee Early Intervention System (TEIS). TEIS services

include planning and coordination of individualized services for the family and child, as well as transition assistance to the local school for special education services as necessary.

TEIS is vital to a comprehensive system of care, not only for the services and service coordination provided directly, but also for their role in facilitating points of entry into the system itself. As young children are referred, TEIS is in a unique position to screen and identify developmental delays, as well as track the use of



screening tools among their referral sources.

Local school districts vary widely in size, in their capacity to address the needs of all children and the complex requirements of statutory mandates. Such variability leads to differences in the quantity and quality of services provided from district to district.

The Department of Education has a role in training and technical assistance to districts, as well as moni-

toring compliance. Teacher training, finance, and guidelines for best practices are other important areas of interest.

DEPARTMENT OF FINANCE AND ADMINISTRATION (F&A)

Health Care Finance and Administration oversees all of the health care related services in F&A, including TennCare, Tennessee's Medicaid program. An estimated 50% of Tennessee's children and youth with ASD are enrolled in TennCare for their primary and acute care health insurance coverage. TennCare's Long Term Supports and Services Division is responsible for the Medicaid waivers operated by DIDD. There are no current long term services and supports waivers for children, youth or adults with DD who do not have co-occurring ID.

As the largest insurance provider for children with ASD, TennCare is the entity in Tennessee's ASD system of care with the greatest capacity to improve access to needed services. Applied Behavioral Analysis (ABA) therapy is among the most crucial services. While ABA is nominally a covered service by all TennCare Managed Care Organizations (MCOs), limits on coverage fall far short of the standard set for comprehensive ABA coverage.

DEPARTMENT OF HUMAN SERVICES (DHS)

Vocational Rehabilitation Services, a part of DHS, is the program that provides employment services to individuals with disabilities. It has a Transition from School to Work Program for high school students pursuing post-secondary education or training or employment. Eligible individuals have access to a range of employment services.

Transition and employment issues for youth and young adults with ASD are challenging, and the number of individuals needing specialized services is growing.

COMMUNITY PARTNERS

State agencies and families also rely on state, regional, district, and local entities that provide direct services. Additionally, families often rely on services provided by not-for-profit autism and disability advocacy groups and University Centers for Excellence in Developmental Disabilities (Vanderbilt Kennedy Center, UT Boling Center). The Summit Team membership reflects a wide range of these entities.

AUTISM SUMMIT TEAM

The Autism Summit Team is a voluntary partnership of stakeholders across the public, private and nonprofit sectors. It is comprised of more than 65 individuals representing State Agencies, family-based or disability support and advocacy organizations, community service providers and universities as well as many family members and individuals on the autism spectrum¹.



The team was initially formed when Tennessee's University Centers on Excellence in Developmental Disabilities at Vanderbilt University and the University of Tennessee hosted the 2009 Summit on Autism for the Southeast region. This Summit brought together leaders from Tennessee, North Carolina, South Carolina and Kentucky to discuss the current state of services for young children with or at risk for autism and related disabilities.

The Summit provided an opportunity for parents, government officials, and healthcare professionals to share concerns, ideas and to collaborate. The Tennessee delegation moved forward independently as a standing body after

the initial 2009 summit. The Tennessee Autism Summit Team has been in place for five years and served as the planning and advisory council for a federally funded State Planning Grant from 2012-2014.

The Summit Team's goal has been to create a plan to build, improve and sustain a coordinated system of care for children and youth with Autism Spectrum Disorders/Developmental Disabilities. The system of care should be family –centered, based on best practices, and focus on quality improvement.





Families need a “one-stop shop” resource
for guidance.

DATA COLLECTION PROCESS



The Summit Team's Planning Council, established to lead this planning project, chose to adopt a two-fold assessment approach that would yield both qualitative and quantitative data. Most of the quantitative data were provided by the results of a family survey authored and analyzed by Summit Team partners at Vanderbilt University.

The survey was designed to provide three levels of information from respondents: demographic information (ethnicity, income, level of education); information about the child with ASD (specific behaviors, age of first concern, and age of

diagnosis); and information related to the services received and/or required for the child. Over 400 families completed the survey.

In order to get a more qualitative representation of life in Tennessee for a family dealing with ASD, the World Café¹⁵ method of collaborative brainstorming was used to hold a series of Community Conversations.

Partners in each region of Tennessee helped to recruit families and professionals in six communities. By hosting Community Conversations in Nashville,

Jackson, Memphis, Chattanooga, Knoxville, and Johnson City, it was possible to include communities on both sides of the rural/non-rural divide and in all three of the state's "grand divisions."

The most significant demographic disparity identified in the family survey was that between rural and non-rural respondents. Families identified a number of challenges faced in rural areas.¹⁶ Of particular concern in the results was report of a higher prevalence (10-15%) of co-occurring medical and behavioral conditions in rural children and youth.¹⁶

This demographic difference is similarly pronounced in the area of certain services received. This included a lack of adequate screening and diagnostic services. Families in rural areas described the challenges they face in obtaining services and supports of all varieties. A two-hour drive for an initial diagnosis is problematic, and a trip the same distance for therapies that require consistent, frequent engagement in order to be effective make them out of reach for many families.

Other needs specifically identified by our survey include school-based and in-home behavior supports. The survey, as well as testimony during Community Conversations, established a relative dearth of parent support groups and parent workshops.

The foremost needs identified through anecdotes from both the survey and Community Conversations relate to diagnostic issues, specifically the amount of



time between initial parental concern and eventual diagnosis.

When services are available and obtained, families are for the most part satisfied with them. However, service coordination, though rated by 89.9% of respondents as “very important,” was only received by 5.9% of respondents.¹⁷ While the need for service coordination was established by the Families Survey, family experiences shared during the Community Conversations emphasized their need for an easily accessible entry point for supports, resources, and services. A common theme across all Community Conversations was the need for a “one-stop shop” resource for guidance.¹⁶

THE PLANNING PROCESS

The Autism Summit Team members developed mechanisms to analyze the data and identify areas of quality improvement that would serve as the basis for this plan. The team split into three groups, each responsible for submitting a series of proposed recommendations.

These three workgroups convened between quarterly Summit Team meetings and focused on discussing structural challenges, successful emerging models, and potential future initiatives. As workgroups were concluding, they reviewed the material they had discussed and developed consensus recommendations. The Summit Team then reviewed these recommendations and identified successful emerging models and subject areas identified as those meriting further study. The product of these discussions was the first outline for a Tennessee Autism Plan.

PLAN STRUCTURE

The Summit Team workgroups addressed six identified areas of a comprehensive system of care: Early Identification; Service Coordination; Information for Families; Education; Healthcare; and Adulthood. The workgroups considered the implications for data, training/workforce, and financing for the system.

For each area, this report outlines the team’s findings, best practices, existing and emerging models, and recommendations for addressing gaps and needs. Many of these recommendations focus on indicators of a quality system of care.

The most significant demographic disparity identified in the family survey was that between rural and non-rural respondents.



EARLY IDENTIFICATION

Diagnosing an Autism Spectrum Disorder as early as possible is critical.

Research shows that young children who receive intensive and specialized treatment early experience better outcomes. Reducing the amount of time between when parents are concerned about their child's development and when they receive a diagnosis must be a priority for our state.

The 2012 Family Survey found that "almost one-quarter of parents (23.1%) were concerned before their child reached one year of age, and over 55% before 18 months. Almost half of these parents (46.8%) then discussed their concern with a professional, but only 4.6% of all parents had received an ASD diagnosis by 18 months, and slightly less than 1/3 (32.1%) had received a diagnosis by the time the child was 30 months (or one year later)."¹⁷

Furthermore, "relatively few parents were first concerned only after the child was 60 months or older (i.e., 5-years old), but a full 1/3 (33.5%) of all ASD diagnoses occurred after this 5-year period 43.2% take place after the benchmark age age of 48 months."¹⁷


The CDC defines a number of benchmarks by which populations can measure the screening and early identification component of a system of care. These include the number of children identified by 24 months, evaluated by 36 months, and enrolled in intervention services by 48 months⁵. These are very modest expectations. In fact, given that in Tennessee, children are only eligible for early intervention services through age two, we should strive for enrollment well below this age.

SCREENING AND DIAGNOSIS

Families must have access to receive appropriate diagnoses of an Autism Spectrum Disorder.

SCREENING TOOLS

In addition to their families, there is a host of people who provide care for young children in Tennessee. Types of providers include preschool educators, childcare staff and primary care clinicians. This diverse array of providers must have the training to recognize when a child needs to be screened for ASD. Equally critical is that when referred for a screening to a primary care clinician or early interventionist, that provider has the training necessary and is able to access standardized screening tools needed.



Primary care clinicians should screen all children and monitor those with risk factors for developmental problems. Widespread use of screening tools would greatly improve the system of care by increasing the number of entry points for families. An online training module with educational resources could be particularly effective at reaching all Tennessee providers.

The Centers for Disease Control and Prevention (CDC) recommends developmental screening tools be incorporated into well-child visits at 9 months, and ASD-specific screening at 18 and 24 months⁵. Assessment is needed if a child is at high risk for ASD or if symptoms are present.⁵

DIAGNOSTIC TOOLS

When screening indicates cause for concern, additional tools are used to diagnose the presence of ASD. Diagnostic tools rely on two sources of information—parents’ or caregivers’ descriptions of their child’s development and a professional’s observation of the child’s behavior. The primary care provider might refer the family to a specialist for further assessment and diagnosis. Referrals to specialized centers are appropriate, but long waits often delay a specific diagnosis.

PATHWAY FROM SCREENING TO SERVICES

When developmental delays are identified and while families are waiting for diagnostic services, it is important that care providers make referrals to intervention services. A diverse array of entry points to a system capable of screening and diagnosing ASD, along with infrastructure to link necessary services are foundations of early intervention.

DATA COLLECTION

Shared access to records documenting screening, diagnosis, treatment, and services received could improve coordination of care. System-wide data collection efforts should begin with tracking the number of children meeting the CDC and developmental milestones.

The 2012 Families Survey provided insight into the age at which some children have been able to access diagnostic services.¹⁷ Future surveys of families would provide progress reports.

EXISTING AND EMERGING MODELS

There are several models that are leading innovation in screening, diagnosis, and service delivery for Tennessee families affected by ASD. They represent a range of operators, including public-private partnerships. Building on their success will widen access to early identification of ASD.

CDC TRAINING CURRICULUM

The CDC Act Early Autism Case Training (ACT) Curriculum includes information on identifying, diagnosing, and managing Autism Spectrum Disorders and is available online for free Continuing Medical Education (CME) credit, as well as for Nursing (CNE), and Continuing Education (CEU) credits by the CDC.

START NETWORK

In partnership with TennCare, the Tennessee Chapter of the American Academy of Pediatrics developed the Screening Tools and Referral Training (START) in 2003. Now funded with assistance from the TN Department of Education through Tennessee Early Intervention

Services (TEIS), START was designed to help pediatric care providers learn skills and strategies to implement routine developmental screening using standardized screening tools as part of their health care procedures. The program incorporates the CDC Training Curriculum *Learn the Signs and Act Early* material, and brings medical practices up to speed on screening tools such as the M-CHAT-R, MCHAT-Follow up or STAT¹⁸. To date, nearly 2,000 providers have participated in the START training.

While the START program initially trained medical practices and will continue to offer training to medical practices across the state, it has expanded to include Tennessee medical school and residency programs. Trainings are provided at no cost and are for anyone who serves the pediatric population in the State of Tennessee.

This public-private partnership offers a strong foundation on which to model a larger statewide implementation of standardized screening tools.

“Only 4.6% of parents had received an ASD diagnosis by 18 months, and slightly less than 1/3 (32.1%) had received a diagnosis by the time the child was 30 months (or one year later).”¹⁷

DEPARTMENT OF HEALTH PILOT PROJECT

The Tennessee Department of Health is working to expand points of entry for families to the system of screening and diagnosis through existing service providers.

This pilot project incorporates a standardized screening tool into the protocols for nurses at local health departments in Rutherford and Sumner Counties. The next phase will be a review of the findings from conducted screenings, potential modification of the protocol, and a determination as to the

feasibility of expanding the program regionally.

If the pilot proves feasible, the Tennessee Department of Health proposes to expand screenings to every local health department by 2015 with training provided by the TN chapter of the American Academy of Pediatrics. State-wide implementation protocol would increase access for families to receive a diagnosis of ASD.

TENNESSEE EARLY INTERVENTION SYSTEM (TEIS)

Increasing awareness about ASD and

resources for screening and referral is a shared responsibility of all agencies that serve Tennessee families. TEIS recognized the need for greater awareness among their referral sources, and has made increasing referrals a current focus.

Should a child be referred for intervention services for any reason, particularly if a screening tool has not yet been used by the referral source, TEIS represents an opportunity for the child to receive services. Adding a standardized screening tool to TEIS protocols could increase access for families to receive a diagnosis of ASD.

DHS LICENSED CHILD CARE FACILITIES

Child care facilities licensed by the Tennessee Department of Human Services need training and technical assistance support in identifying children on the spectrum. Two existing organizations which could develop the capacity to provide these are the Child Care Resource and Referral Network and the Tennessee Early Childhood Training Alliance. There are eight Child Care Resource and Referral Network offices across the state which assist child care providers in all 95 counties. The Tennessee Early Childhood Training Alliance offers financial support to those who work in child care and are earning their CDA or Associate's Degree.



Increasing awareness about ASD and resources for screening and referral is a shared responsibility of all agencies that serve Tennessee families.



RECOMMENDATIONS

TRAINING

- Expand the capacity of existing community providers that serve Tennessee children to recognize the need for an ASD screening.
- Train all primary care providers, clinicians and early interventionists to use and have access to standardized screening tools.
- Develop an online hub for trainings and resources on early identification.
- Primary care physicians must screen all children and monitor those possessing risk factors for developmental problems.

SCREENING AND DIAGNOSIS

- Implement universal, localized screenings by establishing a diverse array of entry points to a system capable of screening and diagnosing ASD.
- Reduce wait times for appropriate diagnosis.

TREATMENT

- Expand the existing infrastructure to link families to necessary services when they or their provider have concerns of developmental delay.
- Encourage enrollment in early intervention services as soon as possible, even before a formal diagnosis has been given. A documented delay is a sufficient criterion for TEIS enrollment.

DATA

- Facilitate sharing of health records documenting at what age a child has been screened, diagnosed, and enrolled in services.
- Collect data on the number of children meeting the CDC developmental mile stones.
- Continually survey families to evaluate progress.



SERVICE COORDINATION

Service Coordination is a central, unifying component of an effective system of care for children and youth with Autism Spectrum Disorders.

Children and youth with ASD and their families often require a broad array of developmental and behavioral services based on age and functional level. Their needs often straddle the medical, behavioral health, social, and education systems. Navigating service systems “poses additional challenges for families already dealing with a fragmented system of health care where specialty services are not coordinated with primary care or other community-based services, and coverage for services is not comprehensive.”¹⁷

The 2012 Family Survey found that a majority of families, even when they expressed overall satisfaction with services, need additional service coordination.¹⁷



Service coordination, though rated by 89.9% of Family Survey Respondents as “very important,” was only received by 5.9% of respondents.¹⁷

Effective service coordination reflects the central role of families, prioritizes child and family concerns, and addresses strengths and needs. In addition to identifying and meeting individual child and family needs, service coordination builds family capacity. The need for effective communication between providers is especially pronounced during transitional periods of an individual's life.

The system of care for ASD must include service coordination with the flexibility to meet changing needs across an individual's lifespan.

EXISTING AND EMERGING MODELS EARLY INTERVENTION

Best practices and outcomes of good service coordination are evident in early intervention. The Tennessee Early Intervention System (TEIS) is the most formalized model of service coordination in our state. Service Coordination is a central service provided by TEIS to families of infants and toddlers with disabilities or at risk of disabilities, including ASD. An Individualized Family Service Plan (IFSP) is created by the parents, an early interventionist, service coordinator, and other team members based on the diverse needs of the child. Service coordination emphasizes assisting children and families within their natural routines, activities and culture.



MEDICAL HOME

Tennessee has joined the national trend toward implementing the Medical Home model of health care delivery. A key feature of medical home is coordination of care across the domains of a patient's life. "The medical home is best described as a model or philosophy of primary care that is patient-centered, comprehensive, team-based, coordinated, accessible, and focused on quality and safety. It is a philosophy of health care delivery that encourages providers and care teams to meet patients where they are, from the most simple to the most complex conditions."¹⁹

The Tennessee Department of Health is the leader in the implementation of medical home in our state. The department is partnering with the Tennessee Chapter of the American Academy of Pediatrics and, among others, Family Voices of Tennessee, to provide education and training for families and health care providers on medical home.

INTEGRATED CARE MODEL

Some health systems in Tennessee are implementing service coordination by adopting an integrated care model. The integrated care model supports primary and behavioral healthcare integration in the clinical setting as a means for delivering quality care and improving overall health outcomes. In practice, this means that different providers may work with a family in the same clinic during the same visit. A pediatrician may access an occupational therapist and consult the child and family together.



RECOMMENDATIONS

Increase the use of medical home across all health care systems that serve individuals with ASD.

Include training on collaboration and coordination in family and professional educational programs.

Explore innovative approaches to increasing the availability of service coordination for families and individuals with ASD.

INFORMATION FOR FAMILIES

Families are the most critical support for individuals with Autism Spectrum Disorders. Effective systems of care inform and engage families in decision-making, service delivery, and care coordination.

Tennessee's principles for a system of care³ and the U.S. Healthy People 2020 objectives²⁰ clearly identify the need for culturally appropriate, family-centered assistance and support for families. Input from the from the Community Conversations further emphasizes the need for a region- based, family-centered resource guide with a user-friendly online presence.¹⁶

Evidence shows that effective systems of service are those that include informed families and youth, engage families as partners and agents of change, and provide effective resources and supports. When families have access to the information, resources, and assistance they need, they report being able to better partner in decision-making, navigate services, and are more confident about getting the health care services that their child needs.²¹

Outreach efforts and resources must be culturally and linguistically appropriate in order to bridge outcome disparities across rural and urban areas, ethnic minority groups, and for families who are identified as having a low socio-economic status.²¹

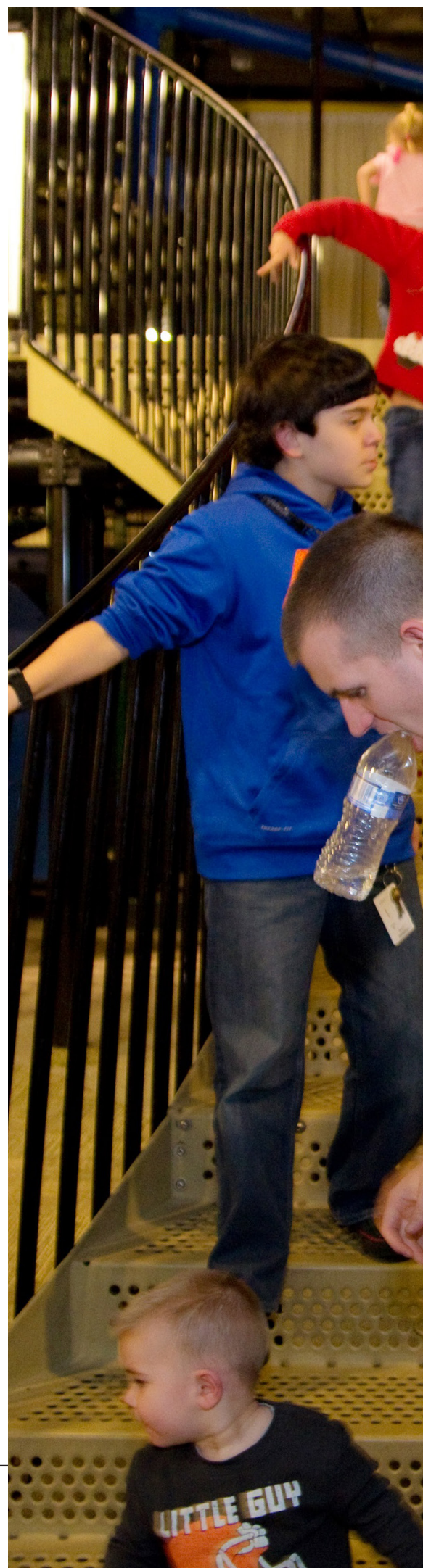
DATA COLLECTION

Using the Family Survey as a baseline, data on availability of services, availability of information and resources, satisfaction, and impact should be collected. This is an area where public-private partnerships could be brought to bear. Monitoring access, use and effectiveness could strengthen and improve the system of care.

One of Tennessee's strongest assets in addressing needs of families affected by Autism Spectrum Disorders is support from other families. A robust set of family-based organizations represents the front lines in our state's system of care. This system supports Tennessee's family-based ASD service providers and peer groups.

EXISTING AND EMERGING MODELS

Family-based organizations have a unique ability to connect with other families affected by ASD based on shared experiences.





Emerging models of supportive programs for Tennessee families affected by ASD emphasize resource and information networks. They are family-centered, provide accessible materials, and have a vibrant online presence.



Autism Tennessee, formerly the Autism Society of Middle Tennessee, staffs Parent Representatives who provide one-on-one assistance and peer support. Autism Tennessee and its sister organizations in East and West Tennessee also provide training, advocacy, information, referrals and technical assistance.

Family Voices of Tennessee operates a Family to Family Health Information Center funded by the Health Resources and Services Administration, Maternal and Child Health Bureau. Through this program, Parent and Family Navigators educate other parents and health care providers about available family-centered resources including tools such as the medical home model.

Family Voices of Tennessee is also partnering with the Tennessee Department of Health, Family and Child Wellness Division to develop a Parent-to-Parent Matching Program. This program facilitates one-to-one connections for parents with children who have special health care needs including ASD.

TENNESSEE DISABILITY PATHFINDER

Direct access to comprehensive, objective information, and resources in their local area helps families. Tennessee Disability Pathfinder is a statewide clearinghouse of disability-related resources and services for persons with disabilities. The program has an expansive website that is

easily navigable and frequently updated. Through Pathfinder, *Camino Seguro* identifies multilingual offerings of agencies and resources across the state. Pathfinder works to ensure that all resources listed are relevant, culturally competent, and representative of best practices.

Through the Summit Team, Pathfinder has developed a partnership with Autism Tennessee to expand an information infrastructure: the Autism Portal. A part of the Pathfinder website, this autism-specific site is designed to respond to the needs expressed by families dealing with ASD. The site has general information on autism as well as a regularly updated resource directory. Ideally, this guide will be more comprehensive as the partnership between Pathfinder and Autism Tennessee develops.

KIDCENTRAL TN

Governor Bill Haslam's Children's Cabinet launched an online listing of state-operated and state-funded programs in 2014. The *kidcentral tn* State Services Directory displays all of the services and programs offered in the website-user's area. Families can also view all services available that match a keyword search such as "autism." A marketing campaign by the state to promote *kidcentral tn* continues to spread the word about this expansive directory.

Where Tennessee Disability Pathfinder and the Autism Portal include only material relevant to families with disabilities and ASD, *kidcentral tn* represents all state funded and operated services for children and families. Although it has a less specific focus, *kidcentral tn* is a central hub that is positioned as an entry point for all state service systems and for all Tennessee families.



RECOMMENDATIONS

Provide families with direct access to comprehensive, objective information and resources in their local areas.

Empower families and youth to be full partners in decision-making.

Support and strengthen collaborations between Tennessee's family-based ASD service providers and peer groups.

Increase the accessibility and availability of peer support, information and referral services.

Improve community awareness of all existing sources of objective, culturally, and linguistically appropriate, user-friendly resources and information.



EDUCATION

No two children with ASD have identical needs. Not only are individuals impacted by different conditions on the spectrum, but their range of symptoms and outcomes differ. Additionally, an individual may have a diagnosis of ASD and other co-occurring conditions or disabilities.

The goal of educational programs for all students, including students with ASD, is a life with independence and purpose in the community. Reaching this goal requires an education based on the individual needs of the child. The Individuals with Disabilities Education Act (IDEA) guarantees early intervention services (Part C) for children ages birth through two years and special education services



“Although every new school year has brought a flurry of calls and emails from the school expressing concerns or seeking my input, the most difficult periods in my parenting life have come when my son has begun at a new school: his first year of preschool, in first grade, and last year when he began at a new middle-high school. During each of these adjustment periods, there has been a sense of crisis, a pervasive urgency for the first few months of school.”²²

(Part B) to children and youth ages three to twenty-one years who require them.¹⁴

The Individualized Educational Program (IEP) process prescribed by the IDEA presents opportunities for cooperation and coordination between the families, educators and other professionals in the child’s life.¹⁴ IEPs should include not only academic goals but address the needs of the whole child, including health and mental health, behavioral health, life skills, and healthy relationships as well.

Integration and coordination between the school and the other systems in a child’s life are critical.

Families and youth are key partners in developing and implementing meaningful and successful IEPs. An effective education program and IEP team for students with ASD requires the expertise and input of family members (including the student) and staff from multiple disciplines trained to understand the implications of Autism Spectrum Disorders.

Transition planning and implementation, from early intervention and preschool to elementary, as well as from secondary to post-secondary education and life after school, are important components of the child’s education. Early strategic transition planning for adulthood, including academic, vocational,

social and medical issues needs to start no later than middle school age.

TRAINING

Pre-service, disability-specific education for general education teachers is not typically addressed by post-secondary programs in Tennessee. The principles of integration, inclusion, and least restrictive environment mean that all classroom teachers will have some responsibility for the education of students with ASD at various points throughout his or her career. Pre-service training specific to meeting the educational needs of students with Autism Spectrum Disorders should be included in post-secondary

curricula for general and special educators. Teachers should have ongoing in-service training and support to meet the educational needs of students with ASD and to coordinate care with family and outside service providers. Educators benefit from internal support through team-building, mentoring, and coaching, as well as access to resources.

Paraprofessionals and others may spend a significant amount of time assisting students with ASD during the school day. Training and resources specific to ASD must be available and accessible to paraprofessionals.

Families and youth are partners in education. They need training and information to be effective. These IEP team members also need access to quality information, training, and resources that prepare them to be equal partners in designing and implementing quality, effective educational programs.



EXISTING AND EMERGING MODELS

TRAINING

Private-Public partnerships can strengthen and improve access to training for school-based personnel, families, and students. One such partner is the Treatment and Research Institute for Autism Spectrum Disorders (TRIAD) at the Vanderbilt Kennedy Center. TRIAD partners with the Department of Education and local school districts to provide training for a variety of professionals. TRIAD provides teacher training in several formats. Several Basic Online Training Sessions (BOTS) are available as well as pre-recorded training sessions that can be downloaded at any time. Tennessee teachers can also schedule in-person trainings based on specific topics (e.g. communication or behavior).

In-depth, localized trainings and consultation services are available at the system or individual school level. At the school district level, TRIAD engages in Autism Program Evaluations to work with teachers and ad-

ministrators on strengthening school programs for students with ASD.

In addition to TRIAD at the Vanderbilt Kennedy Center, the University of Tennessee Boling Center on Developmental Disabilities is another important partner for both pre-service and in-service training of multi-disciplinary professionals, paraprofessionals, and families.

TRAINING RESOURCES FOR FAMILIES

Support and Training for Exceptional Parents (STEP, inc.), is Tennessee's Parent Training and Information Center. Partnering with the Department of Education and other parent-based groups, STEP provides parent-centered services to help families become active participants in their child's education. Through workshops and trainings, conferences and institutes as well as one-on-one assistance, STEP's statewide reach is an important resource for families of

I pray about the IEP.
I meditate. Nothing can
prepare me for those
meetings.
~Parent of a child
with ASD.

children and youth with ASD as well as other disabilities.

TRAINING RESOURCES FOR STUDENTS

The Arc Tennessee's Secondary Transition Project helps students, families and educators understand the secondary transition process, see possibilities for adult life, and become aware of resources available to help make the student's dreams come true. Their Student-Directed IEP trainings use several tools to help students take a leadership role in the planning process.

EDUCATION REFORM

Changes and developments in public education require the involvement of those who understand educational supports and services for children with ASD. Implementation of the new Common Core Standards have implications for students with ASD and other disabilities. Summit Team partners are collaborating with the Department of Education to understand the impact of Common Core on special education teachers and programs, as well as on students with disabilities. Information and training opportunities are anticipated.

There has also been a shift in philosophy within the Department of Education from “special education is a place” to “special education is a continuum of services designed to support student success in the classroom.” The implication of this shift is that more general education teachers will have stu-

dents with ASD in their classrooms and need the skills to effectively support them.

Response to Intervention (RTI) is an approach to student support implementation statewide. It states that “every student can learn, demonstrate growth, and has the right to actively participate in high quality, research-based education that maximizes their potential in the least restrictive environment.”²³ Special Education will no longer be the default for struggling learners. While the concept has great potential, implementation must be monitored closely to ensure students with disabilities, including those with ASD, are referred and evaluated for special education services in a timely matter when needed.

A stronger focus on measurable outcomes has led the Department of Education to implement a “new” way of writing IEPs. IEPs will no longer be “deficit based.” They are

instead meant to include measurable goals that demonstrate progress in key academic skills. “Instructionally appropriate IEP” information sessions were held across the state to introduce families to the new process. For students with ASD, it will be key to monitor IEP development to ensure social and other developmental skills are also addressed.



RECOMMENDATIONS





Increase the ability of all IEP team members to collaborate and communicate for effective individual education programs.

Review policies and practices that support appropriate, quality education and positive outcomes for students with ASD within the public school environment.

Expand family and student access to training and information on IDEA requirements, special education programs and services in order to best collaborate with school-based service providers and other IEP team members.

Expand and develop models of support and in-service training programs for school personnel to meet the educational needs of students with ASD.

Include training specific to meeting the educational needs of students with Autism Spectrum Disorders in curricula for all educators.

HEALTHCARE

Health, according to the World Health Organization, is a state of complete physical, mental, and social well-being. People with ASD experience many barriers to achieving this definition of health.²⁴

The changing health care environment has presented unique challenges for individuals with ASD. The federal Interagency Autism Coordinating Council recently identified the issues of health care disparities, service needs, and access to care as priorities.²⁵ Access to affordable care and required services are a crucial element of an effective, comprehensive, system of care.

Many health care professionals do not feel confident treating individuals with autism, particularly youth and adults. Medical and behavioral services are very limited for Tennesseans with Autism who are adolescent or older.²⁶ Health care professionals need ongoing training and support to develop and improve their ability to serve individuals with ASD. This includes both pre-service training and continuing education opportunities.

APPLIED BEHAVIOR ANALYSIS

For many individuals with ASD, Applied Behavior Analysis (ABA) and other behavioral supports are among the health care services needed, but unavailable.

"The effectiveness of ABA-based intervention in ASD has been well documented through five decades of research by using single-subject methodology and in controlled studies of comprehensive early intensive behavioral intervention programs in university and community settings. According to the [American Academy of Pediatrics], children who receive early intensive

behavioral treatment have been shown to make substantial, sustained gains in IQ, language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups."²⁷

Unfortunately, the 2012 Family Survey identified that ABA or behavioral support services are often not implemented.¹⁷ Families often cited their lack of availability as the reason. This was universal to all regions of the state, but families in rural areas had even less access to behavior supports.¹⁷

LONG-TERM SUPPORTS AND SERVICES

While great strides have been made in diagnosing ASD and addressing its impact on children and even young adults, long term supports and services remain lacking. This is true for both children and adults. Some individuals with Autism require life-long supports and services at home and in the community to achieve safe, healthy, and productive lives.

The Tennessee Department of Intellectual and Developmental Disabilities (DIDD) is the state agency charged with planning, developing, and implementing long-term supports and services for individuals with intellectual and developmental disabilities. However, at this time, the department only serves Tennesseans with intellectual disabilities. There are over 7,000 individuals on the waiting list for these services.

Planning, developing, and implementing services for Tennesseans with other developmental disabilities like ASD became a responsibility of the department in 2001. Despite this change to the law, no funding has been allocated, and no new services have been developed. A 2007 report of a Developmental Disabilities Task Force, established by the TN General Assembly, recommended expanding the Family Support Program, establishing a Medicaid Home- and Community-Based Services Waiver, and establishing a personal assistance program for those with developmental disabilities including ASD.

FAMILY SUPPORT PROGRAM

The Tennessee Family Support Program is a flexible, family-friendly program that supports Tennesseans with all types of severe disabilities including ASD to live in their own homes and communities. Family Support is a very cost-effective program that helps to prevent many people from needing more expensive programs. The program serves approximately 4,500 individuals and families. Approximately 3,000 families are on the waiting list. Operated by DIDD with a maximum allocation of \$4000 and an average allocation of \$1600, this is a supplemental, rather than a long term service, but nonetheless, is an important support for families who are able to access it.

Tennessee needs a more robust system of long term supports and services. The focus should be on a service array that is community-based, person-centered, and flexible enough to provide supports in the context of an individual's life situation. In effect, a system that builds on and strengthens natural supports in the family and community.

EXISTING AND EMERGING MODELS

INSURANCE COVERAGE FOR APPLIED BEHAVIOR ANALYSIS (ABA)

Adequate insurance coverage is the centerpiece of any discussion on healthcare financing options for individuals with ASD. Most private insurance in Tennessee does not cover ABA or does not cover it at sufficient levels. The recommended amount of Applied Behavior Analysis (ABA) varies according to individual needs. However, Behavior Analyst Certification Board Guidelines suggest that comprehensive ABA requires between 26-40 hours per week.²⁸

"Although the recommended number of hours of therapy may seem arduous to some parents of young children, it should be noted that time spent away from therapy may move children even farther away from desired normal developmental trajectories. Such delays will likely result in increased costs and greater dependence on more intensive services across their life span."²⁸

The District of Columbia and 35 states have implemented insurance mandates that specifically require insurers to cover treatments for ASD. Stakeholders in Tennessee, led by families, have been working to expand insurance coverage for ABA in Tennessee.

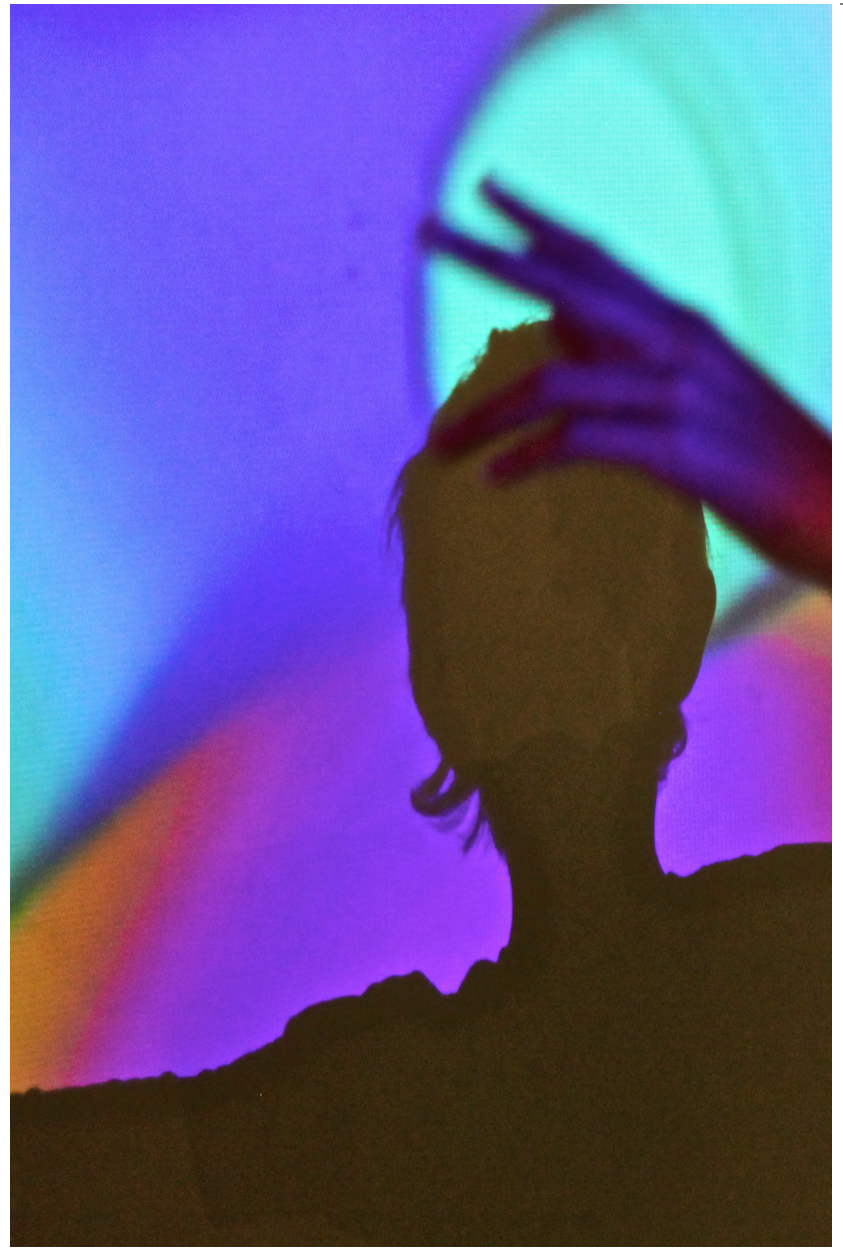


TENNESSEE APPLIED BEHAVIOR ANALYSIS LICENSURE

Over the past 10 years, the field of applied behavior analysis (ABA) has experienced extraordinary growth. More individuals and families are seeking ABA and the number of available practitioners has jumped as well. It is critical that all those who provide behavioral supports and ABA are qualified to do so.

In order to protect consumers, the Tennessee General Assembly passed a law to create a process of licensing ABA practitioners. This will result in the requirement that only those licensed

by the state board can advertise themselves to the public as "applied behavior analysts." The law also provides services definitions for the "scope of practice" of licensed applied behavior analysts.



RECOMMENDATIONS

Expand ongoing training and support for health care practitioners to develop and improve their ability to serve individuals with ASD.

Develop a flexible program of home and community-based long term supports and services for individuals with ASD.

Expand access to comprehensive Applied Behavior Analysis needed through insurance reform.

Respond to rapidly changing best practices and emerging knowledge and incorporate evidence-based practices.



This world is not ready to welcome my son.
A son who will one day outlive me.
A son whom I fear will not, if needed,
be cared for by those with good hearts
and a desire to allow him as much
independence as he is able.
~Mother of a young adult with ASD

AGING AND ADULTHOOD

ASD is a lifelong condition.



The majority of a person's life is spent in adulthood. Preparing for adulthood and transitioning to adult life are just the beginning. Challenges remain. Opportunities for skill development, employment, self-advocacy, social networking, and needed supports must be made available. The desired outcome is a life of one's choosing, rooted in interdependence, meaningful contributions, and inclusion.

Transition and adult services are areas where collaboration between private businesses and public partners can pro-

duce innovative ways to maximize the unique potential of each individual with ASD. To be successful, policies, systems and services need to be coordinated. They must support early planning with youth and families for the transition from youth to adulthood.

Research shows that this transition process is especially difficult for youth with Autism Spectrum Disorders. Services are much more available for children and youth than for adults with ASD. Data from the Family Survey affirmed that parents and adults often

feel they "have been dropped off a cliff" once an individual reaches adulthood.¹⁶

EDUCATION

Transition planning with the student's IEP Team must begin at age fourteen, if not before. It should involve the student, all caregivers, and a representative from each of the service providers who will have a role in this student's transition. This may or may not include vocational rehabilitation but must include parents and/or family members closest to the student. Students should be provided

with information about options for self-directing their IEP and resources to take as large a role as possible in directing their transition planning process.

Before leaving the education system, schools must prepare students with ASD with the basic skills required for work or for additional education or training. All students should receive information about employment options and have access to career counseling and specific skill-building programs. Co-op and work-based learning programs should be also be available to all students with ASD.

Education and post-secondary education needs to be strengthened. Expanded public/private partnerships with employers in the community may be an effective way to address skills and job-readiness. Students should have the opportunity to learn career skills in professional settings outside

the classroom.

Vocational Rehabilitation Services in the state of Tennessee are offered through the Department of Human Services. It is positioned to serve young adults throughout the transition process but lacks capacity to meet the growing demand.

Individuals with ASD need access to the support, accommodations, and tools they need to be successful in the classroom and workplace.

HEALTH CARE

Families and youth need support and guidance from health care providers to make the challenging switch from pediatric to adult practitioners. This includes helping transfer as much health care decision-making as possible to the individual.

Behavioral and mental health resources

that meet the needs of adults with ASD are often difficult to access, and adult health professionals may not have the training and supports they need to provide services. A system of care must build capacity to support the population of new adult patients with special needs relative to their diagnosis of ASD.

Interactions in the community, particularly with law enforcement officers and other first responders, were a topic of interest during each Community Conversation. A number of disturbing incidents could have been avoided had proper understanding of the manifestation of ASD been more widespread.





SELF-ADVOCACY

Self-advocacy is an important skill set for all adults, and one that must be specifically fostered in children and youth with ASD. Peer groups, advocacy groups, and supplemental education and independent living skills classes should be available to every student with ASD.

LONG TERM SUPPORTS AND SERVICES

Successful community living for many adults with ASD requires long term supports and services. Lack of services and supports in Tennessee is a significant problem. Currently, there are no home- and community-based waiver supports for

individuals with ASD who have IQs over 70, and a waiting list of nearly 7000 for individuals with IQs under 70.

EMPLOYMENT

PUBLIC-PRIVATE PARTNERSHIPS

In 2011, Walgreens, the nation's largest drugstore chain, launched their Retail Employees with Disabilities Initiative (REDI) to help create more job opportunities for Americans with disabilities. The program trains candidates on the work and retail skills needed to serve in positions at Walgreens and has hired hundreds of successful trainees.

Project SEARCH High School Transition Program is a one year school-to-work program that immerses the student in the workplace and provides training. This program was developed at Cincinnati Children's Hospital Medical Center and has been adapted to sites across the country.

Project Opportunity at Monroe Carell Jr. Children's Hospital at Vanderbilt was based on the Project SEARCH model. This program provides tuition-free job training and employment opportunities within Vanderbilt. Candidates are youths with disabilities, including ASD, who qualify for State Vocational Rehabilitation Services.

TENNESSEEWORKS PARTNERSHIP

TennesseeWorks is a collaboration of agencies and organizations working together to improve employment outcomes for young people with disabilities. The Vanderbilt Kennedy Center serves as the administrative lead for the grant. Parent support organizations, disability nonprofits, employment-related agencies, and state partners include the Departments of Education, Intellectual and Developmental Disabilities, Health, Human Services Division of Rehabilitation Services, Labor and Workforce Development, and the TN Council on Developmental Disabilities, and TN Higher Education Commission.

The goals of TennesseeWorks are system-wide and include raising expectations for employment outcomes of individuals with disabilities (including ASD), strengthening transition planning, and educating the job candidate and employer community about the bene-

fits of working and hiring people with disabilities.

FAMILY AND CONSUMER ORGANIZATIONS

Family and consumer-based organizations are the leading providers of advocacy training for parents and individuals with disabilities. Statewide examples include Support and Training for Exceptional Parents (STEP, inc.) which offers workshops to empower individuals and families to make educational decisions. They also provide one-on-one assistance and training for students in transition about their options for adult services. Family Voices of Tennessee also works to support parents and students as they navigate their health care and educational transition process to adulthood.

Six Centers for Independent Living across the state of Tennessee may serve as a resource for youth and adults

with ASD for advocacy, peer support, and independent living skills training.

The Tennessee Council on Developmental Disabilities offers a free leadership and advocacy training program for adults with disabilities and family members called Partners in Policymaking.

FIRST RESPONDERS

The Tennessee Department of Mental Health is developing a training program for Law Enforcement Personnel. They requested resources from the Tennessee Autism Summit Team and Autism Tennessee to incorporate information about ASD and how to serve an individual on the spectrum in an emergency. Adapting and implementing this training model for all first response agencies could begin to meet the needs of the professional and the individual on the spectrum.



RECOMMENDATIONS





Align policies, systems and services to support early planning with youth and families for the transition from youth to adulthood.

Empower individuals across the spectrum to take responsibility to make and implement their life choices.

Provide access to the tools, supports and accommodations needed for independence, productivity and community life.

Train all first responders and emergency personnel to interact and support individuals with ASD.

MOVING AHEAD



Autism is a complex disorder that has a crosscutting impact on the people and public policy of our state.

National data depict the explosive growth of ASD and data gathered in Tennessee have identified the critical mass that the system and our community is facing. We need new action to address the emergent needs of individuals, families and service providers affected by ASD.

Tennessee has the building blocks for an effective system of care and the Autism Summit Team recommends that our state government establish an interagency team to coordinate them. Dedicating the financing, staff time and expertise to a formal team would move ahead the implementation process by leaps and bounds. This team would be positioned to lead the development of a comprehensive, coordinated system of care for children and youth with ASD.

Serving as the focal point of statewide efforts, this team could develop cohesive recommendations for the Administration and the Tennessee General Assembly as they address the epidemic of Autism.

The team would be responsible for setting milestones and timelines for the planning process and overseeing progress toward those goals.

As the system of care grows, the team could coordinate state agencies, universities, non-profits and service providers to improve community access to information and resources.

We must build our state's capacity to support the new and the aging generation of individuals with ASD so that they may live quality, independent and productive lives alongside their peers. The Tennessee Autism Summit Team is committed to this effort and our strongest recommendation is that an interagency team in state government lead us on from here.



APPENDIX A

1. Autism Summit Team Membership [See Appendix B]
2. In response to a legislative inquiry, the Tennessee Comptroller of the Treasury, Offices of Research and Education Accountability (OREA) authored three reports about public services for infants, children, and youth with autism in the state. Published between 2009-2012, the series was divided into public policy areas directly connected to autism services (i.e., data collection, education, and healthcare services). Part 1 includes an overview of autism as a disability and associated laws, and a review of autism data collection and prevalence estimates. Part 2 includes an overview of the special education process and associated laws, and includes approaches being taken by Tennessee and other states to prepare teachers and school staff to educate children with autism. Part 3 covers issues related to state and federal health-related programs and laws that intersect with the state and federal special education programs in Tennessee. These include federal laws, funding mechanisms, and treatments. This series may be accessed at: <http://www.comptroller.tn.gov/orea/PublicationDetails.aspx?ReportKey=e7d186c5-aaa3-4616-8328-43ef1a917741>
3. The State of Tennessee. 105th General Assembly. Tennessee Public Chapter 1062. Nashville: 2008. Web.
4. Hammett, Leisa A., Pope, Rebekah. From Heartache to Hope. Nashville: Fields Publishing, Inc., 2009. Print.
5. Division of Birth Defects, National Center on Birth Defects and Developmental Disabilities, "Screening and Diagnosis." Autism Spectrum Disorder (ASD). Centers for Disease Control and Prevention. 2014.
6. Moran, John S., Casey, Christine G., Rutledge, Teresa F., et al. "Prevalence of Autism Spectrum Disorder Among Children aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010." Centers for Disease Control and Prevention Morbidity and Mortality Weekly Report Surveillance Summaries 63.2 (2014): 1-21. Web.
7. Tennessee Office of the Comptroller of the Treasury. Offices of Research and Education Accountability. Autism in Tennessee: Part 1 – An Introduction to Issues and Data Collection Methods. Woodson, Joseph. Nashville: Oct 2009. Web.
8. Tennessee Department of Education. Department of Special Education. Report by the State of Tennessee in accordance with Section 618 of IDEA to U.S. Department of Education, Office of Special Education Programs. Nashville: 2013. Web.
9. Lutenbacher, Melanie. "2006-2007 Tennessee Statewide Survey of Families with CYSHCN." Tennessee Family-to-Family Health Information Center. Nashville: 2007. Print.
10. Lavelle Tara A., Weinstein Milton C., Newhouse Joseph P., et al. "Economic burden of childhood autism spectrum disorders." Pediatrics 133.3 (2014). Web.
11. Shimabukuro, T., Grosse S., Rice C. "Medical Expenditures for children with an autism spectrum disorder in a privately insured population." Journal of Autism and Developmental Disorders 38.3 (2008). Web.
12. United States Department of Education. National Center for Special Education Research. Wave 3 parent interview and youth interview/survey. National Longitudinal Transition Study-2 (NLTS2). Washington: 2012. Web.
13. Tennessee Office of the Comptroller of the Treasury. Offices of Research and Education Accountability. Autism in Tennessee: Part 2 – Education. Woodson, Joseph. Nashville: Dec 2010. Web.
14. The Individuals with Disabilities Education Act (IDEA) is the United States federal law governing how states serve the early intervention and special education needs of children with disabilities. IDEA also guarantees a Free Appropriate Public Education (FAPE) for students with disabilities in the least restrictive environment (LRE).
15. Trainor, Audrey A., Carter, Erik W., Swedeen, Beth, Pickett, Kelly. "Community Conversations: An approach for expanding and connecting opportunities for employment for adolescents with disabilities." Career Development and Transition for Exceptional Individuals 35.1 (2012): 50-60. Sage Journals. Web.
16. Bradfield, Cory. "Community Conversations: Utilizing the World Cafe Method to Assess the State of ASD Care in Tennessee." Tennessee Disability Coalition. 2012. Print.

17. Hodapp, Robert M., Mello, Maria., Goldman, Samantha E., Urbano, Richard C. "Toward Coordinated Services for Tennessee's Children with Autism Spectrum Disorders: A Report to Tennessee's Autism Summit Team." Vanderbilt Kennedy Center. 2012. Print.
18. The Modified Checklist for Autism in Toddlers-Revised (M-CHAT-R) is a scientifically validated tool for screening children between 16 and 30 months of age for symptoms of Autism Spectrum Disorder. To improve the accuracy of the M-CHAT-R, the authors developed a structured M-CHAT-R Follow-up Interview with questions. The Screening Tool for Autism in Toddlers and Young Children (STAT) is an empirically derived, interactive measure developed for screening children between 24 and 36 months of age for symptoms of Autism Spectrum Disorder. These are just two of the standardized screening tools that are considered effective by the medical community. Screening tools do not provide a diagnosis, but help to determine whether additional investigation and a diagnostic evaluation by clinicians with expertise in developmental pediatrics is necessary.
19. Nielson, Marci. "Defining the Medical Home." Patient-Centered Primary Care Collaborative. 2013. Web.
20. The U.S. Department of Health and Human Services is the lead agency for the "Healthy People" initiative. For the past 30 years, Healthy People has been committed to improving the quality of our Nation's health by producing a framework for public health prevention priorities and actions. Healthy People 2020 represents the nation's new 10-year goals and objectives for health promotion and disease prevention. Topic areas for improvement include "Access to Services" and "Disability and Health." Accessed at: <http://www.healthypeople.gov/2020/topics-objectives/2020-Topics-and-Objectives-Objectives-A-Z>
21. Murphy, Nancy A., Carbone, Paul S., Council on Children with Disabilities, "Parent-Provider-Community Partnerships: Optimizing Outcomes for Children with Disabilities." Pediatrics 128.4 (2011): Web.
22. Gilman, Patricia. *The Anti-Romantic Child: A Memoir of Unexpected Joy*. New York: Harper Perennial, 2011. Print.
23. Response to Intervention (RTI) is a method used to provide early, systematic assistance to children who are having difficulty learning. It is a multi-tier approach intended to match student need and modify based on progress. RTI was included in the 2006 Office of Special Education and Rehabilitative Services Regulations intended to assist states with implementation of the Individuals with Disabilities Education Act (IDEA).
24. World Health Assembly. World Health Organization. Preamble to the Constitution of the World Health Organization. International Health Conference. New York: 22 June 1946. Web.
25. Dawson, Geraldine. "IACC Tackles Health Disparities and Access to Care." Autism Speaks. 1 Feb 2013. Web.
26. Vahabzadeh, Arshya. "Minority Children with Autism Lack Access to Specialists." CNN. 17 June 2013. Web.
27. Tennessee Office of the Comptroller of the Treasury. Offices of Research and Education Accountability. Autism in Tennessee: Part 3 – Health. Wright, Doug. Nashville: May 2012. Web.
28. "Guidelines: Health Plan Coverage of Applied Behavior Analysis Treatment for Autism Spectrum Disorder." Behavior Analyst Certification Board, Inc., 2012. Web.

APPENDIX B



The Tennessee Autism Summit Team began in 2009 with the leadership of the Tennessee Boling Center on Developmental Disabilities and the Vanderbilt Kennedy Center.

As of 2017, the Team is co-chaired by Toni Whitaker, M.D., and Tyler Reimschisel, M.D. The following is a current list of Team members.

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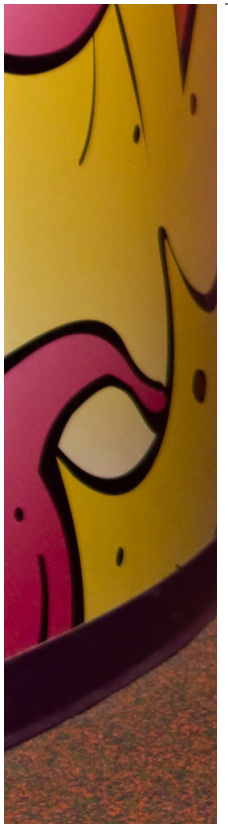
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The recommendations made herein represent years of work collating experiences and expertise. Yet we sincerely hope they are only the beginning.