

Show-Me State Plan

FOR AUTISM SPECTRUM DISORDERS

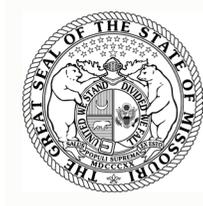


PRESENTED BY

Missouri Commission on
Autism Spectrum Disorders

JEREMIAH W. (JAY) NIXON
GOVERNOR

KEITH SCHAFFER, Ed.D.
DIRECTOR



MARK STRINGER
Director
DIVISION OF ALCOHOL AND DRUG ABUSE
(573) 751-4942
(573) 751-7814 FAX

MARK STRINGER
ACTING DIRECTOR
DIVISION OF COMPREHENSIVE
PSYCHIATRIC SERVICES
(573) 751-8017
(573) 751-7815 FAX

BERNARD SIMONS
DIRECTOR
DIVISION OF DEVELOPMENTAL DISABILITIES
(573) 751-4054
(573) 751-9207 FAX

STATE OF MISSOURI
DEPARTMENT OF MENTAL HEALTH

1706 EAST ELM STREET
P.O. BOX 687
JEFFERSON CITY, MISSOURI 65102
(573) 751-4122
(573) 751-8224 FAX
www.dmh.mo.gov

June 2011

Dear Stakeholder:

Senate Bill 768 was signed into law on June 23, 2008, creating the Missouri Commission on Autism Spectrum Disorders and the Office of Autism Services to be housed within the Department of Mental Health and the Division of Developmental Disabilities, respectively (633.200, 633.225 RSMo).

Charged with making "recommendations for developing a comprehensive statewide plan for an integrated system of training, treatment, and services for individuals of all ages with autism spectrum disorder," the commission has displayed unwavering commitment to fulfill that charge in the ensuing months.

I am pleased to present the approved Show-Me State Plan, a cornerstone in the completion of that charge, and wish to express my heartfelt gratitude for the selflessness displayed by the individuals, both present and past, serving on this body. The plan represents countless volunteer hours of collaboration, all with the overarching goal of serving the public trust.

The adoption of this plan serves as an important milestone in Missouri's journey toward an integrated system of care for individuals with autism spectrum disorders and their families.

Sincerely,

A handwritten signature in black ink, appearing to read "Bernard Simons".

Bernard Simons
Chair, Missouri Commission on Autism Spectrum Disorders
Director, Division of Developmental Disabilities

Show-Me

Acknowledgments

There is a long and luminous list of entities and individuals who deserve recognition for their tireless efforts to support and craft recommendations for a “comprehensive statewide plan for an integrated system of training, treatment, and services for individuals of all ages with autism spectrum disorders” (633.220 RSMo).

This document presents recurrent themes – challenges faced on both the national and state level as well as efforts that demonstrate progress toward those challenges. Always at the core of articulating those challenges and advocating for progress have been families who know far better than clinicians, educators, providers, and policymakers the reality of providing for their loved ones with autism spectrum disorders (ASDs). Throughout the following narrative, it is evident that families were the first to seek autism-specific services for their family members due to the complexity of their needs. Families urged legislators to convene panels to carefully consider the services Missouri offers across systems as well as the gaps that exist both within and across them. Families gave voice to their challenges and appeared at the State Capitol to convey their messages firsthand. The results of their efforts are detailed in the following pages, but it is important here to acknowledge their endeavors and thank them for the energy and perseverance they have displayed throughout the years. With that in mind, we dedicate this volume to them in hopes of advancing better outcomes for individuals with autism spectrum disorders and their families.

Another feature of this document is a sense of acceleration in advocacy and focus toward improving Missouri’s system of care. The Missouri Planning Council supported the earliest record of recommendations for a coordinated state plan, and we are grateful to have that foundational document to inform and guide present processes. Additionally, Missouri’s Autism Projects’ Parent Advisory Committees along with the Missouri Parent Advisory Committee on Autism have, for many years, been the “boots on the ground” in advocating for ASD-specific services, and we acknowledge their selfless

devotion to that cause long before the creation of the Blue Ribbon Panel on Autism or the Commission on Autism Spectrum Disorders. Missouri’s Autism Centers have contributed immensely to reducing the length of time individuals remain on wait lists for diagnostic evaluations and have been standard bearers in statewide public outreach and training efforts. Public-private partnerships, such as those with the Thompson Foundation for Autism, have fostered best practice collaboration while relationships with community service providers have promoted ASD-specific services. Important relationships between state departments provide key supports to individuals with autism spectrum disorders, notably the Medicaid Waivers that are administered by the MO HealthNet Division (MHD) of the Department of Social Services (DSS) and operated by the Division of Developmental Disabilities (DDD) in the Department of Mental Health (DMH).

Finally, we must acknowledge, amid unprecedented budget concerns, landmark ASD insurance legislation, known as House Bill 1311, passed in the 2010 legislative session and the result of the bipartisan, bicameral sponsorship of Representatives Dwight Scharnhorst and Jeff Grisamore and Senators Scott Rupp and Eric Schmitt. Missouri counts itself fortunate to have had the unwavering and vocal support of Gov. Jeremiah W. (Jay) Nixon and representatives and senators from both sides of the aisle who were instrumental in the bill’s sponsorship and eventual passage. We acknowledge the work of the full commission and especially thank the subcommittee chairs for their generous donation of time and expertise. Last, the Office of Autism Services provided invaluable technical assistance and support throughout the process of drafting a state plan.

We look forward to implementing and monitoring these recommendations and thank all, present and past, who have helped advance the concepts of self-determination, community integration, and independence for individuals with autism spectrum disorders and their families.

State Pla

Executive Summary

IN 2008, THE MISSOURI GENERAL ASSEMBLY PASSED INTO LAW Senate Bill 768, creating the Commission on Autism Spectrum Disorders and the Office of Autism Services to be housed within the Division of Developmental Disabilities in the Department of Mental Health. This legislation followed the December 2007 publication of the Blue Ribbon Panel on Autism report, which distilled over 60 hours of testimony from stakeholders in five cities along with written testimony from those who were unable to participate in person. Charged with “determining the state of autism in Missouri, including services, teaching, training, and research and making recommendations to improve the quality of life throughout the lifespan of individuals with ASD and their families,” the panel released 36 recommendations, the first of which was to create a commission which, in turn, would be responsible for “making recommendations for developing a comprehensive state plan that would consistently focus Missouri on the priorities and means for enhancing resources required to provide the full complement of ASD services necessary in the state.”

The Commission first met in October 2008 and has met regularly thereafter to fulfill its statutory obligation – to make recommendations for a state plan. The Show-Me State Plan on Autism Spectrum Disorders has evolved thoughtfully and organically, with the Commission dividing itself into subcommittees organized around the topics of education, healthcare, individual and family supports, and workforce development. These subcommittees met in person and via teleconference and accessed professional expertise beyond the Commission proper. The Show-Me State Plan has been revised three times, once with feedback and commentary from the full commission and the Missouri Parent Advisory Committee on Autism and once with feedback and commentary from the public at large. It has received consensus approval by the Commission and, per statute, been forwarded to Gov. Jeremiah W. (Jay) Nixon, the general assembly, and relevant state agencies. The pages that follow provide fuller context around the history of ASDs in Missouri and the work of the subcommittees. The specific recommendations are listed below:

Education Subcommittee Recommendations

1. To conduct an assessment of the need for coordinated, enhanced, and targeted special education capabilities within each region of the state
2. To develop a recommendation for enlisting appropriate universities and colleges to ensure support and collaboration in developing certification or degree programs for students specializing in ASD intervention
3. To provide recommendations regarding training programs and the content of training programs being developed to ensure a variety of training opportunities that reflect the application of best practice and standards of care for individuals with ASDs
4. To participate in recommending a panel of qualified professionals and experts to review evidence-based educational practices for adaptation specific to Missouri

Healthcare Subcommittee Recommendations

1. To determine the need for creation of additional centers of diagnostic excellence
2. To develop recommendations for expanding services with hospitals after review of specialty clinic/hospitals and inpatient care
3. To recommend individuals to participate in a committee charged with developing screening, diagnostic, assessment, and treatment standards for Missouri
4. To examine information barriers to accurate information of reporting ASD prevalence across the state and recommend a process for accurate reporting

Individual and Family Supports Subcommittee Recommendations

1. To evaluate the strengths and weaknesses of regional service areas throughout Missouri of support provided to children and adults with ASDs and their families within their homes and communities and assess ways to expand access to behavior intervention capabilities in both urban and rural regions {633.200(1)(b) RSMo}
2. To expand the availability of and access to information regarding services and support for individuals with ASDs throughout the lifespan. This would include individualized assistance in navigating the system of care.
3. To develop autism-specific training programs across the state agencies, enhancing existing training programs as practicable and, in addition, ensuring that training is made available to families and direct support professionals
4. To develop a statewide service delivery plan specifically addressing the needs for specialized services for adults with ASDs. This plan will address work, housing, transportation, community integration, eldercare, and other needs as identified and shall include strategies for implementation.

Workforce Development Subcommittee Recommendations

1. To develop more effective and consistent collaboration at the state, regional, and local levels to improve statewide capacity to employ individuals with ASDs
2. To develop and implement practical and credible education and training at the state, regional, and local levels to improve statewide capacity to employ individuals with ASDs
3. To develop and disseminate practical and credible resources at the state, regional, and local levels to improve statewide capacity to employ individuals with ASDs
4. To establish integrated data systems among public and private stakeholders to track employment data and employment outcomes for individuals with ASDs

Autism Spec

Missouri Commission on Autism Spectrum Disorders

ROSTER OF COMMISSIONERS

Department of Mental Health Appointee

Keith Schafer, EdD, Director

Designee

Bernard Simons, Commission Chair
Director, Division of Developmental
Disabilities

Department of Elementary and Secondary Education Appointee

Chris Nicastro, PhD, Commissioner

Designee

Stephen Barr, EdD, Assistant
Commissioner, Office of Special Education

Department of Health and Senior Services Appointee

Margaret T. Donnelly, Director

Designee

Gary Harbison, MA, LPC, NBCC, ACMHA,
Chief, Bureau of Special Health Care Needs

Department of Public Safety Appointee

John Britt, Director

Designee

Vicky Scott, MEd, Program Manager

Department of Higher Education Appointee

David Russell, PhD, Commissioner

Designee

Bridget Johnston, MPA, Research
Associate

Department of Social Services Appointee

Ronald J. Levy, Director

Designee

Julie Creach, Interim Deputy Division
Director, Operations

Department of Insurance, Financial Institutions, and Professional Registration Appointee

John Huff, Director

Designee

Molly White, MHA, Insurance Regulatory
Manager, Life and Healthcare Section

Institution of Higher Learning Appointees

Connie L. Hébert, MS

Southeast Missouri State University
Autism Center for Diagnosis and
Treatment

Janet E. Farmer, PhD, ABPP

MU Thompson Center for Autism and
Neurodevelopmental Disorders

Director of Special Education Appointee

Phyllis Wolfram, MS

Director of Special Services,
Ozark School District

Speech Language Pathologist Appointee

Vacant

Diagnostician Appointee

John F. Mantovani, MD

St. John's Mercy Children's Hospital and Child
Development Center

Primary Care Physician Appointee

Michele G. Kilo, MD

Children's Mercy Hospitals and Clinics

Mental Health Provider Appointee

Paula F. Baker, MS

Ozark Center for Autism

Private Provider/Non-Profit Appointee

Rebecca Blackwell, MA, BCBA

Judevine Center for Autism

Parent of Individual Under 18 Appointee

Lee Bascom, MSW, LCSW

Parent of Individual Over 18 Appointee

David Crowe, DDS

Individuals with ASD Appointees

Jean-Paul Bovee, MA, MALS

Tiffany Daniels

County Board Appointee

Vicki McCarrell, MA, Executive Director

Unlimited Opportunities, Inc.

Legislative Appointees

Honorable Scott T. Rupp

Senate Majority

Vacant

Senate Minority

Honorable Dwight Scharnhorst

House Majority

Honorable Sara Lampe

House Minority

Department & Division Staff

Julia LePage, MS, BCBA

Director, Office of Autism Services

Division of Developmental Disabilities

Kit Glover, MEd

Coordinator, Office of Autism Services

Division of Developmental Disabilities

Monica Hoy

Assistant to the Director

Department of Mental Health

Katherine Pigg

Project Specialist, Office of Autism

Services, Division of Developmental

Disabilities

Dana Opie

Office Support, Office of Autism Services

Division of Developmental Disabilities

Anita Contreras

District Administrator

Division of Developmental Disabilities

Teresa Rodgers, PhD, BCBA

Chief Behavior Analyst

Division of Developmental Disabilities

Nancy Nickolaus, MSW, LCSW

Director of Employment and Training

Division of Developmental Disabilities

Robin Rust, MPA

Director of Federal Programs

Division of Developmental Disabilities

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The History of Autism Spectrum Disorders in Missouri

THE FOLLOWING PAGES REFLECT THE WORK of the Missouri Commission on Autism Spectrum Disorders and its response to the statutory purpose of making “recommendations for developing a comprehensive statewide plan for an integrated system of training, treatment, and services for individuals of all ages with autism spectrum disorders” (633.220 RSMo).

Relevant to a discussion of state plan recommendations is Missouri’s history of organized efforts to focus public attention, policy, and services on individuals with autism spectrum disorders (ASDs). In the late 1980s, Missouri families undertook a grassroots campaign aimed at obtaining services designed to address the complex needs of families and their loved ones with ASDs, especially in rural areas where access to specialized services was virtually nonexistent. The result of efforts led by then Sen. Roger Wilson, Alan Baumgartner, George Woodward, former First Lady Betty Hearnes, and others is a current budgetary allocation of over \$5.5 million that provides for family-centered services through providers recommended by parent committees representing five geographical areas known as “Missouri Autism Projects.” Additionally, the Council on State Governments featured the Missouri Autism Projects in its June 1996 issue of *State Innovations Briefs: New and Best Practices in State Government*. Three of the five Missouri Autism Projects encompass the majority of rural Missouri, and initially the Judevine Center, under the direction of Lois J. Blackwell, was selected to provide parent training and support services to families in those counties. In 2009, the Missouri Autism Projects were codified in Missouri Statute with the passage of Senate Bill 157, sponsored by Sen. Eric Schmitt.

The Missouri Department of Elementary and Secondary Education (DESE) introduced ASD-specific professional development by creating Project ACCESS in 1985. Contracted through DESE, Project ACCESS is operated by Missouri State University in Springfield and provides two levels of training designed for educators and para-educators as well as consultation to help school districts serve students with ASDs.

As the Missouri Autism Projects’ momentum grew beginning in the 1990s and throughout the next two decades, the first state plan for autism was published in 1990. Funded by the Missouri Planning Council, this booklet, entitled *Autism in Missouri: Bridging the Gaps – A State Plan for Autism*, was perhaps the first scholarly attempt to document not only the complexities of the needs of individuals with ASDs but also the multi-systemic nature of the institutions providing services to those individuals, including medical, educational, and community services. The plan included a literature review, provided a national profile, identified model programs, and utilized a family-needs survey. The section devoted to recommendations was structured around fifteen components, each with additional subcomponents. Some of the recommendations relate to concerns brought forth during subsequent ASD-specific activities, e.g., the Missouri Autism Research and Response Agenda (MARRA) and the Blue Ribbon Panel on Autism, while other recommendations were acted upon and served to provide baseline programmatic information as other initiatives emerged.

At about the same time that families’ grassroots efforts helped establish the Missouri Autism Projects, the Division of Developmental Disabilities (DDD) provided funding for the Center for the Evaluation of Children with Autism Disorders at Children’s Hospital at the University of

Missouri (MU) Hospital and Clinics, located on the University of Missouri's flagship campus in Columbia. Beginning in 1991 with a modest \$50,000, the program supported both multidisciplinary diagnostic services for Missouri children and a genetic research corollary focused on identifying subtypes of ASDs in order to individualize treatment and improve outcomes. This program was developed by Judith Miles, MD, PhD, and is known today as the Autism Medical Clinic, housed within the MU Thompson Center for Autism and Neurodevelopmental Disorders (MU Thompson Center).

Throughout the 1990s, as services under the Missouri Autism Projects were refined and expanded, Missouri also hosted annual national Autism Symposia. From 1992 until 2005, these symposia were convened at various locations throughout the state and featured keynote speakers such as Ami Klin, Tony Atwood, Bernard Rimland, Margaret Bauman, and Temple Grandin. Grandin attended on three occasions and her commitment to Missouri continues to this day as evidenced by her October 2010 presentation at the University of Missouri-Columbia, co-sponsored by the MU Thompson Center's Exceptional Achievement Series.

In 2002, a different symposium was held in Jefferson City to address the state's need for direction in developing public policy to address more comprehensively and appropriately the needs of children with ASDs, their families, and the agencies that provide services. Symposium participants represented the medical and educational communities, legislators, civil servants, and family members and were urged by audience members to move Missouri forward by focusing on collaborative research efforts and coordinated dissemination of information regarding existing and future services throughout the state.

In 2003, the Missouri Educational and Public Policy Symposium on Autism presented *The Missouri Autism Research Agenda (MARA)*. This document chronicled the work of the Symposium Planning Team Task Force participants who met with over 50 parents, family members, state agency staff, educators, providers, and Department Mental Health Commission members at the conclusion of the National Autism Symposium held in Springfield, MO, in April 2003. The stated purpose of *MARA* was to "establish a cohesive, integrated research agenda that will positively affect the lives of people with autism spectrum disorders (ASDs) and their families." Central to the challenge of meeting that goal was the fragmented nature of databases that housed information specific to individuals with ASDs. *MARA* identified 15 databases that housed information about children and families affected by ASDs in Missouri and concluded that there was a strong need for a collaborative statewide database with research-related information about all of the children in the state whose families were willing to participate.¹ Parents participating in this initiative urged the panel to rename this initiative the Missouri Autism Research and Response Agenda (MARRA) to reflect the breadth and depth of the information reviewed and to emphasize the need for a response to the needs identified. That suggestion was adopted.

In 2004, the University of Missouri-Columbia was awarded a 1-year planning grant to facilitate the development of the Missouri Autism Project (MAP) Registry with the following statement of purpose:

The Missouri Autism Project Registry will make available a comprehensive, online information resource: (a) to facilitate research that will improve the outcomes of Missouri children and adults with autism spectrum disorders; (b) to direct Missouri state policies and service decisions; and (c) to provide the added benefit of supportive relevant autism information for families, health care providers and educators that will attract users to the site.

A document titled *Missouri Autism Project Registry: Final Project Report and Recommendations* was released in June 2005 and provided an overview of the history of the ASD research agenda in Missouri along with more elaborate discussion around a voluntary registry, a data warehouse, the research process, and other legal, technical, and implementation points.² This document formed the basis for a partnership with the Interactive Autism Network (IAN) to develop StateStats in 2008 (see below).

In 2006, the Kennedy Krieger Institute at Johns Hopkins Medical School in Baltimore and the advocacy and funding organization Autism Speaks partnered to develop the Interactive Autism Network (IAN; Paul Law, MD, PI), a voluntary web-based project designed to connect researchers, clinicians, and families to foster collaboration for the purpose of advancing the understanding of ASDs. Subsequently, MU Thompson Center researchers and DDD staff obtained funding from DDD's Real Choices Systems Transformation Grant and partnered with IAN to establish the StateStats link on the website. This site provides a method of obtaining state-specific data for comparative purposes in order to facilitate research, foster evidence-based treatment, and provide family supports.

Also in 2006, the Central Missouri Rapid Response Initiative was launched. Supported through DDD funding, Janet Farmer, PhD, ABPP, Director of Academic Programs of the MU Thompson Center, chairs this group. The initiative has representative membership from MU professionals, child-serving state agencies, local school districts, community provider agencies, and parents of individuals with ASDs. Currently, the stated goals of this initiative are 1) to increase the number of children who are routinely screened for ASDs; 2) to improve access to timely and accurate diagnosis for individuals at risk for ASDs; 3) to improve access to timely and effective interventions for individuals with ASDs; and 4) to provide family members with education and supports. To date, this group has produced both statewide and regional brochures and two online training modules, *Understanding Autism and Screening and Referral*. This community collaborative became the impetus for a Health Resources and Services Administration (HRSA) State Implementation grant facilitated by the MU Thompson Center to expand the model throughout Missouri and to support improvements in the system of care.

In 2007, Senate President Pro Tem Michael Gibbons convened the Blue Ribbon Panel on Autism. Chaired by Sen. Scott Rupp, the Blue Ribbon Panel was charged with "identifying issues of children, youth, and adults with autism and with making appropriate recommendations to address those identified needs."³ Sixteen appointed members conducted public hearings in five cities around the state and compiled over 60 hours of testimony from families, experts in autism spectrum disorders, and individuals with ASDs. The panel published its report in December 2007 and outlined 36 recommendations which have formed the blueprint for much of what has transpired subsequently.

In many ways, 2008 was a watershed year. Based on the recommendations of the Blue Ribbon Panel, specific funding was allocated to the designated Missouri Autism Centers for staff and program support in order to reduce patient/client waitlists for diagnosis; to foster dissemination of core, credible information for families; to enhance access to intervention services; and to expand training opportunities for professionals. Initially, three university-based centers were identified:

- Children's Mercy Hospitals and Clinics, Kansas City – Michele Kilo, MD, Bureau Chief
- Knights of Columbus Developmental Center, Cardinal Glennon Children's Medical Center, St. Louis – Rolanda Maxim, MD, Medical Director

– MU Thompson Center for Autism and Neurodevelopmental Disorders, Columbia –
Janet Farmer, PhD, ABPP, Director of Academic Programs

A fourth site was added in 2009: the Southeast Missouri State University Autism Center for Diagnosis and Treatment in Cape Girardeau – Connie Hébert, MS, Director.

Also in 2008, a public-private task force was formed to evaluate and explore the feasibility of the DDD pursuing an autism-specific Medicaid Waiver. Five meetings were held between March and June 2008, and an application for an autism-specific Medicaid Waiver was submitted to the Centers for Medicare and Medicaid (CMS) for approval in early 2009. The application was approved and, effective July 1, 2009, Missouri was able to offer 150 slots to individuals with ASDs in completion of recommendation 18 of the 2007 Blue Ribbon Panel. This waiver is targeted to provide in-home supports for children between the ages of 3 and 19. For more information about Missouri's Autism Medicaid Waiver, visit www.dmh.mo.gov/dd/progs/waiver/autism.htm.

Although mental health parity laws have existed in Missouri statutes for a number of years, in 2008, legislation requiring health carriers to provide the full complement of treatment services, including applied behavior analysis therapy, to children with ASDs was introduced for the first time. Although bills were introduced in both the House and Senate, they remained in committee and were never put on the calendar.

In addition, the Missouri School Boards' Association (MSBA) convened an Autism Task Force to provide a broader perspective on the recommendations regarding public education from the 2007 Blue Ribbon Panel on Autism report. This group met four times and in early 2009 published ten recommendations aimed at improving early intervention services as well as building service capacity and promoting improved services among public agencies, private agencies, and organizations.⁴

Legislation was introduced and passed in 2008 creating the Missouri Commission on Autism Spectrum Disorders as well as the Office of Autism Services (OAS), housed organizationally within DDD. Charged with making "recommendations for developing a comprehensive state-wide plan for an integrated system of training, treatment, and services for individuals of all ages with autism spectrum disorders" (633.220 RSMo), the 24-member Commission addressed this charge by establishing four subcommittees to respond to specific legislative responsibilities and to develop recommendations for a state plan. The statutory responsibilities of the OAS are to "provide leadership in program development for children and adults with autism spectrum disorders, to include establishment of program standards and coordination of program capacity" (633.225 RSMo).

In 2008, OAS contracted with Anne Roux, former Executive Director of Missouri Families for Effective Autism Treatment (MO-FEAT) to produce a handbook that would inform families of newly diagnosed loved ones about a variety of services in Missouri. Titled *Navigating Autism Services in Missouri: A Community Guide for Missouri*, this publication combined information about how to navigate the medical, educational, and community services that presently exist in Missouri with resource information in the form of credible websites and relevant telephone contact numbers. While not intended to be fully inclusive or exhaustive, this guide has been well-received by both families and professionals and has drawn the attention of other states.

Missouri was one of only six states in the nation to be awarded a State Implementation Grant to improve comprehensive and coordinated care for children and youth with ASDs and other developmental disorders (HRSA/Maternal & Child Health Bureau, funded 2008-2011). This grant was awarded to the MU Thompson Center to facilitate improvements in care at the individual, community, and state systems levels. This submission was successful because of the clarity of Missouri's state plan for ASD service improvements and its history of support for ASD programs.

Finally, in December 2008, partnering with the Thompson Foundation for Autism, DDD undertook sponsorship of a project to create a state-of-the-art document pertaining to screening, diagnosis, and assessment for intervention planning of ASDs for Missouri. The project leadership team included Janet Farmer, PhD, ABPP, and Stephen Kanne, PhD, ABPP, from the MU Thompson Center; Michele Kilo, MD, from Children's Mercy Hospital and the University of Missouri-Kansas City School of Medicine; and John Mantovani, MD, from St. John's Mercy Children's Hospital and Child Development Center; and involved the work of 38 other professionals, family members, and state agency staff as members of the Missouri Autism Guidelines Initiative project for more than a year to reach consensus on practice guidelines specifically applicable to Missouri. The final document production and dissemination was supported by a grant from the Missouri Foundation for Health and was published in April 2010 as *Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment*.

2010 might rival 2008 in terms of noteworthy activities related to the field of ASDs. The best practice guidelines debuted in April. Additionally, Gov. Nixon and Missouri legislators led an aggressive campaign for insurance reform that would require health insurance carriers to provide coverage for children with an ASD diagnosis, and in May 2010, Missouri became the 21st state to enact insurance legislation specifically targeted at ASDs. A component of the law is coverage for applied behavior analysis (ABA) services, perhaps the most researched evidence-based therapy for children with ASDs.

2011 will mark yet another milestone in Missouri's pursuit of improved services and outcomes for all individuals with ASDs as the Commission on Autism Spectrum Disorders adopts the state plan, and activities are developed and undertaken to measure progress and further refine the plan itself.

This document provides written context surrounding the topic of ASDs in Missouri and outlines the specific work of the four subcommittees of the Commission on Autism Spectrum Disorders. Subcommittee narratives provide descriptions of the processes and ideologies that guided goal development and decision-making. The actual goal sheets used to capture subcommittee work, including identified action steps are located in Appendix B. Finally, this plan is designed to remain fluid and reflect changes in program development, public policy, interagency collaboration, family input, and applied research as information about this complex disability increases exponentially with increased public focus.

Spectrum Dis

Documenting the Need

Prevalence and Costs

The most recent report from the Autism and Developmental Disabilities Monitoring (ADDM) Network of the Centers for Disease Control and Prevention (CDC) cites prevalence data for ASD between 1 in 80 and 1 in 240 children in the United States in the 2006 study period.⁵ That is about 1 in 110 children on average, which is an estimated prevalence of about 1%. Notably, this rate has increased with each surveillance period since the ADDM project began in 2002.

The causes of increasing prevalence are not completely understood, but multiple factors appear to be involved, including greater public awareness and surveillance for ASDs, improved data collection and research, the broadened diagnostic criteria for ASDs beginning with the 1994 edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*, and the addition of autism as an eligibility category for special education services in 1990.

STUDENTS

Regardless of the many factors which influence diagnosis and affect changing ASD prevalence rates, the impact of that increase on publicly funded systems is of major concern. Missouri, like all other states, relies on its state agencies for data collection. For example, the annual child count from the US Department of Education yields relevant data on the number of children receiving special education services under the categorical eligibility criterion of autism, but, by virtue of the legislative intent of the Individuals with Disabilities in Education Act, only captures children whose impairments are significant enough to impact their ability to learn. Disaggregated from the national total, Missouri-specific special education child count numbers reflect an increase in the autism child count of 397.5% for the 10-year period beginning 1998-99 and ending 2008-09. The 1-year increase from 2007-08 to 2008-09 was 12.3%, and the average annual increase for the 5-year period ending with the 2008-09 school year is 15.6%. These numbers are compelling in their correlation to the need for increased services provided at the local level.

CONSUMERS

Likewise, DDD reports significant increases in enrollment of individuals diagnosed with ASDs. Consumer counts were collected for testimony for Missouri's Blue Ribbon Panel on Autism in 2007, and for the 12-month period ending in April 2007, DDD reported a total of 5,497 consumers with ASD diagnoses. At the end of the 2008 state fiscal year (FY), as the chart that follows illustrates, DDD experienced a 15.7% increase in that total with 6,362 individuals enrolled, and at the end of fiscal year 2009, DDD reported another 7% increase from 2008 with 6,817 enrolled. These numbers stand in stark contrast to those reported by DMH in the 1990 state plan, *Autism in Missouri: Bridging the Gaps – A State Plan for Autism* in which the number of individuals with ASDs, as classified under the *DSM III*, was cited as 133 for fiscal year 1987.⁶

CENSUS DATA – DIVISION OF DEVELOPMENTAL DISABILITIES

AGE	BASELINE (MAY '06 – APRIL '07)	FY 2008	% INCREASE BASELINE-2008	FY 2009	% INCREASE FY2008-2009
Birth through 3	194	245	26%	87	-64%
4 through 18	3806	4290	13%	4588	+7%
19 through adult	1497	1827	22%	2142	+16%
TOTAL	5497	6362	15.7%	6817	+7%

Notable in the table above is the significant decrease in the birth to 3 population served by DDD in FY 2009. Missouri's early intervention program for infants and toddlers, birth to age 3, who have delayed development or are diagnosed with conditions associated with developmental disabilities, is First Steps. It was during FY 2009 that First Steps case management responsibilities previously shared by DDD and DESE were transitioned solely to DESE; therefore, enrollment of infants and toddlers with DDD decreased dramatically. In other words, infants and toddlers, age birth to 3, utilize First Steps as a point of entry into eligibility and services. After age 3, eligible children would likely enter the rolls of DDD. The 87 infants and toddlers enrolled with DDD in FY 2009 likely encountered a co-occurring developmental disability that resulted in enrollment in the DDD and, presumably, First Steps as well. Given the sharp increases in census for both DESE and DDD in school-aged individuals and adults and the need for data-driven decision making, public policy should, with all due haste, begin to reflect attention to the growing numbers of the children who will soon enter adulthood and require a very different array of services and supports.

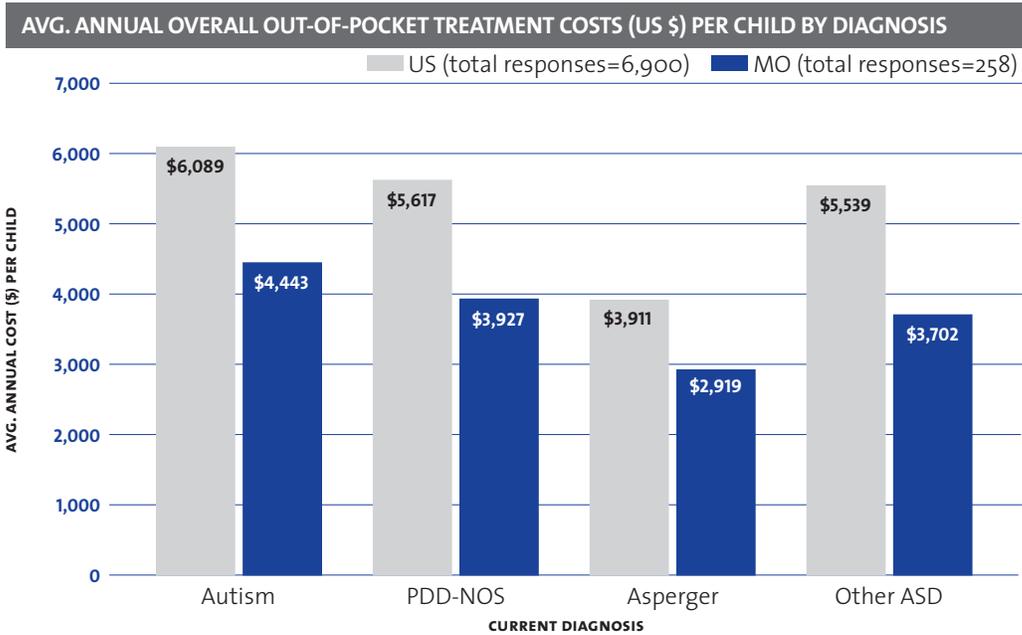
PATIENTS

In Missouri, the agency responsible for purchasing and monitoring healthcare services for low-income and vulnerable Missourians is the MO HealthNet Division (MHD) in the Department of Social Services (DSS). At the August 2009 meeting of the Commission, MHD reported that a total of 6,986 persons diagnosed with ASDs received services covered by this agency in FY 2008.⁷ The number of consumers enrolled with DDD for that same time period was 6,362. Both agencies' totals are inclusive of all ages and represent individuals who have received any service covered by that agency for that time period. DDD and MHD share many of the individuals represented by these numbers but not necessarily all. There are cases where individuals with ASDs might be covered under Missouri Medicaid and not be enrolled with DDD. Reasons for this might include instances where an individual who has Medicaid insurance does not qualify for services in DDD since eligibility for services by DDD is more restrictive than income and diagnostic qualifications alone. For more information on eligibility for services through DDD, visit www.dmh.mo.gov/dd/faqs.htm#eligible.

COSTS

While the true cost of supporting a person with an ASD diagnosis may never be known, some data are available. Perhaps the most frequently cited national estimate of the lifetime cost of caring for a person with an ASD is from Michael Ganz's 2006 study, which cited an estimate of \$3.2 million with a cumulative societal cost of at least \$35 billion annually.⁸

The following chart, however, provides a snapshot of national and Missouri-specific out-of-pocket expenses associated with caring for a child with an ASD.⁹ These amounts are self-reported by families who voluntarily register with IAN.



State agencies in Missouri have also reported expenditures on persons with ASDs. While these reports only reflect expenses linked to individuals enrolled in state programs, most notably in DSS and DMH, they nonetheless contribute to the picture of costs associated with this disorder.

Missouri’s Medicaid agency, MHD, reported the following expenditures for FY 2008 for individuals diagnosed with ASDs.¹⁰

MO HEALTHNET FY 2008 EXPENDITURES ON INDIVIDUALS WITH A DIAGNOSIS OF ASD		
AGE RANGE	AMOUNT	% OF TOTAL
Birth through Age 20	\$ 31,549,756	55%
Age 21 and Older	26,130,705	45%
Total	57,680,461	100%

For that same period, FY 2008, the DDD reported an increase of nearly 27% in Home and Community-Based Medicaid Waiver expenditures on individuals diagnosed with ASDs over the 12-month period (May 2006 – April 2007) used for benchmarking data for testimony at the public hearings of the Blue Ribbon Panel on Autism.¹¹

DDD HOME AND COMMUNITY-BASED EXPENDITURES			
AGE RANGE	05/06-04/07 AMOUNT	FY 2008 AMOUNT	% CHANGE
4 through 18	NA	\$ 9,034,181	NA
19 though adult	NA	43,827,303	NA
Total	41,659,350	52,861,484	26.9%

Screening, Diagnosis, and Assessment

As prevalence and incidence rates rise, the imperative for early screening and diagnosis becomes more compelling. Internet technology allows families to access independent information relating to their children's issues and may impact the diagnostic process. Professionals, including physicians and psychologists most likely to diagnose an ASD, use the *DSM-IV-TR*, published by the American Psychiatric Association (2000). The lack of a medical test for ASDs presents the medical community with its own set of challenges, e.g., who can diagnose, what are the components of a diagnostic evaluation, how can credible screening be assured and who should do it, etc. These challenges have been met with several Missouri-specific best practice responses.

CENTRAL MISSOURI RAPID RESPONSE INITIATIVE

In 2006, a handful of committed individuals representing families of individuals with ASDs, public agencies, and private organizations met to develop a coordinated response aimed at increasing the number of children routinely screened for ASDs, decreasing the wait times for diagnosis and interventions, and providing family members with education and supports during the diagnostic process and immediately afterwards. With support from DDD, the Central Missouri Rapid Response Initiative under the leadership of the MU Thompson Center has grown to over 40 members, and participation and collaboration around the identified goals have been sufficiently intriguing to the HRSA that, under the Maternal and Child Health Bureau, a grant was awarded to the MU Thompson Center to expand this initiative statewide.

Activity devoted to outreach and education includes the principles of best practice embedded in brochures and training, conducted in person, via Interactive Television, and via the internet as well. The second locus of collaboration replicating the Central Missouri Rapid Response Initiative is underway with the establishment of the St. Louis Rapid Response Initiative whose early goals include outreach to underserved populations with an emphasis on developmental screening. Third and fourth community collaboratives have been initiated for the Kansas City and Cape Girardeau regions.

AUTISM SPECTRUM DISORDERS: MISSOURI BEST PRACTICE GUIDELINES FOR SCREENING, DIAGNOSIS, AND ASSESSMENT

In late 2008, DDD and the Thompson Foundation for Autism embarked on a public-private partnership to forge new ground in developing clinical best practice guidelines for screening, diagnosis, and assessment for intervention planning for an individual with a diagnosis or suspected diagnosis of ASD. Cognizant of the ever-increasing prevalence statistics surrounding diagnoses of ASDs along with the strength of research supporting the fact that earlier identification and intervention lead to better outcomes for persons on the spectrum, the Missouri Autism Guidelines Initiative was created, bringing together a cadre of experts from across the state including physicians, psychologists, educators, representatives of other professions, representatives from DDD, and parents. Permission was sought and granted to use California's Department of Developmental Disabilities' publication titled *Autistic Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis, and Assessment* as a foundation for Missouri's work, and assistance from those involved in the creation of that publication was secured to guide work processes. Finally, financial support was garnered from both DDD's Real Choices Systems Transformation grant and a grant from the Missouri Foundation for Health to support the costs of printing and dissemination. The whole of 2009 was devoted to creating guidelines that reflect Missouri's point of entry for services, which differs significantly from California's.

Early 2010 marked consensus gathering, and the final product, *Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment*, was released in April 2010. Within one month of publication, pre-orders combined with media events resulted in dissemination of 6,700 of the 10,000 *Guidelines* printed. In addition, the *Guidelines* were used by the University of Missouri-Columbia's Leadership Education and Neurodevelopmental Disorders (LEND) graduate course.

Access to Intervention

Established in accordance with the federal Combating Autism Act (See www.govtrack.us/congress/billtext.xpd?bill=s109-843), the Services Subcommittee of the Interagency Autism Coordinating Council (IACC) published an action plan or ASD Services Roadmap in 2005 that distills issues, challenges, and makes recommendations related to access to health, mental health, education, and social services. Its stated intent "to provide a national blueprint to enhance existing systems, expand services for children, youth, and adults with ASD and their families, and coordinate services across systems," is "based on the premise that all individuals, including those with ASD deserve to grow, learn, live, and work in inclusive communities where differences are respected and needs met."¹² Woven throughout the document are recurrent themes expressed by stakeholder groups, including the:

- Fragmented nature of services and systems;
- Uneven access to quality services;
- Dearth of services for adults;
- Pronounced gaps in transition;
- Need for standards of care for screening, diagnosis, and treatment; and
- Need for expansion of funding mechanisms, both public and private; national, state, and local.

Interestingly, the 1990 publication of The Institute for Human Development at the University of Missouri – Kansas City, titled *Autism in Missouri: Bridging the Gaps – A State Plan for Autism* in its Summary of Findings uses similar language and conveys an undeniably similar message as the IACC roadmap:

It is now time to implement a comprehensive set of recommendations that will put into place those components of the human service delivery system that are needed in Missouri to realize our shared vision that all citizens with autism, regardless of their level of impairment, have the right to learn, live, work, and recreate in their local communities with their non-handicapped peers and neighbors.¹³

The imperatives of both the 1990 call to action and the national blueprint perhaps most directly intersect in Missouri's 2007 Blue Ribbon Panel on Autism Report, which echoed these concerns by putting forth 36 recommendations, the first of which was to create the Missouri Commission on Autism Spectrum Disorders whose specific charge is "making recommendations for developing a comprehensive state plan that would consistently focus Missouri on the priorities and means for enhancing resources required to provide the full complement of ASD services necessary in the state." Passage of Senate Bill 768, sponsored by Sen. Scott Rupp, in 2008 transformed that recommendation into reality with this specific legislative charge:

The commission shall make recommendations for developing a comprehensive statewide plan for an integrated system of training, treatment, and services for individuals of all ages with autism spectrum disorder (633.220.5, RSMo).

The sections that follow, outlining goals and actions of the subcommittees of the Commission, represent Missouri's response to those complex and interconnected challenges that have been articulated by both the IACC's *ASD Services Roadmap* and Missouri's Blue Ribbon on Autism Report's recommendation 1.

Infrastructure

The IACC's roadmap provides fundamental narrative which speaks to service infrastructure across continua.

The success and well being of individuals with ASD and their families are affected by, and in large part, depend on communities and their resources. Thus, we must respond by developing community systems that are integrated across service sectors and are collectively responsible for achieving appropriate individual, family, and community outcomes.¹⁴

In Missouri (and nationwide), varying points of entry into medical and educational systems with different eligibility criteria and uneven access to quality providers often puts families at odds with the systems they attempt to access. The Commission is charged with providing recommendations to bridge those gaps. And, while state agencies have independently answered many of the recommendations contained in the Blue Ribbon Panel on Autism Report, the Commission creates opportunity for cross-departmental and public-private networking and collaboration. This will prove invaluable in achieving positive progress and outcomes through interconnecting services and supports for individuals of all ages with ASDs and their families. There is both commitment and momentum displayed by the Commission to translate bureaucratic policies into real involvement at the local level in communities across Missouri.

One girder in bridging disparate systems is the publication of *Navigating Autism Services in Missouri: A Community Guide for Missouri*. In 2009, OAS contracted with Anne Roux, then Executive Director of the advocacy organization MO-FEAT, to produce a handbook that would inform families of loved ones newly diagnosed with ASDs about a variety of services in Missouri. This guide combines information about how to navigate the medical, educational, and community services that presently exist in Missouri with resource information in the form of credible websites and relevant telephone contact numbers. Intended to be neither fully inclusive nor exhaustive, this guide has been well-received by families and professionals and has even drawn the attention of other states. In fact, Wisconsin has contacted Missouri indicating its intention to pursue a similar publication and has sought permission to utilize Missouri's format. As grant-funded activities at the MU Thompson Center unfold, plans are underway to create a similar navigation guide centered on the theme of transition to adulthood. In fact, the MU Thompson Center's HRSA grant and funding from DDD have supported the development of the Family Resource Service, which provides direct assistance to families as they navigate systems of care.

TELEHEALTH

One Missouri effort to address gaps in infrastructure includes a pilot project designed to analyze the merits of using telehealth to screen and diagnose children who are suspected of having developmental concerns. To that end, DDD partnered with John Mantovani, MD, Medical Director of St. John's Mercy Children's Hospital and Child Development Center, to investigate telehealth as a clinically appropriate method of delivering diagnostic and treatment services to children with ASDs in the context of improving access to qualified, licensed

physicians and other qualified diagnosticians, as well as providing an opportunity to improve access for intervention services. Advantages of using this technology may include reduction in travel time, reduction in stress resulting from long distance travel with a child whose needs may be extraordinary, and reduction in costs such as respite care or overnight accommodations. At the time of this writing, the preliminary results are reported as promising and, if success is achieved in linking rural Missouri to highly qualified clinicians, one significant gap in access will have been addressed.

DESE

Since 1985, DESE has partnered with Missouri State University to support Project ACCESS. Project ACCESS offers professional development opportunities to educators and para-educators. Additionally, with an eye toward building local capacity, it provides ASD consultation to Missouri's schools. These services are available on a statewide basis. The first tier of training consists of at least 6 days of autism-specific training and 3 days of Project ACCESS consultant training, resulting in the designation of Missouri Autism Consultant (MAC). MACs provide on-site consultation to school districts. The second tier of training consists of at least 6 days of ASD-specific training and an additional 3 days of consultant training, resulting in the designation of In-District Autism Consultant (IDAC). IDACs consult at the discretion of their school districts and do not consult beyond their districts. The 25-year longevity of Project ACCESS speaks to the commitment of Missouri's educational community to address gaps in providing ASD-specific technical assistance to the infrastructure of public education.

Additionally, DESE's Office of Special Education has, since 2004, funded scholarships, distance learning opportunities, online coursework as well as actual out-of-state coursework to teachers and staff in order to enhance their ability to serve the needs of students with ASDs.

COMMUNITY COLLABORATION

The IACC's *ASD Services Roadmap* states:

A community-based system of services refers to the framework within which a variety of programs work together to meet the many, varied needs of the individuals it serves. Development of community-based systems of services requires that their governance, planning, and management involve key community stakeholders.¹⁵

Missouri began collaborative relationships well in advance of the legislative mandate requiring recommendations for a state plan. The Central Missouri Rapid Response Initiative represents a model program in which various stakeholders meet and collaborate around surveillance, early diagnosis, and intervention, linking families to appropriate resources and producing and disseminating core, credible information to families and stakeholders about ASDs. Membership in the Central Missouri Rapid Response Initiative includes parents of individuals with ASDs, university faculty, licensed psychologists, multi-department state agencies, community providers, and professional organizations. That model is being replicated statewide and holds great promise as a conduit of integrated resources and supports. The reality of community collaboration will be strengthened by a state plan that is mindful of existing relationships and seeks to expand and promote them.

Lifespan

Improving services and supports for adults with ASDs is receiving much attention in Missouri, as it is elsewhere in the country. There is a real paucity in the literature for best practice standards for adults with ASDs. In fact, according to the IACC 2010 Strategic Plan:

Most autism research has focused on behavioral interventions for young children. Behavioral interventions for youth and adults, as well as community supports that address the quality of life (as opposed to core symptoms) for people with autism and their families have almost no traditional evidence base to support them. Yet these types of services are some of the most requested and most needed.¹⁶

The research focus on children is further borne out by funding. The *2008 IACC Autism Spectrum Disorder Research Portfolio Analysis Report* sheds interesting light on the longstanding concern over lifespan issues for persons with ASDs, indicating that of a total of over \$222 million accounted for in the portfolio analysis report, little more than 5% (\$11 million) was devoted to issues associated with adults.

Additionally, IMPAQ International, LLC's *Autism Spectrum Disorders (ASD) Services – Final Report on Environmental Scan* released in March 2010, underscores the dearth of research into evidence-based young adult and adult interventions, citing only 7% of the 15 studies of interventions for transitioning youth with ASD as meeting the criteria for evidence-based practices and of the only 9 intervention studies targeted for adults with ASDs, only one-third was rated as evidence-based.¹⁷ Post-secondary education and training, housing, employment, access to health services, and independent living are pressing concerns which will become even more pressing as the influx of children with ASDs reach adulthood.

Notwithstanding the considerable work to be done toward attaining better outcomes in the areas discussed above, programming developed to address these gaps does exist in Missouri. In May 2007, the University of Central Missouri announced the launch of THRIVE (Transformation, Health, Responsibility, Independence, Vocation, Education). This program is designed for exceptional learners who have finished high school and are working toward full inclusion in the workplace and society. A unique aspect of this program is that THRIVE participants will live on a college campus with upper level student mentors and community advisors to assist them in learning the skills of day-to-day living on a college campus.

Additionally, DESE has worked to close gaps in transition planning by initiating a multi-pronged professional development effort which includes transition-specific training, interagency collaboration, community transition teams, online *Ask the Expert* events, and online transition training. Data around this program are positive as shown from participant pre- and post-testing. Notably, Community Transition Teams, a component of this professional development program, have engaged other state agencies such as DDD, the Division of Vocational Rehabilitation (DVR), the juvenile court system and others to coordinate transition services beyond those mandated by the Individuals with Disabilities Education Act (IDEA). By forming strategic alliances and meeting regularly, these teams have undertaken to address gaps such as those identified in the IACC Strategic Plan and have worked to understand each other's system and operational frameworks.

The 2007 Blue Ribbon Panel on Autism Report lists as recommendation number 7: “...that the Division of Vocational Rehabilitation designate a counselor in each region with a specialty of serving clients with ASD and provide them with adequate training or professional development in the area of ASD.” Recognizing Missouri’s need to improve employment outcomes for individuals with developmental disabilities, in 2008 DDD began a statewide employment initiative by both hiring a Director of Employment and Training and appointing Employment Coordinators in each of the 11 regional offices with the vision of increasing the number of individuals with developmental disabilities in integrated employment and making employment the first priority option provided before any other during the person centered planning process. Shortly after that, in August 2009, Dr. Scott Standifer of the MU’s Disabilities Policy and Studies in Columbia published *Adult Autism and Employment – A Guide for Vocational Rehabilitation Professionals*, which provides strong autism-specific technical assistance for serving individuals with ASD.

Much remains to be done to effect seamless transition, but the focus that the Commission on Autism Spectrum Disorders has accorded the many lifespan issues bodes well for real and measurable progress.

Autism Spec

State Plan Development

Commission Structure and Charge

Senate Bill 768 was the impetus for the enabling legislation which resulted in the following “recommendations for developing a comprehensive statewide plan for an integrated system of training, treatment, and services for individuals of all ages with autism spectrum disorders” (633.220 RSMo). That bill was introduced in the 2008 legislative session and signed into law on June 23, 2008.

This legislation created the Commission and specified that the directors of seven of Missouri’s 16 state departments serve on the Commission or identify designees in their stead. Those positions account for seven of the 24-member Commission. In addition to state departments, individuals with ASDs; parents of individuals with ASDs; representatives from the medical community, the education community – elementary, secondary, and post-secondary – and private providers; and a representative from a county developmental disability board have seats on the Commission. Each state department represented on the Commission has provided a report to the Commission about dedicated programming to and expenditures on persons with ASDs.

At the time of this writing, the Commission has elected a chair and has approved a set of guiding principles, a protocol for public communication, a framework document that illustrates the structure around which subcommittees approached their respective legislative charges, and a flow chart pertaining to the development of a state plan. The four subcommittees are:

- Education
- Healthcare
- Individual and Family Supports
- Workforce Development

In turn, each subcommittee has elected a chair and has been assigned a staff person from OAS or DMH to provide technical assistance. OAS schedules monthly meetings for each subcommittee held via teleconference and face-to-face. Additionally, subcommittees have invited experts to participate in meetings on an ad hoc basis to better inform goal development and action steps. Subcommittee goals deliberately identify significant considerations for committee reflection, including perceived barriers or challenges, resources, the identification of partners in lead or supporting roles, and timelines for accomplishing the goals.

The chairs of each subcommittee make up a Steering Committee which meets periodically via teleconference to provide updates on committee activities. The chairs also met in person to review the draft state plan before it was presented to the full Commission and posted for public comment. Additionally, Steering Committee members served as filters for their respective subcommittees to manage reactions and comments to the document as a whole and ultimately provide further edits prior to publishing the plan for public comment.

Throughout the development of the state plan, the role of OAS has been to research promising practices and model programming, identify and connect with state and national experts, serve as a liaison between subcommittees (particularly when committee interests intersect), maintain communication and correspondence among subcommittees, compose the narrative content of the state plan, and coordinate the elements of the state plan once subcommittee work had sufficiently advanced.

The remaining pages in this section are the “framework” documents that provide a visual model of the statutory charge, cross-cutting issues, and the organizational structure of the activities devoted to the development of the state plan.

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Missouri Commission on Autism Spectrum Disorders

“Show-Me State Plan”

Guidance for State Plan Development

OBJECTIVE: The commission shall make recommendations for developing a comprehensive, quality statewide plan for an integrated system of training, treatment, and services for individuals of all ages with autism spectrum disorder.

State Plan Development Subcommittees

Steering Committee*
Education
Healthcare
Individual and Family Supports
Workforce Development

**comprised of workgroup leadership and others*

Guidance for Committee Work

Each subcommittee should address each of the areas below, giving consideration to the needs of:

1. the person who has an ASD, and
 2. persons within the natural environment who require supports in order to best care for the person with an ASD
- Screening, Diagnosis, and Assessment Issues
 - Service Delivery Within and Across Regions
 - Affordability
 - Access
 - Quality
 - Collaboration Within and Across Systems (with consideration of what system collaboration means from agency, family, and provider perspectives)
 - Personnel Development Within and Across Systems
 - Training
 - Capacity-building
 - Outcomes Measurement
 - Transition Planning

Particular consideration must be given to **Lifespan Periods (and transitions)** below and the spectrum of abilities

- Infant-Toddler
- Early Childhood
- Elementary-Secondary
- Post-Secondary
- Adulthood

Resources for Plan Development (not exclusive)

- MSBA Autism Task Force Recommendations (2009) and identified gaps in service delivery
- MARRA Report
- Missouri Blue Ribbon Panel on Autism Report (2007) and additional Panel documentation
- Invited expert testimony
- Agency documentation
- Model state plans
- Missouri Autism Guidelines Initiative

Guidelines for Subcommittee Work per SB768*

All Subcommittees:

- **Shall** study and report on means for developing a comprehensive, coordinated system of care delivery across the state to address increased and increasing presence of ASD and ensure resources are created, well-utilized, and spread across the state.
- **Shall** plan for evaluating regional services areas and capacity, outlining personnel and skills within service areas, other capabilities that exist, and unmet resource needs.
- May explore need to create interagency councils and evaluate current councils to ensure a comprehensive, coordinated system care for individuals with ASD.

Healthcare

- **Shall** determine need for the creation of additional centers for diagnostic excellence
- **Shall** develop recommendations for expanding services with hospitals after review of specialty clinics/hospitals and hospital inpatient care capabilities
- May recommend individuals to participate in a committee charged with developing screening, diagnostic, assessment, and treatment standards for Missouri
- May examine information barriers to accurate information of reporting ASD prevalence across the state and recommend process for accurate reporting

Education

- **Shall** conduct an assessment of the need for coordinated, enhanced, and targeted special education capabilities within each region of the state
- **Shall** develop a recommendation for enlisting appropriate universities and colleges to ensure support and collaboration in developing certification or degree programs for students specializing ASD intervention (may include degree programs in education, special education, social work, psychology)
- May provide recommendations regarding training programs and the content of training programs being developed
- May recommend a panel of qualified professionals and experts to review existing models of evidence-based educational practices for adaptation specific to Missouri

Individual and Family Supports

(community integration, childcare and respite, long term care for individuals)

- **Shall** assess the need for additional behavior intervention capabilities and, as necessary, the means for expanding these capabilities in a regional service area

Workforce Development

- Employment (While SB 768 did not contain language specific to employment issues for individuals with ASDs, the Workforce Development Subcommittee embedded statutory references applicable to this critical issue in its goals)

* Items worded "shall" must be addressed within the State Plan per SB768 (2008) language. Committees should also consider recommendations made by the Blue Ribbon Panel on Autism (2007) and priorities for areas to be addressed as outlined by this Commission and its committees.

State Plan

Next Steps

THE JULY 2009 STATUS REPORT titled *Framework for the Future*, submitted on behalf of the Missouri Commission on Autism Spectrum Disorders (the Commission), identifies key national legislation that merits continued monitoring. Nationally, President Barack Obama signed into law the Affordable Care Act on March 23, 2010. An important component of this legislation is its effort to address persons denied health care coverage based upon pre-existing conditions. Additionally, Section 5306 of the Affordable Care Act authorizes grant funds for colleges and universities for students who will specialize in social work, psychology, and other mental health professions. The grants authorized under the Affordable Care Act will offer Missouri universities and colleges an opportunity to develop and enhance educational programs to increase the behavioral health workforce in Missouri. Grant notifications from the Health Resources and Services Administration are monitored daily. The Department of Mental Health (DMH), in collaboration with the Department of Health and Senior Services (DHSS), Department of Elementary and Secondary Education (DESE), and the Department of Higher Education (DHE) will provide support for Missouri institutions for higher education to develop competitive applications for funding. These four state agencies have membership on the Commission.

Furthermore, the Autism Treatment Acceleration Act, introduced on April 2, 2009, bears watching as it has been referred to the Senate Committee on Health, Education, Labor, and Pensions. If passed, this act includes targeted grant funding for:

- Autism Care Centers Demonstration Project
- Planning and Demonstration Grant for Services for Adults
- National Registry for Autism Spectrum Disorders
- Multimedia Campaign
- Interdepartmental Autism Coordinating Committee
- National Network for Autism Spectrum Disorders Research and Services
- National Training Initiatives on ASDs

If funded, Missouri is well-positioned to apply for these grants and further its commitment to provide enhanced services.

At the state level, the passage of HB 1311 mandated private insurance policies to provide coverage for ASDs, making Missouri the 21st state to pass such legislation. Of particular consequence is the provision in this legislation to cover applied behavior analysis services in an amount not to exceed \$40,000 a year to children until they reach their 19th birthdays. Missouri is fortunate to have the support of Gov. Jeremiah (Jay) Nixon who, along with committed legislators, remained steadfast in his support of this legislation despite unprecedented fiscal challenges.

Significant challenges lie ahead, however. Missouri, without question, needs to cultivate opportunities for individuals to become Board Certified Behavior Analysts (BCBAs). The Division of Developmental Disabilities (DDD) has partnered with colleges and universities to develop and deliver the required coursework leading to that credential. Scheduled to begin in the fall of 2011, St. Louis University and Forest Professional School of Psychology have approved course sequences leading to board certification for Behavior Analysts. Furthermore, results from the *Autism Spectrum Disorders Program and Competency Survey of Higher Education – 2010* indicated that 13 of 32 respondent institutions have ASD or ABA program delivery with an additional three institutions in the process of ASD or ABA program development. Such increased programming by these institutions, together with others which will undoubtedly follow, bodes well for increasing professional capacity.

While much research and effort have been devoted to children, not as much attention has been devoted to adults with ASDs. The pressing needs of adults – including issues such as transition from school, post-secondary education and training, employment, independent living, community integration, access to medical care, training for direct care staff – all require attention and applied research.

Finally, this document has attempted to highlight events and activities in Missouri that illustrate endeavors to address some of the challenges listed above. Certainly, a cross-cutting challenge often cited is the lack of coordination among various state departments and agencies that provide services to individuals with ASDs. The consistency of this message resonates at all levels – national, state, and local. And, while the armor of bureaucratic institutions seems impregnable, it unquestionably serves the greater good to have representatives at the table with the knowledge, experience, and decision-making authority to expose and expand chinks in that armor. The Commission offers this state plan as a platform upon which to build a better system of care for all persons affected by ASDs.

This document must change; it must remain fluid and respond as research and practice advance by continually raising the bar of excellence. The logical next step is to develop quality performance indicators around the goals and action steps. That task will be undertaken as the work of the Commission itself unfolds to address the changing landscape of services for individuals with ASDs.

Autism Spec

Goals

Education Subcommittee

GOAL DEVELOPMENT: The Education Subcommittee of the Missouri Commission on Autism Spectrum Disorders (the Commission) organized itself quickly around statutory language directed toward education and training. Mindful of that, goals were intentionally created incorporating the language of the statute in order to maintain focus and set parameters in planning. The following goals reflect that focus and structure:

- Goal 1: To conduct an assessment of the need for coordinated, enhanced and targeted special education capabilities within each region of the state {633.200.6(2) RSMo}
- Goal 2: To develop a recommendation for enlisting appropriate universities and colleges to ensure support and collaboration in developing certification or degree programs for students specializing in autism spectrum disorder intervention {633.200.6(3) RSMo}
- Goal 3: To provide recommendations regarding training programs and the content of training programs being developed {633.220.6(4)(a) RSMo} to ensure a variety of training opportunities that reflect the application of best practice and standards of care for individuals with autism spectrum disorders
- Goal 4: To participate in recommending a panel of qualified professionals and experts to review evidence-based educational practices for adaptation specific to Missouri {633.220.6(4)(c) RSMo}

BARRIERS AND CHALLENGES: Barriers and challenges associated with addressing the statutory charges included finding common ground with the language of the statute. Particularly difficult was determining what was meant by “coordinated, enhanced and targeted special education capabilities within each region of the state.” The Education Subcommittee quickly agreed, however, that no recommendation for improving special education capabilities or recommendation for enlisting institutions of higher learning to initiate or expand certification or degree programs could be created without first viewing the landscape of what currently exists in Missouri.

PROGRESS AND ACCOMPLISHMENTS: Once goals were established, Commission members and others joining the subcommittee quickly began to prioritize these goals, starting with what was feasible with the given resources and what appeared to be the most pressing with the language of SHALL in the statute. Both goals containing “shall” require assimilating information to provide the most current and relevant reporting and subsequent recommendations. The subcommittee began its work by attempting to acquire and assimilate the information necessary to make informed recommendations for each area. Work in meeting the first two goals will ultimately inform much of what is needed for Goal 3 regarding training programs and content, and some of the information to address Goal 4 regarding evidence-based educational practices.

GOAL 1: The Subcommittee capitalized on existing efforts in Missouri by accessing information available through surveys already conducted as well as program reports and evaluations regarding special education services and needs within each region of the state. This included review of the following:

- Blue Ribbon Panel on Autism Report
- Results of a survey conducted jointly by Missouri Council for Administrators of Special Education (MO-CASE) and the Missouri School Boards Association (MSBA)
- Recommendations of the MSBA Autism Task Force
- Surveys conducted by Project ACCESS
- Program reports/ evaluations from Project ACCESS
- Relevant reports and data from the Department of Elementary and Secondary Education (DESE)
- Reports of activities conducted and proposed by Missouri Autism Centers in Kansas City, Columbia, St Louis, and Cape Girardeau
- Reports generated and activities conducted by various provider organizations around the state (e.g., TouchPoint Autism Services, Judevine, and others).

All organizations have been extremely cooperative in providing information requested as well as offering guidance regarding additional resources. In the spring of 2010, Project ACCESS conducted a targeted survey using suggested items from the subcommittee and pursued responses from representatives in every Missouri public school district. The results of this survey have been tabulated by Project ACCESS and have been shared with the subcommittee for use with other information gathered.

In addition to the review of information specific to Missouri, the Subcommittee gathered information to educate members regarding effective and evidenced based practices. These included the meta-analysis completed by Richard Simpson in 2005; competencies endorsed by the Council for Exceptional Children (CEC) in the area of Special Education; competencies endorsed by DESE for general and special educators; and the National Standards Project from the National Autism Center.

The Subcommittee will continue to aggregate the information available, determine the need to ascertain additional information and the means by which to do so, and then disseminate the results of this overarching assessment to the larger commission as well as make it available to the public and interested organizations along with any recommendations for identified needs and enhancements.

GOAL 2: The Subcommittee, with substantial assistance from the Department of Higher Education (DHE) under the leadership of then Commissioner Dr. Robert Stein, solicited information from 60 post-secondary institutions in Missouri to determine the current provision of coursework specific to the preparation of professionals for serving individuals with ASDs. The survey was distributed to chief academic officers in each institution of higher education in December 2009. Responding institutions were given the opportunity to amend information in April 2010.

The Subcommittee reviewed and compiled the results, and in August 2010, a completed report including recommendations entitled *Autism Spectrum Disorders Program and Competency Survey of Higher Education Institutions – 2010* was presented to the full Commission. This report is available at www.dmh.mo.gov/dd/autism/autcommaterials.htm and will be disseminated to institutions of higher education in Spring 2011.

Subcommittee members were encouraged to learn of several programs in development or implementation after the report was finalized. Therefore, the Subcommittee plans to re-issue this survey through DHE to monitor the status of programs on a regular basis and will expand those surveyed to include additional private and proprietary schools in Missouri.

GOAL 3: The Subcommittee determined that making recommendations regarding training programs and their content is needed as a result of the current legislation. In order to make recommendations for training, the Subcommittee determined that it must first know what evidenced-based training opportunities and programs currently exist at the state and national level. The Subcommittee determined that it is not productive to make recommendations that would effectively duplicate training already in existence.

The Subcommittee is in the process of identifying existing training programs and resources through the surveys developed and conducted as outlined in the action steps of goals 1 and 2 and information solicited from existing organizations and facilities. Information acquired includes the training plans developed by Missouri Autism Centers funded through DMH, the Central Missouri Rapid Response Initiative training modules, and Project ACCESS. Two surveys have been completed; one conducted by Project Access and one conducted by DHE.

The next step is for the Subcommittee to analyze the data in order to identify training programs that ensure best practice and standards of care for individuals with ASDs and to determine the most practical manner in which to make this information available to all Missourians.

GOAL 4: Action steps for this goal are in the formative stages. The Subcommittee has reviewed and discussed evidence-based practices with regard to the development of the surveys that were conducted.

The Subcommittee will address this goal by working with stakeholders across the state to identify evidence-based practices already being implemented as well as practices that should be considered for implementation. Additionally, as specifically stated in the legislation, the Subcommittee will identify qualified professionals to review the practices for use in Missouri.

The Subcommittee has also begun discussions on how it might provide resources to meet the challenges associated with the consistent implementation of evidence-based practices. This discussion merges considerably with discussions on each of the previous goals, allowing the Subcommittee to realize the interrelated nature of each of goals and plan accordingly for coordination and collaboration for implementation.

The process of the work of the Education Subcommittee and, indeed, the Commission as a whole, necessarily involves change as individuals change careers, retire, or are replaced by others. The Education Subcommittee has been most fortunate in its association with individuals who no longer serve either on the Commission or in a capacity to provide technical assistance. Those individuals merit mention and thanks for the commitment and effort exerted on behalf of the Subcommittee. They include:

- **Heidi Atkins Lieberman**, former Assistant Commissioner, Office of Special Education, Department of Elementary and Secondary Education, Jefferson City
- **Brian Crouse**, former Research Associate – Academic Affairs, Department of Higher Education, Jefferson City

- **Robin Marsh**, PhD, former Senior Continuing Education Coordinator, MU Thompson Center for Autism and Neurodevelopmental Disorders, Columbia
- **Robert Stein**, PhD, former Commissioner of the Department of Higher Education, Jefferson City

Healthcare Subcommittee

OVERVIEW: The Healthcare Subcommittee of the Missouri Commission on Autism Spectrum Disorders (the Commission) was charged with the tasks of assessing the current status of diagnostic as well as in-patient and out-patient hospital and clinic healthcare-related services for individuals with ASDs, supporting the development of screening, diagnostic, and assessment standards for Missouri practitioners, and evaluating the current situation and recommending potential processes for accurate reporting of ASD prevalence across the state. This report provides a narrative summary of the subcommittee’s deliberations to date and its current recommendations.

GOAL 1: To determine the need for creation of additional centers for diagnostic excellence

This has been the most complex and time-consuming issue for this Subcommittee because the members view the issue as broader than the number or location of Missouri Autism Centers. Rather, the core issue is how to provide accessible, timely, high-quality, and family-centered ASD diagnostic services to Missouri families. There is no question that access to diagnostic services is critically important and that it informs and leads to therapeutic interventions and family support which improve outcomes. It is agreed that the current Missouri Autism Centers are necessary components of a statewide network of care for ASDs. However, it is also clear that many children with ASDs are not diagnosed within Missouri Autism Centers, and the continuing question is how to distribute additional diagnostic services most effectively.

Additionally, the Subcommittee members want to emphasize the need to consider additional intervention and treatment programs for those with ASDs. Diagnosis of an individual with an ASD is only the first step on the road to effective intervention and therapy. Subsequent assessment of the person with ASD’s unique profile of strengths and challenges leads to an individualized program of intervention which may be provided in schools, treatment centers, medical and/or therapy facilities, and by individual practitioners and may include a broad array of medical, behavioral, and therapeutic approaches. Any recommendations for increased and enhanced diagnostic services must also emphasize the primary importance of intervention and therapy for those with ASDs.

1. To assess the current need, the Subcommittee produced an updated estimate of the ASD population in each Missouri county using Missouri Kids Count and current CDC prevalence data (.7-1.2% prevalence) to evaluate the geographically based need for ASD services. Based on these data, between 10,000 and 14,000 Missouri children less than 18 years of age are expected to be affected by ASDs. Approximately 7,000 children with ASDs are identified within DDD Regional Offices, DESE (K-12), and DESE First Steps databases but because DDD and DESE databases are separate, it is quite possible that some children will have been counted twice within estimated population of 7,000. Based on these estimates, there appear to be thousands of children with ASDs who are not identified as such in state databases and whose location and service needs are unknown.

2. To evaluate the status quo regarding diagnosis, the Subcommittee reviewed data from the Missouri Autism Centers:
 - Children’s Mercy Hospital and Clinics (Kansas City);
 - Knights of Columbus Center, Cardinal Glennon Children’s Hospital (St. Louis);
 - MU Thompson Center for Autism and Neurodevelopmental Disorders (Columbia).

This data included the number of patients seen, the waiting times, and the diagnoses given for 2008-2010 for the initial three centers and, for the first 6 months of operation in 2010, the same data for the Southeast Missouri State University Autism Center for Diagnosis and Treatment (Cape Girardeau).

We also note the existence of additional centers for ASD diagnosis and/or treatment services in Missouri including Burrell Behavioral Health Center in Springfield, Grace Hill Child Development Center in St. Louis, St. John’s Mercy Child Development Center in St. Louis, the Midwest Center for ASD in Warrensburg, and the diagnostic center at the Ozark Center in Joplin, but we do not have specific data on diagnostic capacity or current service volumes for these centers.

Additionally, the Subcommittee members recognize that there are a small number of individual medical and psychological practitioners in Missouri who provide diagnostic services for ASDs on a regular basis, but we do not have data to inform further analysis of their current or potential role in statewide ASD diagnostic efforts.

3. In collaboration with Rob Fitzgerald, MPH, the Co-Chief Investigator of the CDC-sponsored Autism Diagnosis and Developmental Monitoring Network Project (ADDM) at Washington University in St. Louis, the Subcommittee obtained data on ASD diagnosis in the St. Louis region. We also accessed the StateStats section of IAN to review Missouri diagnostic data.

Both of these sources indicate that approximately 70% of Missouri children with ASDs have received their diagnosis from an individual practitioner rather than a diagnostic team.

4. To evaluate the potential of telehealth as an extender of ASD services for Missouri, the Subcommittee met with E. Rachel Mutrix, Director of the MTN, to discuss the existing network and held a telephone conference with Paula Slusher, RN, CPNP, the nurse practitioner working in the MU Thompson Center’s ASD follow-up telehealth program to discuss the current practices there. Janet Farmer, PhD, ABPP, and John Mantovani, MD, each visited the telehealth diagnostic site at the Center for Child Health & Development (CCHD) at University of Kansas (KU) Medical Center. The Subcommittee endorsed the Division of Developmental Disabilities (DDD) grant-supported pilot project on the feasibility and reliability of diagnostic evaluation for children with ASDs conducted in DDD’s Regional Offices by Dr. Mantovani which produced encouraging results. Telehealth clearly is a promising approach to expanding access to care for those with ASDs across Missouri and offers promise for expansion of both diagnostic and continuing care services as discussed below.

In view of the geographical and historical complexities relating to current sites for ASD diagnosis in Missouri, the Healthcare Subcommittee has no current recommendation regarding the need for additional Missouri Autism Centers.

Instead, we recommend that the currently designated Missouri Autism Centers and other recognized state leaders in clinical care and service provision be charged with and funded to extend and build collaborations among the existing programs and individuals in Missouri serving those with ASDs.

A network in which the existing Missouri Autism Centers serve as hubs and establish or expand close working relationships with community-based centers and local practitioners based on the tiered diagnostic approach published in *Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment* (see # 3 below) would improve access to care, reduce diagnostic delays, facilitate dissemination and adoption of best practices, increase clinical efficiencies, and reduce costs by providing care as close to home as possible. Further exploration of the utility of existing telehealth services for the diagnosis and treatment of ASD is warranted. Perhaps additional telehealth networking opportunities through DDD Regional Office facilities should be included in this statewide effort.

GOAL 2: To develop recommendations for expanding services with hospitals after review of specialty clinic/hospitals and inpatient care

In assessing the current status of such care in Missouri, the Subcommittee established that there is little empirical information about specialty clinics' and hospitals' care of individuals with ASDs in the state. This is a major barrier to further planning in this regard. However, public testimony at the Blue Ribbon Panel on Autism highlighted major problems with access to adequate specialty care with a particularly acute need for effective inpatient services. We recognize that there is an unmet need for medical care for children and adults with ASDs statewide and envision an integrated network of providers with several centers for ASD medical treatment as a component of the diagnostic Missouri Autism Centers network described above.

1. To begin to build a basis for medical care recommendations, input was sought from Stephen Kanne, PhD, ABPP, Associate Director and Neuropsychologist from the MU Thompson Center who is involved with the national Autism Treatment Network (ATN) collaborative; and Dan Coury, MD, Medical Director of ATN, during his visit to Columbia in April 2010. Establishing standards for medical care for ASD is currently under investigation and there are very few published guidelines for best practice at this time. Based on the topics of current research projects, recommendations are expected to be published incrementally over the next few years. The first recommendations regarding care for gastrointestinal disorders in individuals with ASDs were published in 2010 and were incorporated into this discussion as a model for things to come. Ultimately, data-based recommendations and national standards for ASD medical and mental health care should serve as the basis for establishing such programs in Missouri. The committee recommends continuing communication with Dr. Kanne and Dr. Coury as well as monitoring the published literature for best practice guidelines.
2. The Subcommittee met with Patsy Carter, PhD, from the Division of Comprehensive Psychiatric Services and reviewed current data on inpatient mental health care for children with ASDs. Again, the empirical data are limited with regard to the specific ASD population, but the consensus is that mental health care services are becoming harder to access overall and that data collection and evaluation of such care is complex because of the variability in private and public locations for care.

GOAL 3: To recommend individuals to participate in a committee charged with developing screening, diagnostic, assessment and treatment standards for Missouri

This goal has been largely met with the publication in April 2010 of the book, *Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment* (www.autismguidelines.dmh.mo.gov). The book resulted from a collaborative project sponsored by DDD and the Thompson Foundation for Autism. The project involved more than 40 professionals, parents, and Office of Autism (OAS) staff working together for more than a year to produce a consensus document which has been distributed free of charge to thousands of Missouri physicians, psychologists, therapists, educators, parents, and others through a grant from the Missouri Foundation for Health (MFH).

A similar process leading to a companion publication on treatment standards for ASDs is underway and is strongly endorsed by the Subcommittee.

GOAL 4: To examine information barriers to accurate information of reporting ASD prevalence across the state and recommend a process for accurate reporting

1. With regard to prevalence data, the Subcommittee reviewed the current national prevalence data from various research projects and noted that they all coalesce around a current prevalence statistic of approximately 1%. These national research projects include the Centers for Disease Control and Prevention's ongoing ADDM project referenced above which includes the five counties in the St. Louis region (St. Louis City and St. Louis, St. Charles, Jefferson, and Franklin counties) and reported a prevalence of 1.2% in 2010.
2. In discussion with Heidi Atkins Lieberman, we learned that the Department of Elementary and Secondary Education (DESE) has established a relatively new student identification number phased in over the last few years for all children in Missouri public schools. This is a different number from the Department Client Number (DCN) given to children born in Missouri and/or accessing state services. The possibility of integrating identification data related to young children is being discussed at a number of levels and could provide an opportunity for discussion of coordination of data collection including young children with ASDs in the future.
3. We identified the lack of a single database in Missouri for data collection across systems such as education, health, mental health, child welfare, etc., and the lack of any voluntary reporting system for those diagnosing ASDs. In consideration of the voluntary reporting option, we evaluated information from the Schaefer Autism Report on New Jersey's voluntary registry project (www.sarnet.org/lib/todaySAR14-htm), reviewed the report on options for ASD surveillance in Maine (January 2007), and discussed the logistical and financial implications of such a project within Missouri. There was little enthusiasm for this approach at the present time due to the expense of such an undertaking and the notable lack of compliance in other states.
4. The Subcommittee met with Paul Law, MD, from the IAN Project to discuss the possibility of adding a Missouri-specific gateway at the beginning of the IAN online registration site. This would provide the opportunity to obtain additional information relevant to Missouri families. Although Dr. Law was supportive of this possibility, he was unable to provide staff or funding support. Subsequent discussions among Dr. Janet Farmer, OAS,

and others on the Subcommittee have kept this option open. As yet, we have not had the requisite funding to explore this process further, but the Subcommittee and its members remain interested in this possibility.

In summary, it is the Subcommittee's opinion there is no existing database or reasonable short-term probability of producing a Missouri-specific registry for ASDs. Current national prevalence figures are consistent enough to use operationally in terms of planning, but continuing discussion about integration of current databases, including information relative to ASDs, is recommended.

BARRIERS AND CHALLENGES: Potential barriers and challenges associated with the goals were identified and discussed. They included the recognition of the complexity of the current systems of diagnostic and care provision within the state for those with ASDs, the lack of data regarding inpatient and medical care services for those with ASDs, the lack of established guidelines for medical and mental health care for ASDs, and the lack of a single or coordinated dataset integrating health, mental health, educational, and other services to enable better documentation and analysis of current trends and opportunities.

In closing, it is appropriate to recognize an individual who has supported this committee but who has moved on from direct involvement. We appreciate the invaluable support provided by Katie Dunne, MS, Project Development Specialist with the MU Thompson Center.

Individual and Family Supports Subcommittee

Individuals with autism and their families should receive care which affords the support, assistance, and access to services that permits them to achieve their greatest potential.

– Mission Statement

GOAL DEVELOPMENT: The Individual and Family Supports (IFS) Subcommittee organized itself first by reviewing the Missouri Commission on Autism Spectrum Disorders' framework document for state plan development. Guidance from that document included bulleted topics that the Commission recommended as areas of common ground for consideration by all subcommittees. The Commission recognized at the outset that the goals and actions developed by the IFS Subcommittee might include a broad range of issues due to the wide range of family needs across individuals with ASDs throughout their lifespan, across the state, and across different populations of families.

Initially, concern was expressed that some of the goals and action steps developed by the IFS Subcommittee might actually duplicate work from other subcommittees. The IFS Subcommittee did agree that its work was not constrained by the legislative "shall(s)" and "may(s)" and could expand its initiatives, notably to include the recommendations of the Missouri Blue Ribbon Panel on Autism. The Subcommittee further agreed that it should address the issues that families experience within the home environment, the long-term needs of adults with ASDs which are not covered under the Workforce Development Subcommittee, and delivery of services in underserved urban and rural areas in Missouri.

GOAL 1: To evaluate the strengths and weaknesses of regional service areas throughout the state of the support provided to children and adults with ASDs and their families within their homes and communities and to assess ways to expand access to behavior intervention capabilities in both urban and rural regions

GOAL 2: To expand availability of access to information regarding services and support for individuals with ASDs throughout their lifespan. This would include individualized assistance in navigating the system of care.

GOAL 3: To develop autism-specific training programs across state agencies, enhancing existing training programs as practicable and, in addition, ensuring that training is made available to families and to direct support professionals

GOAL 4: To develop a statewide service delivery plan specifically addressing the needs for specialized services for adults with ASDs. This plan shall address work, housing, transportation, community integration, eldercare, and other needs as identified and shall include strategies for implementation.

BARRIERS AND CHALLENGES: Barriers and challenges around goal development and action steps arose from both a systems and a scope perspective. As the Commission moves from state plan adoption to state plan implementation, the established goals will necessarily be refined so that more focused scopes are identified to encompass relevant state agencies, the provider community, families, and other stakeholder groups. Additionally, as acknowledged earlier in the plan, disparate information systems among agencies is an ongoing challenge that requires close collaboration and resource commitment to capture meaningful data upon which policy recommendations can be made with credibility. An identified resource that may be helpful in collecting data across environments is the potential to access existing councils, committees, boards, etc. where networking about this topic is already in process. Likewise, determining outcome measures requires refinement to scope and system, and the IFS Subcommittee will collaborate closely with other subcommittees to avoid duplication of effort as the plan moves from adoption to implementation. Finally, the lack of clearly identified model programs, especially regarding adult services has presented its own set of challenges, since few model programs exist in the nation. Model programs that emerge would also likely need to be adapted for various populations, programs, and ages.

RESOURCES: The IFS Subcommittee utilized a variety of means to inform its work. Articles about care for children with special health care needs and care coordination were consulted. Additionally, the Subcommittee recommended collecting information regarding models of parent training, respite, and service delivery to underserved urban and rural areas. The Subcommittee also consulted with Patsy Carter, PhD, Clinical Director for Children and Youth for DMH, to discuss the issues of dual diagnosis, accessing the mental health system, and how to access crisis care.

In developing recommendations for adult services, the Subcommittee had the opportunity to consult with Peter Gerhardt, EdD, by phone to obtain his views on adult and vocational services for individuals with ASDs. The Subcommittee further reviewed the report from the Advancing Futures for Adults with Autism (AFAA) 2009 Think Tank Report, the State of Texas Department of Aging and Disability Services Study on the Costs and Benefits of Initiating a Pilot Project to Provide Services to Adults with Autism Spectrum Disorders and Related Disabilities, and the quality indicators for adult services recommended by the National Association of Residential Providers for Adults with Autism (NARPA).

The Subcommittee recognized the existence of the Office of Autism’s Navigation Guide as a positive step in the effort to provide families with core, credible information at the time of diagnosis. Conversely, a gap in resources is information and tools to reach diverse populations with information about autism, its identification, and treatment options.

Finally, the IFS Subcommittee recognized the need to develop and expand training for parents and for direct care workers who may not have the opportunity to access higher education offerings to develop an understanding of ASDs and support skill sets.

It would be remiss of the IFS Subcommittee not to recognize the effort of one individual whose leadership provided critical structure around a committee whose purview could legitimately be considered all-encompassing. That person is Anne Roux, MA, CCC-SLP, former Chair of the Individual and Family Supports Subcommittee and former Executive Director of MO-FEAT, St. Louis.

Workforce Development Subcommittee

GOAL DEVELOPMENT: While the legislation did not specifically address employment for individuals with ASDs, the Workforce Development Subcommittee of the Missouri Commission on Autism Spectrum Disorders enthusiastically organized itself around the need for training and employment of individuals with ASDs with specific requirements of the statute in mind. The following goals were developed after an extensive review of the literature, analysis of available resources concerning employment for individuals with ASDs, and a review of employment goals in other state plans:

GOAL 1: To develop more effective and consistent collaboration at the state, regional, and local levels to improve statewide capacity to employ individuals with ASDs

It is important to bring together funders of employment services, including the Department of Elementary and Secondary Education’s (DESE), Division of Vocational Rehabilitation (DVR), the Division of Developmental Disabilities (DDD), Missouri’s sheltered workshops, and SB40 Boards to review funding and other policies which affect the employment of individuals with ASDs. Per Blue Ribbon Report recommendations, DVR has designated a statewide director of autism who will train counselors in each region to work specifically with individuals with ASDs. DDD now has a Director of Employment and Training and each of the Regional Offices now has an employment coordinator.

GOAL 2: To develop and implement practical and credible education/training at the state, regional, and local levels to improve statewide capacity to employ individuals with ASDs

Members of the Subcommittee reviewed training opportunities targeted specifically for individuals with ASDs that are available for providers of employment services. DVR provides the majority of training for providers of employment services in Missouri, along with some private agencies such as TouchPoint Autism Services and Judevine. The Subcommittee identified and reviewed various training packages specific to the ASD population developed by Scott Standifer, PhD, James Emmett, PhD, and Peter Gerhardt, EdD, as well as the Missouri affiliate of the Association for Persons in Supported Employment (APSEMO) and Technical Assistance and Continuing Education (TACE). Work by the State Employment Leadership Network (SELN) was reviewed as well.

GOAL 3: To develop and disseminate practical and credible resources at the state, regional, and local levels to improve statewide capacity to employ individuals with ASDs

The Subcommittee determined that it is important to raise awareness so that the general public is able to consider and understand, engage, and support adults with autism and their potential contributions in the workforce. This includes providers, educators, and employers.

The Subcommittee compiled and published a list of resources currently available to assist individuals with ASDs in accessing and maintaining employment which includes helpful websites, books, practical information developed by employment experts, transition information, and a list of state offices which assist with employment including DVR, Career Centers, and DDD Employment Services. The resource list is available on the OAS website and the DVR website.

GOAL 4: To establish integrated data systems among public and private stakeholders to track employment data and employment outcomes for individuals with ASDs

In order to track progress toward the goal of increasing the number of people with ASDs in Missouri who are employed, it is vital to know how many individuals with ASDs are currently employed. The DVR tracks the numbers of individuals that they fund who are successfully placed in jobs on a yearly basis, but the data is not readily available from other state agencies. The Subcommittee recommends that all state agencies involved in funding employment of persons with disabilities develop a system for tracking the numbers of individuals with ASDs who are employed.

GOAL 5: To develop efficient and effective funding systems at the state, regional, and local levels to improve statewide capacity to employ individuals with ASDs

The review of other state ASD plans includes a variety of suggestions for providing incentives for employers to hire individuals with ASDs. The Subcommittee recommends collaboration of employment-related agencies such as the Career Centers, Department of Economic Development, Chambers of Commerce, statewide industry councils, etc. to educate employers about the benefits of hiring people with ASDs.

BARRIERS AND CHALLENGES: Potential barriers and challenges associated with the goals were identified and discussed. They included the ability to gather accurate data on the number of people with ASDs who are currently employed in Missouri and the number waiting for employment, promoting interagency collaboration, enlisting participation from relevant stakeholders and employers, costs associated with training providers of employment services and employers, as well as the current economic climate and unemployment rate.

Finally, the Workforce Development Subcommittee wishes to express its gratitude to Darla Wilkerson, former Director of Employment and Training for the DDD, for her assistance and expertise in the early stages of goal development.

Show-Me

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ism Spectrum

Appendix A

MISSOURI COMMISSION ON AUTISM SPECTRUM DISORDERS SUBCOMMITTEE MEMBERS

Education Subcommittee

Connie Hébert, MS Ed, Chair

Director, Southeast Missouri State University Autism Center for Diagnosis and Treatment, Cape Girardeau

Stephen Barr, PhD, Assistant Commissioner, Office of Special Education, Department of Elementary and Secondary Education, Jefferson City

Bridget Johnston, MPA

Research Associate, Academic Affairs, Department of Higher Education, Jefferson City

Sue Schoemehl

Missouri State Representative, 100th District, St. Louis County

Phyllis Wolfram, MS

Special Services Director, Ozark R-VI School District, Ozark

Ad Hoc Member:

Joanie Armstrong, MS

Director, Project ACCESS, Missouri State University, Springfield

Technical Support Provided by:

Kit Glover, MEd, Coordinator, Office of Autism Services, Division of Developmental Disabilities, Department of Mental Health, Jefferson City

Teresa Rodgers, PhD, BCBA, Chief Behavior Analyst, Division of Developmental Disabilities, Department of Mental Health, Jefferson City

Robin Rust, MPA, Director of Federal Programs, Division of Developmental Disabilities, Department of Mental Health, Jefferson City

Healthcare Subcommittee

John F. Mantovani, MD, Chair

Medical Director and Chief of Child Neurology, St. John's Mercy Children's Hospital and Child Development Center, St. Louis

Paula Baker, MS, Freeman Chief Clinical Officer and CEO of the Ozark Center, Joplin

Julie Creach, Interim Deputy Division Director of Operations, MO HealthNet Division, Department of Social Services, Jefferson City

Janet Farmer, PhD, ABPP, Director of Academic Programs, MU Thompson Center for Autism and Neurodevelopmental Disabilities, Columbia

Gary Harbison, MA, LPC, NBCC, ACMHA, Chief, Bureau of Special Health Care Needs, Department of Health and Senior Services, Jefferson City

Michele Kilo, MD, Section Chief, Developmental and Behavioral Sciences, Children's Mercy Hospital and Clinics, Kansas City

Molly White, MHA, Insurance Regulatory Manager; Healthcare and Life Section; Department of Insurance, Financial Institutions, and Professional Registration; Jefferson City

Technical Support Provided by:

Monica Hoy, Office of the Director, Department of Mental Health, Jefferson City

Kit Glover, MEd, Coordinator, Office of Autism Services, Division of Developmental Disabilities, Department of Mental Health, Jefferson City

Individual and Family Supports Subcommittee

Rebecca Blackwell, MA, BCBA, Chair
President/Director, Judevine Center, St. Louis

Lee Bascom, MSW, LCSW, St. Louis

David Crowe, DDS, Executive Director, Tailor Institute, Cape Girardeau

Technical Support Provided by:

Office of Autism Services, Division of Developmental Disabilities, Department of Mental Health, Jefferson City

Workforce Development Subcommittee

Vicki McCarrell, MA, Chair
Executive Director, Unlimited Opportunities, Inc., Boonville

Rebecca Blackwell, MA, BCBA, President/Director, Judevine Center, St. Louis

Jean-Paul Bovee, MA, MALS, Kansas City

Tiffany Daniels, Springfield

Ad Hoc Member:

Karla Bunch, MS, Assistant Director of Special Projects and Proprietary Schools, Division of Vocational Rehabilitation, Department of Elementary and Secondary Education, Jefferson City

Technical Support Provided by:

Anita Contreras, Eastern District Administrator, Division of Disabilities, Department of Mental Health, St. Louis

Nancy Nickolaus, MSW, LCSW, Director of Employment and Training, Division of Developmental Disabilities, Department of Mental Health, Jefferson City

Katherine Pigg, Project Specialist, Office of Autism Services, Division of Developmental Disabilities, Department of Mental Health, Springfield

State Plan

Appendix B

EDUCATION SUBCOMMITTEE GOAL NUMBER 1

1

To conduct an assessment of the need for coordinated, enhanced and targeted special education capabilities within each region of the state {633.200.6(2) RSMo}

Perceived Barriers or Challenges

1. Low school district response rate to surveys:
 - Project ACCESS survey has historically received low response with about 15% of districts responding – about 78 of 525 districts
 - Missouri Council of Administrators of Special Education (MO-CASE) survey used in Missouri School Boards' Association (MSBA) Autism Task Force deliberations received 63 district responses – or 12% response
2. Common definitions for terms used in statute

Resources – may be experts, articles, books, etc.

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3. Executive Summary: Educating Children with Autism (www.nap.edu/catalog/10017.html)
4. Project ACCESS FY 2009 Impact Data
5. MoSTEP 1.2.1.1: Selected SPED Cross-Categorical Education Competencies (For: All General Education Majors / Differentiated Instruction: Approved by Missouri State Board of Education (MSBE – August 2008)
6. Joanie Armstrong – Project ACCESS
7. Janet Farmer, PhD, ABPP – MU Thompson Center for Autism and Neurodevelopmental Disorders

Action Steps – list steps necessary to achieve the goal

- 1.1 Compare and contrast Project ACCESS survey with MO-CASE survey
- 1.2 Decide what needs to be assessed
- 1.3 Develop tool for assessment
- 1.4 Engage appropriate individuals to increase survey participation
- 1.5 Quantify results
- 1.6 Identify gaps based upon survey results
- 1.7 Formulate recommendation for state plan

Timelines

Projected Start Date:
November 2009

Projected Completion Date:
Ongoing

Partners – private entities, advocacy groups, state agencies, etc.

- Lead Role(s):**
1. Education Subcommittee
 2. DESE
 3. DHE
 4. OAS, DDD

- Supporting Role(s):**
1. Commission on Autism Spectrum Disorders
 2. Project ACCESS and MO-CASE

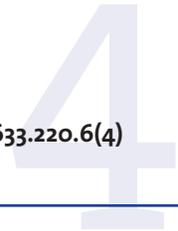
To develop a recommendation for enlisting appropriate universities and colleges to ensure support and collaboration in developing certification or degree programs for students specializing in autism spectrum disorder intervention {633.200.6(3) RSMo}

<p>Perceived Barriers or Challenges</p>	<ol style="list-style-type: none"> 1. Knowing what currently exists in Missouri universities and colleges in order to make an informed recommendation 2. Ensuring statistically valid sampling of institutions of public learning in order to make an informed recommendation 	
<p>Resources – may be experts, articles, books, etc.</p>	<ol style="list-style-type: none"> 1. Department of Higher Education (DHE) 2. Project ACCESS 3. Offices of Disabilities (institutions of higher education) 4. Missouri Association on Higher Education and Disability (MO-AHEAD) 5. Expanding College for Exceptional Learners (EXCEL) College Initiative – www.ThinkCollege.net, www.transitiontocollege.net, www.education.uiowa.edu/reach/, www.education.umd.edu/oco, www.heath.gwu.edu 	
<p>Action Steps – list steps necessary to achieve the goal</p>	<ol style="list-style-type: none"> 2.1 Develop a survey to be sent to Missouri colleges and universities to gauge what is currently being offered 2.2 Send survey out under the authority of Robert Stein, PhD, Commissioner, Department of Higher Education 2.3 Analyze and sort survey responses by 1) coursework offered specific to ASDs; 2) coursework offered specific to applied behavior analysis; 3) coursework offered specific to both ASDs and applied behavior analysis; and 4) institutions indicating future development of coursework specific to ASDs, applied behavior analysis, or both 2.4 Synthesize external resource information to inform state plan recommendation 	
<p>Timelines</p>	<p>Projected Start Date: October 2009</p>	<p>Completion Date: August 2010</p>
<p>Partners – private entities, advocacy groups, state agencies, etc.</p>	<p>Lead Role(s):</p> <ol style="list-style-type: none"> 1. Education Subcommittee 2. DHE 3. Office of Autism Services, Division of Developmental Disabilities 	<p>Supporting Role(s): Commission on Autism Spectrum Disorders</p>

3

To provide recommendations regarding training programs and the content of training programs being developed {633.220.6(4)(a) RSMo} to ensure a variety of training opportunities that reflect the application of best practice and standards of care for individuals with ASDs

<p>Perceived Barriers or Challenges</p>	<p>Diverse trainings conducted by various groups, e.g., provider groups, secondary and higher education, developmental disabilities, vocational rehabilitation, employment, workforce development, in seeming isolation of each other</p>	
<p>Resources – may be experts, articles, books, etc.</p>	<ol style="list-style-type: none"> 1. Central Missouri Rapid Response Initiative – electronic training modules: <ul style="list-style-type: none"> • Understanding Autism • Screening and Referral 2. Missouri Autism Centers Training Plan – FY 2008 and following 3. Project ACCESS 4. National Standards Project 	
<p>Action Steps – list steps necessary to achieve the goal</p>	<ol style="list-style-type: none"> 3.1 Compile a directory of training, listing entities or agencies which conduct ASD training to ensure application of best practice and standards of care 3.2 Connect the disparate groups in ways that promote common goals and outcomes and avoid duplication with emphasis on best practices 3.3 Contact Department of Mental Health (DMH) System Transformation Action Plan Chairperson to coordinate efforts between the commission and DMH Transformation workgroup 3.4 Pool resources for greater leverage 	
<p>Timelines</p>	<p>Projected Start Date: Spring 2010</p>	<p>Projected Completion Date: Ongoing</p>
<p>Partners – private entities, advocacy groups, state agencies, etc.</p>	<p>Lead Role(s):</p> <ol style="list-style-type: none"> 1. All 4 subcommittees of the Commission 2. Office of Autism Services, Division of Developmental Disabilities 	<p>Supporting Role(s):</p> <ol style="list-style-type: none"> 1. Central Missouri Rapid Response Initiative 2. Missouri Autism Centers 3. Project ACCESS



To participate in recommending a panel of qualified professionals and experts to review evidence-based educational practices for adaptation specific to Missouri {633.220.6(4) (c) RSMo}

<p>Perceived Barriers or Challenges</p>	<ol style="list-style-type: none"> 1. Convening a panel of experts 2. Competing points of view about evidence-based practice 3. Assuring representation of varying view points 4. Capturing lifespan initiatives 	
<p>Resources – may be experts, articles, books, etc.</p>	<ol style="list-style-type: none"> 1. Missouri Autism Guidelines Initiative on which there was representation from Missouri School Boards’ Association (MSBA) and Project ACCESS and Missouri Council of Administrators of Special Education (MO-CASE) 2. MSBA’s Autism Task Force: Recommendations for Policy and Practice in Missouri (March 2009) 3. <i>Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment</i> (Spring 2010) 4. National Standards Project published by the National Autism Center (December 2009) 	
<p>Action Steps – list steps necessary to achieve the goal</p>	<ol style="list-style-type: none"> 4.1 Contact MSBA for further communication regarding best practices in education 4.2 Communicate with Department of Elementary and Secondary Education (DESE) for best practice/evidence-based educational practices 	
<p>Timelines</p>	<p>Projected Start Date: Spring 2010</p>	<p>Projected Completion Date: Ongoing</p>
<p>Partners – private entities, advocacy groups, state agencies, etc.</p>	<p>Lead Role(s):</p> <ol style="list-style-type: none"> 1. Education Subcommittee 2. DESE 	<p>Supporting Role(s):</p> <ol style="list-style-type: none"> 1. Commission on Autism Spectrum Disorders 2. Project ACCESS

To determine the need for creation of additional centers of diagnostic excellence {633.2.00. 6(1)(a) RSMo}

Perceived Barriers or Challenges

1. Determining best estimates of distribution of individuals with ASDs throughout the state and compile regional estimates of prevalence
2. Determining present situation for diagnosis: site of diagnosis; single practitioner versus team (Tier 1 vs. Tiers 2 and 3 in *Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment* terminology); private practitioner vs. university center; specialty distribution of diagnosticians (pediatrics, neurology, psychology, psychiatry, other)
3. Evaluating how these sites for diagnosis and diagnosticians vary for different regions of the state
4. Evaluating options for distribution of diagnostic capacity: additional Missouri Autism Centers, practitioner network, telehealth network utilization through existing sites of Missouri Telehealth Network (MTN), Department of Mental Health (DMH) Regional Offices, other
5. Determining optimal number and distribution of practitioners and sites for diagnosis including estimates of Tier 1, 2, and 3 diagnostic needs and how the interdisciplinary assessment process will coordinate with the diagnostic process

Resources – may be experts, articles, books, etc.

1. Use current CDC data and best estimates from Missouri data sources: IDEA, Regional Offices, Missouri Autism Centers, other
2. Compile data on diagnosis from current Missouri Autism Centers
3. Compile ADDM surveillance data (John Mantovani, MD, working with Rob Fitzgerald, MPH, at Washington University Medical Center)
 - Dr. Mantovani’s literature review – what’s happening elsewhere around the country
 - Current Thompson Center telehealth utilization: interview and discuss with Paula Slusher, RN, CPNP
 - Evaluate other capacity for telehealth connections (Regional Offices, etc.)
4. Explore Missouri Foundation for Health (MPH) as possible funder for ASD telehealth services
5. Involve Pam Kelly, Assistant Director of MTN, and others as needed
6. MTN Provider Bulletins on telehealth:
 - www.dss.mo.gov/mhd/providers/pdf/bulletin32-02_2009jul15.pdf
 - www.dss.mo.gov/mhd/providers/pdf/bulletin31-47_2009mar12.pdf
 - www.dss.mo.gov/mhd/providers/pdf/bulletin32-08_2009aug7.pdf

Action Steps – list steps necessary to achieve the goal

- 1.1 Improve access to care by creating a network of professional expertise (enlisting help of American Academy of Pediatrics-Missouri Chapter, organizing group similar to Missouri Autism Guidelines Initiative)
- 1.2 Connect diagnosis to treatment in an organized way (seamless path from diagnosis to intervention planning)
 - 1.2.a Assess the current status of the assessment and treatment processes following diagnosis to identify opportunities for improving the bridges between these processes—First Steps, school districts, and other community providers

1

CONTINUED

Action Steps – list steps necessary to achieve the goal

- 1.3 Broaden role of medical treatment and ongoing care at the specialty level to provide services to patients/families
 - 1.3.a Expand and organize the medical support and treatment programs to create a new network of autism treatment centers (see item 2.2)
- 1.4 Continue to work with ADDM to inform diagnostic and network services for the St. Louis region
- 1.5 Explore telehealth as a potentially innovative diagnostic milieu – Consult with Rachel Mutrix, Director of MTN:
 - 1.5.a What is the telehealth network like in Missouri?
 - 1.5.b How is telehealth used in Missouri?
 - 1.5.c How many patients with developmental disabilities are seen via telehealth?
 - 1.5.d Which sites are most active with the population?
 - 1.5.e How are appointments set up?
 - 1.5.f How does reimbursement for both sites work?
 - 1.5.g Does insurance help cover these appointments?

Timelines

Projected Start Date:
August 2009

Projected Completion Date:
Ongoing

Partners – private entities, advocacy groups, state agencies, etc.

- Lead Role(s):**
- 1. Healthcare Subcommittee
 - 2. Missouri Autism Centers

- Supporting Role(s):**
- 1. Commission on Autism Spectrum Disorders
 - 2. American Academy of Pediatrics – Missouri Chapter
 - 3. Missouri Academy of Family Practitioners
 - 4. MO HealthNet Division
 - 5. MTN

2

HEALTHCARE SUBCOMMITTEE

GOAL NUMBER 2

To develop recommendations for expanding services with hospitals after review of specialty clinic/hospitals and inpatient care {633.200.6(1)(d) RSMo}

<p>Perceived Barriers or Challenges</p>	<ol style="list-style-type: none"> 1. Lack of empirical information about specialty clinics/hospitals serving persons with ASDs. 2. Understanding the needs based on specialty and geography, and capitalizing on existing structures/capabilities 3. Recognition that the broad range of medical needs for those with ASDs are underserved statewide and will require an integrated network of providers and a few new centers for autism medical treatment to coordinate and support the process 	
<p>Resources – may be experts, articles, books, etc.</p>	<ol style="list-style-type: none"> 1. Access specialty care algorithms as they become available through the Autism Treatment Network (ATN) and other sources (collaboration with Stephen Kanne, PhD, ABPP; Janet Farmer, PhD, ABPP; and Michele Kilo, MD) to aid in determining baseline information 2. Ongoing contact with Dan Coury, MD, (Medical Director, Autism Treatment Network) 3. Access to Care Survey results from MU Thompson Center for Autism and Neurodevelopmental Disorders (MU Thompson Center) via IAN 4. Report from Patsy Carter, PhD, from Comprehensive Psychiatric Services on inpatient care for children with ASDs 5. Care Management Technologies (provides data analytics around Medicaid paid claims) 6. Report from John Mantovani, MD, on Autism and Developmental Disabilities Monitoring results for St. Louis: distribution of diagnostic specialists, etc. 7. Inclusion of newest research publications from ATN, eg., Buie T.et al. (2010). Evaluation, diagnoses, and treatment of gastrointestinal disorders in individuals with ASDs: A consensus report. <i>Pediatrics</i>, 125(suppl), S1-S29 	
<p>Action Steps – list steps necessary to achieve the goal</p>	<ol style="list-style-type: none"> 2.1 Meet with Dr. Dan Coury during Autism Intervention Conference about ATN algorithms 2.2 Begin the process of organizing and networking a small number of autism medical treatment centers statewide to supplement the diagnostic and treatment programs—define levels of care and specialty representation 2.3 Revisit ATN quality improvement initiative for algorithms for targeted referral and outcome measures with possible adaptation for Missouri 2.4 Develop capacity from empirical information with emphasis on innovation and technology 2.5 Arrange meeting between Joe Parks, MD, Chief Medical Officer, Department of Mental Health, and Healthcare Subcommittee regarding what data Care Management Technologies could provide around questions implicit in this goal 	
<p>Timelines</p>	<p>Projected Start Date: 2009</p>	<p>Projected Completion Date: Ongoing</p>
<p>Partners – private entities, advocacy groups, state agencies, etc.</p>	<p>Lead Role(s): Healthcare Subcommittee</p>	<p>Supporting Role(s):</p> <ol style="list-style-type: none"> 1. Missouri Commission on Autism Spectrum Disorders 2. Experts from specialty clinics

To recommend individuals to participate in a committee charged with developing screening, diagnostic, assessment, and treatment standards for Missouri {633.200.6(4)(b) RSMo}

Perceived Barriers or Challenges	<ol style="list-style-type: none"> 1. Lack of consistent best practice standards 2. Assembling a panel with representative expertise, including families 	
Resources – may be experts, articles, books, etc.	<ol style="list-style-type: none"> 1. Members of the Missouri Autism Guidelines Initiative 2. California’s best practice guidelines—to be adapted as necessary for Missouri usage 3. Thompson Foundation for Autism 4. Division of Developmental Disabilities (DDD) 5. Missouri’s Blue Ribbon Report on Autism 	
Action Steps – list steps necessary to achieve the goal	<ol style="list-style-type: none"> 3.1 Assemble (with input from the Missouri Commission on ASD) a panel of experts to develop best practice guidelines for Missouri. This group is known as the Missouri Autism Guidelines Initiative 3.2 Conduct a literature review 3.3 Meet with stakeholders 3.4 Develop best practice guidelines for the state of Missouri 3.5 Develop ongoing training, dissemination, and implementation plan 3.6 Disseminate the guidelines through a coordinated statewide effort involving Missouri Autism Guidelines Initiative members, parent and professional groups, and marketing 3.7 Determine impact of best practice guidelines 3.8 Support the development of a document to serve as a reference and users’ guide for the treatment of ASDs which will serve as a companion to the previously published <i>Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment</i> 	
Timelines	Projected Start Date: 2008	Projected Completion Date: Ongoing
Partners – private entities, advocacy groups, state agencies, etc.	Lead Role(s): <ol style="list-style-type: none"> 1. Thompson Foundation for Autism 2. Office of Autism Services, DDD 3. Missouri Autism Guidelines Initiative members 4. Missouri Commission on Autism Spectrum Disorders 	Supporting Role(s): <ol style="list-style-type: none"> 1. OAS, DDD 2. Missouri Parent Advisory Committee on Autism

To examine information barriers to accurate information of reporting ASD prevalence across the state and recommend process for accurate reporting {633.200.6(4)(d) RSMo}

<p>Perceived Barriers or Challenges</p>	<ol style="list-style-type: none"> 1. No single uniform database to collect data across systems, e.g., education, health, mental health, child welfare 2. Obtaining total state prevalence data; include persons not served by state agencies and breakdown by age and county of residence 	
<p>Resources – may be experts, articles, books, etc.</p>	<ol style="list-style-type: none"> 1. Department of Elementary and Secondary Education (DESE) grant opportunity for longitudinal data system 2. 2007 Report from Maine www.maine.gov/dhhs/reports/ASD_SurveillanceOptions.pdf 3. Missouri Autism Project Registry: Final Project Report and Recommendations, J.E. Farmer, J.H. Miles, and G. Demiris. University of Missouri-Columbia, June 30, 2005. 4. Article from Schafer Autism Report on New Jersey’s expanded voluntary registry. www.sarnet.org/lib/todaySAR14-6.htm 5. Interactive Autism Network (IAN) Project (national voluntary registry): www.ianproject.org 	
<p>Action Steps – list steps necessary to achieve the goal</p>	<ol style="list-style-type: none"> 4.1 Ensure that there is Department of Mental Health (DMH) representation on the P-20 Council so that longitudinal data opportunities are monitored 4.2 Get schedule of P-20 Council meetings and request meeting updates from DMH liaison 4.3 Explore autism census project for Missouri in the context of other statewide projects as in New Jersey and Pennsylvania 4.4 Support and/or encourage IAN as an information resource and opportunity to enroll in national voluntary registry 4.5 Explore the possibility of an external grant-supported project with experienced consultants and support from Missouri stakeholders, including parents, Missouri Autism Guidelines Initiative members, Missouri Autism Centers, etc 	
<p>Timelines</p>	<p>Projected Start Date: 2009</p>	<p>Projected Completion Date: Ongoing</p>
<p>Partners – private entities, advocacy groups, state agencies, etc.</p>	<p>Lead Role(s):</p> <ol style="list-style-type: none"> 1. Healthcare Subcommittee 2. Office of Autism Services, Division of Developmental Disabilities 	<p>Supporting Role(s):</p> <ol style="list-style-type: none"> 1. Missouri Commission on Autism Spectrum Disorders 2. P-20 Council 3. DESE 4. IAN 5. MO HealthNet Division

INDIVIDUAL AND FAMILY SUPPORTS SUBCOMMITTEE GOAL NUMBER 1

To evaluate the strengths and weaknesses of regional service areas throughout Missouri of support provided to children and adults with autism and their families within their homes and communities and assess ways to expand access to behavior intervention capabilities in both urban and rural regions {633.200.6(1)(c) RSMo}

1

<p>Perceived Barriers or Challenges</p>	<ol style="list-style-type: none"> 1. Lack of access to regional and statewide data 2. Need for development of outcomes measurements specific to autism services 3. Need for greater access to Board Certified Behavioral Analysts and skilled behavior interventionists outside of major cities 	
<p>Resources – may be experts, articles, books, etc.</p>	<ol style="list-style-type: none"> 1. Publicly accessible data from other agencies in Missouri and review of evaluations conducted in other states and resulting data 2. Review of outcomes measurement tools for individuals with autism and other developmental disabilities 3. MO-FEAT 4. Service providers specializing in services to individuals with ASDs 	
<p>Action Steps – list steps necessary to achieve the goal</p>	<ol style="list-style-type: none"> 1.1 Develop a provider survey on family needs for a biannual assessment of access to, utilization and effectiveness of services and supports; and identification of unmet needs and resulting gaps in services and supports 1.2 Create an online database of services available in the state kept by the Division of Developmental Disabilities’ (DDD) Office of Autism Services (OAS) 1.3 Provide annual data from each state agency represented on the Missouri Commission on Autism Spectrum Disorders regarding services/supports/numbers served/money spent 1.4 Establish a care coordination system for individuals with ASDs who are dually diagnosed and support for their families or caretakers 1.5 Identify alternate means of addressing service and support needs for individuals and families living in areas with limited access to care (e.g., rural and inner city regions) 	
<p>Timelines</p>	<p>Projected Start Date: August 2010</p>	<p>Projected Completion Date: Ongoing</p>
<p>Partners – private entities, advocacy groups, state agencies, etc.</p>	<p>Lead Role(s):</p> <ol style="list-style-type: none"> 1. OAS, DDD 2. All four subcommittees of the Commission 	<p>Supporting Role(s):</p> <ol style="list-style-type: none"> 1. Missouri Planning Council for Developmental Disabilities 2. DDD Regional Offices 3. Division of Comprehensive Psychiatric Services, Department of Mental Health

To expand the availability of and access to information regarding services and support for individuals with ASDs throughout their lifespan. This would include individualized assistance in navigating the system of care.

2

<p>Perceived Barriers or Challenges</p>	<ol style="list-style-type: none"> 1. Financing and funding from different state agencies 2. Lack of coordinated supports and care
<p>Resources – may be experts, articles, books, etc.</p>	<ol style="list-style-type: none"> 1. Current Department of Mental Health (DMH) materials for staff and families regarding person-centered care, transition, etc. 2. Transition guides from school districts 3. Southwestern Autism Research and Resource Center (www.autismcenter.org/) 4. National organizations: (Autism Speaks (www.autismspeaks.org), Autism Society of America (www.autism-society.org), United States Autism and Asperger Association (www.usautism.org/), National Association of Residential Providers for Adults with Autism (www.narpaa.org), Advancing Futures for Adults with Autism (www.afa-us.org), etc. 5. OAS, <i>Navigating Autism Services: A Community Guide for Missouri</i> 6. Advancing Futures for Adults with Autism, 2009 Think Tank Report 7. Paul Shattuck, PhD, Washington University, St. Louis 8. State of Texas Department of Aging and Disability Services: Study on Costs and Benefits of Initiating a Pilot Project to Provide Services to Adults with Autism Spectrum Disorders and Related Disabilities as Mandated by HB1574 9. www.autismriskmanagement.com 10. Autism Speaks Transition Tool Kit www.autismspeaks.org/docs/family_services_docs/transition/Missouri.pdf 11. MO-FEAT
<p>Action Steps – list steps necessary to achieve the goal</p>	<ol style="list-style-type: none"> 2.1 Evaluate the availability and accessibility of individualized information and training for families and make recommendations for improvement. Needs and methods of information delivery should be defined by service providers, individuals with ASDs, and their families. Key identified topics include: <ol style="list-style-type: none"> 2.1.1 Evolving behavioral needs 2.1.2 Crisis intervention 2.1.3 Supports for individuals with dual diagnoses and their families 2.1.4 Physical growth and health including issues specific to changes in adolescence 2.1.5 Emergency preparation and training of emergency responders 2.1.6 Community-based recreation and leisure 2.1.7 Pharmacology and mental health issues 2.1.8 Respite 2.1.9 Residential services 2.1.10 In-home supports 2.1.11 Social skill development 2.1.12 Support for siblings and sib-shops 2.1.13 Specialized autism training (see Goal 3.) 2.2 Identify and promote a toll-free statewide autism response center. <ol style="list-style-type: none"> 2.2.1 Locate state agency to house and promote both a toll-free and web-based response center

Timelines	Projected Start Date: August 2009	Projected Completion Date: Ongoing
Partners – private entities, advocacy groups, state agencies, etc.	Lead Role(s): <ol style="list-style-type: none"> 1. OAS, DDD 2. Individual and Family Supports Committee 3. Family and caregiver stakeholders 4. Missouri Parent Advisory Committee on Autism 5. Service providers specializing in services to individuals with ASDs 6. MO-FEAT 7. Autism Society of America 	Supporting Role(s): <ol style="list-style-type: none"> 1. Missouri Planning Council for Developmental Disabilities 2. Family Support Division (FSD), Department of Social Services (DSS) 3. Department of Health and Senior Services (DHSS) 4. Division of Comprehensive Psychiatric Services (CPS), DMH

INDIVIDUAL AND FAMILY SUPPORTS SUBCOMMITTEE GOAL NUMBER 3

To develop autism-specific training programs across state agencies, enhancing existing training programs as practicable and, in addition, ensuring that training is made available to families and to direct support professionals

<p>Perceived Barriers or Challenges</p>	<ol style="list-style-type: none"> 1. An evolving knowledge base requiring dynamic updates to trainings 2. Access to trainings at regional level or via the internet 3. Interagency collaboration to include ASD-related issues into existing trainings 4. Lack of specialized training on ASDs for direct support providers (in-home supports, respite, personal care attendants, direct support professionals, etc.) 	
<p>Resources – may be experts, articles, books, etc.</p>	<ol style="list-style-type: none"> 1. Central Missouri Rapid Response Initiative’s electronic training modules: <i>Understanding Autism, Screening and Referral, and Autism Spectrum Disorders: Evidence-Based Practice and Interventions</i> 2. College of Direct Support’s autism modules 3. Specialized parent training service providers, such as TouchPoint Autism Services, Judevine Center, OCALI, etc. 4. Positive Behavior Supports curriculum 	
<p>Action Steps – list steps necessary to achieve the goal</p>	<ol style="list-style-type: none"> 3.1 Develop and implement a survey to assess ASD training needs across service coordinators, service implementers, and providers at least every 3 years to determine appropriate training competencies 3.2 Review and/or develop a training plan for service coordinators, service implementers, and other key providers that includes recommendations for training content, frequency of trainings, who should be trained, and process of training dissemination <ol style="list-style-type: none"> 3.2.1 Competencies and plans for training service coordinators and Qualified Developmental Disabilities Professionals (QDDPs) 3.2.2 Competencies and plans for training direct support professionals 3.3 Develop and implement training in crisis intervention strategies within and across environments with a focus on prevention of escalation to crisis states. Include crisis intervention strategies in training plans for items 3.2.1 and 3.2.2. Review work with Regional Offices behavior teams developed by DDD’s Chief Behavior Analyst for inclusion in training development 3.4 Develop and annually update a training directory listing training resources and providers across the state, both public and private, available by region 3.5 Based on information gleaned from 3.1 and 3.4, develop plan to ensure access to training in areas that are unserved or underserved 	
<p>Timelines</p>	<p>Projected Start Date: August 2009</p>	<p>Projected Completion Date: Ongoing</p>
<p>Partners – private entities, advocacy groups, state agencies, etc.</p>	<p>Lead Role(s):</p> <ol style="list-style-type: none"> 1. Office of Autism Services, Division of Developmental Disabilities 2. Individual and Family Supports Subcommittee 3. Service providers specializing in services to individuals with ASDs 	<p>Supporting Role(s):</p> <ol style="list-style-type: none"> 1. Missouri Planning Council for Developmental Disabilities 2. Division of Comprehensive Psychiatric Services (CPS), Department of Mental Health (DMH) 3. Family Support Division (FSD), Department of Social Services (DSS) 4. Children’s Division (CD), DSS 5. Department of Health and Senior Services (DHSS)



INDIVIDUAL AND FAMILY SUPPORTS SUBCOMMITTEE GOAL NUMBER 4

To develop a statewide service delivery plan specifically addressing the needs for specialized services for adults with ASDs. This plan shall address work, housing, transportation, community integration, eldercare, and other needs as identified, and shall include strategies for implementation



<p>Perceived Barriers or Challenges</p>	<ol style="list-style-type: none"> 1. Financing and funding from different state agencies 2. Lack of coordinated supports and care 3. Lack of specialized training and providers for adults with ASDs 	
<p>Resources – may be experts, articles, books, etc.</p>	<ol style="list-style-type: none"> 1. National organizations: (Autism Speaks (www.autismspeaks.org), Autism Society of America (www.autism-society.org), United States Autism and Asperger Association (www.usautism.org), National Association of Residential Providers for Adults with Autism (www.narpaa.org), Advancing Futures for Adults with Autism (www.afa-us.org), etc. 2. Advancing Futures for Adults with Autism, 2009 Think Tank Report 3. Paul Shattuck, PhD, Washington University, St. Louis 4. State of Texas Department of Aging and Disability Services: <i>Study on the Costs and Benefits of Initiating a Pilot Project to Provide Services to Adults with Autism Spectrum Disorders and Related Disabilities as Mandated by HB1574</i> 5. Commission on Accreditation of Rehabilitation Facilities 2011 <i>Employment and Community Services Standards Manual, Section 4N. Supports for Persons with Autism Spectrum Disorder (ASD-A)</i> 6. Specialized adult service providers such as TouchPoint Autism Services, Judevine Center 7. Special School District of St. Louis County SSD Transition Guidebook: <i>Through the Doorway to Adult Life</i> www.ssdmo.org/Step3.html 	
<p>Action Steps – list steps necessary to achieve the goal</p>	<ol style="list-style-type: none"> 4.1 Identify model systems which promote quality services and seamless coordination for adults with ASDs, including but not limited to individualized planning, funding options, self-directed supports, employment practices, housing and living arrangements, long term care, healthcare, higher education, family estate planning, and eldercare 4.2 Formulate service delivery plan and implementation strategies for specialized adult services for individuals with ASDs to include work, housing, transportation, and community integration 4.3 Recommend process for Missouri interagency collaboration and training for implementation 	
<p>Timelines</p>	<p>Projected Start Date: February 2011</p>	<p>Projected Completion Date: Ongoing</p>
<p>Partners – private entities, advocacy groups, state agencies, etc.</p>	<p>Lead Role(s):</p> <ol style="list-style-type: none"> 1. Office of Autism Services, Division of Developmental Disabilities 2. IFS Subcommittee 3. Service providers specializing in services to adults with ASDs 4. Autism Society of America – local chapters 5. Autism Speaks 	<p>Supporting Role(s):</p> <ol style="list-style-type: none"> 1. Missouri Planning Council for Developmental Disabilities 2. Division of Comprehensive Psychiatric Services, Department of Mental Health 3. Department of Health and Senior Services

To develop more effective and consistent collaboration at the state, regional, and local levels to improve statewide capacity to employ individuals with ASD

- The commission **SHALL** study and report on the means for developing a comprehensive, coordinated system of care delivery across the state to address the increased and increasing presence of autism spectrum disorder and ensure that resources are created, well-utilized, and appropriately spread across the state {633.200.6(1) RSMo}
- The commission **MAY** explore the need for the creation of interagency councils and evaluation of current councils to ensure a comprehensive, coordinated system of care for all individuals with autism spectrum disorder {633.200.6(4)(e) RSMo}

<p>Perceived Barriers or Challenges</p>	<ol style="list-style-type: none"> 1. The time, manpower, and funding required to identify: <ul style="list-style-type: none"> • Potential partners, initiatives, and models • Existing employment collaborations and gaps in collaborations • The best way to build strategic coalitions, and coordinate and promote inter-agency collaboration • Strategic coalitions and partnerships 2. Participation and representation from all critical stakeholders – individuals with ASDs, families, providers, educators, state/local agencies, and advocacy councils/foundations/entities 3. Enlisting participation from employers 	
<p>Resources – may be experts, articles, books, etc.</p>	<ol style="list-style-type: none"> 1. Karla Bunch, Division of Vocational Rehabilitation (DVR), Department of Elementary and Secondary Education (DESE) 2. Nancy Nickolaus, Division of Developmental Disabilities (DDD), Department of Mental Health (DMH) 3. Individuals with ASDs and their families 4. DES and other agencies who are involved in employment initiatives, collaborations, and coalitions 5. Providers of employment services 	
<p>Action Steps – list steps necessary to achieve the goal</p>	<ol style="list-style-type: none"> 1.1 Identify potential partners 1.2 Identify ASD employment initiatives and models of potential partners 1.3 Identify existing employment collaborations and gaps in collaborations 1.4 Identify the best way to build strategic coalitions, and coordinate and promote inter-agency collaboration 1.5 Facilitate strategic coalitions and partnerships to improve statewide capacity to employ individuals with ASDs 	
<p>Timelines</p>	<p>Projected Start Date: August 19, 2009</p>	<p>Projected Completion Date: Ongoing</p>
<p>Partners – private entities, advocacy groups, state agencies, etc.</p>	<p>Lead Role(s):</p> <ol style="list-style-type: none"> 1. Workforce Development Subcommittee 2. DVR, DESE 3. Missouri Community Transition Teams, DESE 4. Missouri Career Centers 5. DDD 6. Universities and colleges 	<p>Supporting Role(s): Missouri Commission on Autism Spectrum Disorders</p>



To develop and implement practical and credible education/training at the state, regional, and local levels to improve statewide capacity to employ individuals with ASD

- The commission SHALL study and report on the means for developing a comprehensive, coordinated system of care delivery across the state to address the increased and increasing presence of autism spectrum disorder and ensure that resources are created, well-utilized, and appropriately spread across the state {633.200.6(1) RSMo}
- The commission SHALL plan for effectively evaluating regional service areas throughout the state and their capacity, including outlining personnel and skills that exist within the service area, other capabilities that exist, and resource needs that may be unmet {633.200.6(1)(b) RSMo}
- The commission MAY provide recommendations regarding training programs and the content of training programs being developed {633.220.6(4)(a) RSMo}
- The commission MAY explore the need for the creation of interagency councils and evaluation of current councils to ensure a comprehensive, coordinated system of care for all individuals with autism spectrum disorder {633.200.6(4)(e) RSMo}

<p>Perceived Barriers or Challenges</p>	<ol style="list-style-type: none"> 1. Training time, costs associated 2. Schedules, opposition to change, costs, follow-up 3. Educating providers and employers 	
<p>Resources – may be experts, articles, books, etc.</p>	<ol style="list-style-type: none"> 1. Scott Standifer, <i>Adult Autism & Employment: A Guide for Vocational Rehabilitation Professionals</i> 2. 32nd IRI 2007, Institute on Rehabilitation Issues, Rehabilitation of Individuals with Autism Spectrum Disorders 3. James Emmett’s curriculum on career planning for Individuals with ASD 4. State Employment Leadership Network (SELN) 5. Missouri State Employment Workplan http://www.dmh.mo.gov/mrdd/employteam/employment.htm 6. Division of Vocational Rehabilitation (DVR), Department of Elementary and Secondary Education (DESE) 7. Technical Assistance and Continuing Education (TACE) 8. Association for Persons in Supported Employment in Missouri (APSEMO): The Network on Employment 9. Division of Developmental Disabilities’ (DDD) employment sector community-based providers 	
<p>Action Steps – list steps necessary to achieve the goal</p>	<ol style="list-style-type: none"> 2.1 Identify target audiences for training and education 2.2 Identify best practices for training/education of target audiences 2.3 Identify who is currently providing training, to whom they are providing the training, and if there are gaps in training components and in training target audiences 2.4 Develop practical and credible education/training systems for all target audiences 2.5 Identify training opportunities and implement practical and credible education/training systems for all target audiences 	
<p>Partners – private entities, advocacy groups, state agencies, etc.</p>	<p>Lead Role(s):</p> <ol style="list-style-type: none"> 1. Workforce Development Subcommittee 2. DVR, DESE 3. DDD Employment Coordinators 	<p>Supporting Role(s):</p> <ol style="list-style-type: none"> 1. State Employment Leadership Network (SELN) 2. Community-based providers of employment and/or employment training 3. Autism groups 4. Missouri Career Centers 5. Missouri Centers for Independent Living

To develop and disseminate practical and credible resources at the state, regional, and local levels to improve statewide capacity to employ individuals with ASD

- The commission SHALL study and report on the means for developing a comprehensive, coordinated system of care delivery across the state to address the increased and increasing presence of autism spectrum disorder and ensure that resources are created, well-utilized, and appropriately spread across the state {633.200.6(1) RSMo}
- The commission SHALL plan for effectively evaluating regional service areas throughout the state and their capacity, including outlining personnel and skills that exist within the service area, other capabilities that exist, and resource needs that may be unmet {633.200.6(1)(b) RSMo}
- The commission MAY explore the need for the creation of interagency councils and evaluation of current councils to ensure a comprehensive, coordinated system of care for all individuals with autism spectrum disorder {633.200.6(4)(e) RSMo}

<p>Perceived Barriers or Challenges</p>	<ol style="list-style-type: none"> 1. The time, manpower, and funding required to carry out the action steps 2. Representation, education, and participation from all critical stakeholders (individuals with ASDs, families, providers, educators, state/local agencies, and advocacy councils/ foundations/entities. 	
<p>Resources – may be experts, articles, books, etc.</p>	<ol style="list-style-type: none"> 1. Karla Bunch, Division of Vocational Rehabilitation (DVR), Department of Elementary and Secondary Education (DESE) 2. Nancy Nickolaus, Division of Developmental Disabilities (DDD), Department of Mental Health (DMH) 3. Individuals with ASDs and their families 4. DESE and other agencies who are involved in employment initiatives, collaborations, and coalitions 5. Providers of employment services 	
<p>Action Steps – list steps necessary to achieve the goal</p>	<ol style="list-style-type: none"> 3.1 Identify who needs resources and what resources they need 3.2 Identify what practical and credible resources are available, what other resources are needed, and if there are gaps 3.3 Develop other needed practical and credible resources 3.4 Develop a system to disseminate the practical and credible resources to appropriate target audiences 	
<p>Timelines</p>	<p>Projected Start Date: August 19, 2009</p>	<p>Projected Completion Date: Ongoing</p>
<p>Partners – private entities, advocacy groups, state agencies, etc.</p>	<p>Lead Role(s):</p> <ol style="list-style-type: none"> 1. Workforce Development Subcommittee 2. DVR, DESE 3. Missouri Community Transition Teams, DESE 4. Missouri Career Centers 5. DDD Employment Coordinators 6. Universities and colleges 	<p>Supporting Role(s):</p> <ol style="list-style-type: none"> 1. Missouri Commission on Autism Spectrum Disorders



To establish integrated data systems among public and private stakeholders to track employment data and employment outcomes for individuals with ASD

- The commission SHALL study and report on the means for developing a comprehensive, coordinated system of care delivery across the state to address the increased and increasing presence of autism spectrum disorder and ensure that resources are created, well-utilized, and appropriately spread across the state {633.200.6(1) RSMo}
- The commission SHALL plan for effectively evaluating regional service areas throughout the state and their capacity, including outlining personnel and skills that exist within the service area, other capabilities that exist, and resource needs that may be unmet {633.200.6(1)(b) RSMo}
- The commission MAY explore the need for the creation of interagency councils and evaluation of current councils to ensure a comprehensive, coordinated system of care for all individuals with autism spectrum disorder {633.200.6(4)(e) RSMo}

<p>Perceived Barriers or Challenges</p>	<ol style="list-style-type: none"> 1. Buy-in from and agreement among stakeholders 2. Costs, time, and manpower to determine the: <ul style="list-style-type: none"> • Number of individuals with ASDs employed, and • Number of individuals with ASDs waiting for employment 3. How to integrate and report data 	
<p>Resources – may be experts, articles, books, etc.</p>	<ol style="list-style-type: none"> 1. Information technology, administrative and frontline personnel (case management and providers) from Department of Mental Health (DMH), Division of Vocational Rehabilitation (DVR), Department of Elementary and Secondary Education (DESE), and other identified stakeholders 2. Division of Developmental Disabilities’ (DDD) Director of Employment and Training 3. DVR’s Assistant Director of Mental Health Services and Data Reporting 4. DVR’s Assistant Director of Special Programs and Proprietary Schools 5. Janet Farmer, PhD, ABPP, et al. (Missouri Autism Project Registry, June 30, 2005) 	
<p>Action Steps – list steps necessary to achieve the goal</p>	<ol style="list-style-type: none"> 4.1 Identify essential stakeholders 4.2 Determine how to integrate data from different systems 4.3 Identify and collect data that is currently available 4.4 Determine if there is a need to collect other relevant data 4.5 Determine how to collect relevant data and implement data collection 4.6 Collect data to benchmark and track over time 4.7 Monitor ongoing data (studies) related to addressing barriers of employment 	
<p>Timelines</p>	<p>Projected Start Date: To be determined</p>	<p>Projected Completion Date: To be determined</p>
<p>Partners – private entities, advocacy groups, state agencies, etc.</p>	<p>Lead Role(s):</p> <ol style="list-style-type: none"> 1. Workforce Development Subcommittee 2. DVR, DESE 3. DESE (sheltered workshops) 	<p>Supporting Role(s):</p> <ol style="list-style-type: none"> 1. Missouri Commission on Autism Spectrum Disorders

To develop efficient and effective funding systems at the state, regional, and local levels to improve statewide capacity to employ individuals with ASD

- The commission SHALL study and report on the means for developing a comprehensive, coordinated system of care delivery across the state to address the increased and increasing presence of autism spectrum disorder and ensure that resources are created, well-utilized, and appropriately spread across the state {633.200.6(1) RSMo}
- The commission MAY explore the need for the creation of interagency councils and evaluation of current councils to ensure a comprehensive, coordinated system of care for all individuals with autism spectrum disorder {633.200.6(4)(e) RSMo}

<p>Perceived Barriers or Challenges</p>	<ol style="list-style-type: none"> 1. Agreement among stakeholders 2. Costs, time, and manpower to carry out action steps 3. Economic climate and unemployment rate 4. Need to educate employers 	
<p>Resources – may be experts, articles, books, etc.</p>	<ol style="list-style-type: none"> 1. Funding entities 2. Administrative and frontline personnel from Department of Mental Health (DMH), Department of Elementary and Secondary Education (DESE), Division of Vocational Rehabilitation (DVR) 3. DVR-contracted providers and Missouri Career Centers 4. Individuals with ASDs and their families 	
<p>Action Steps – list steps necessary to achieve the goal</p>	<ol style="list-style-type: none"> 5.1 Identify current funding 5.2 Identify needed funding and who needs it 5.3 Identify potential sources of funding 5.4 Facilitate the development of efficient and effective funding systems 	
<p>Timelines</p>	<p>Projected Start Date: To be determined</p>	<p>Projected Completion Date: To be determined</p>
<p>Partners – private entities, advocacy groups, state agencies, etc.</p>	<p>Lead Role(s):</p> <ol style="list-style-type: none"> 1. Workforce Development Subcommittee 2. DVR 3. DESE 4. DMH 	<p>Supporting Role(s):</p> <ol style="list-style-type: none"> 1. Missouri Commission on Autism Spectrum Disorders



Spectrum Di

Appendix C

SECOND REGULAR SESSION
[TRULY AGREED TO AND FINALLY PASSED]
SENATE SUBSTITUTE FOR
SENATE COMMITTEE SUBSTITUTE FOR

SENATE BILL NO. 768

94TH GENERAL ASSEMBLY
2008

Unofficial

3524S.08T

AN ACT

To amend chapter 633, RSMo, by adding thereto two new sections relating to autism spectrum disorders as addressed by the department of mental health.

Be it enacted by the General Assembly of the State of Missouri, as follows:

Section A. Chapter 633, RSMo, is amended by adding thereto two new sections, to be known as sections 633.200 and 633.225, to read as follows:

633.200. 1. For purposes of this section, the term "autism spectrum disorder" shall be defined as in standard diagnostic criteria for pervasive developmental disorder, to include autistic disorder; Asperger's syndrome; pervasive developmental disorder-not otherwise specified; childhood disintegrative disorder; and Rett's syndrome.

2. There is hereby created the "Missouri Commission on Autism Spectrum Disorders" to be housed within the department of mental health. The department of mental health shall provide technical and administrative support as required by the commission. The commission shall meet on at least four occasions annually, including at least two occasions before the end of December of the first year the committee is fully established. The commission may hold meetings by telephone or video conference. The commission shall advise and make recommendations to the governor, general assembly, and relevant state

15 agencies regarding matters concerning all state levels of autism
16 spectrum disorder services, including healthcare, education, and other
17 adult and adolescent services.

18 3. The commission shall be composed of twenty-four members,
19 consisting of the following:

20 (1) Four members of the general assembly, with two members
21 from the senate and two members from the house of
22 representatives. The president pro tem of the senate shall appoint one
23 member from the senate and the minority leader of the senate shall
24 appoint one member from the senate. The speaker of the house shall
25 appoint one member from the house of representatives and the
26 minority leader of the house shall appoint one member from the house
27 of representatives;

28 (2) The director of the department of mental health, or his or her
29 designee;

30 (3) The commissioner of the department of elementary and
31 secondary education, or his or her designee;

32 (4) The director of the department of health and senior services,
33 or his or her designee;

34 (5) The director of the department of public safety, or his or her
35 designee;

36 (6) The commissioner of the department of higher education, or
37 his or her designee;

38 (7) The director of the department of social services, or his or
39 her designee;

40 (8) The director of the department of insurance, financial
41 institutions and professional registration, or his or her designee;

42 (9) Two representatives from different institutions of higher
43 learning located in Missouri;

44 **(10) An individual employed as a director of special education at**
45 **a school district located in Missouri;**

46 **(11) A speech and language pathologist;**

47 **(12) A diagnostician;**

48 **(13) A mental health provider;**

49 **(14) A primary care physician;**

50 **(15) Two parents of individuals with autism spectrum disorder,**
51 **including one parent of an individual under the age of eighteen and**
52 **one parent of an individual over the age of eighteen;**

53 **(16) Two individuals with autism spectrum disorder;**

54 **(17) A representative from an independent private provider or**
55 **non-profit provider or organization;**

56 **(18) A member of a county developmental disability board.**

57 **The members of the commission, other than the members from the**
58 **general assembly and ex-officio members, shall be appointed by the**
59 **governor with the advice and consent of the senate. A chair of the**
60 **commission shall be selected by the members of the commission. Of the**
61 **members first appointed to the commission by the governor, half shall**
62 **serve a term of four years and half shall serve a term of two years, and**
63 **thereafter, members shall serve a term of four years. Members shall**
64 **continue to serve until their successor is duly appointed and**
65 **qualified. Any vacancy on the commission shall be filled in the same**
66 **manner as the original appointment. Members shall serve on the**
67 **commission without compensation but may be reimbursed for their**
68 **actual and necessary expenses from moneys appropriated to the**
69 **department of mental health.**

70 **4. The members of the commission shall consist of a broad**
71 **representation of Missouri citizens, both urban and rural, who are**
72 **concerned with the health and quality of life for individuals with**
73 **autism spectrum disorder.**

74 **5. The commission shall make recommendations for developing**
75 **a comprehensive statewide plan for an integrated system of training,**
76 **treatment, and services for individuals of all ages with autism spectrum**
77 **disorder. By July 1, 2009, the commission shall issue preliminary**
78 **findings and recommendations to the general assembly.**

79 **6. In preparing the state plan, the commission shall specifically**
80 **perform the following responsibilities and report on them accordingly,**
81 **in conjunction with state agencies and the Office of Autism Services:**

82 **(1) Study and report on the means for developing a**
83 **comprehensive, coordinated system of care delivery across the state to**
84 **address the increased and increasing presence of autism spectrum**
85 **disorder and ensure that resources are created, well-utilized, and**
86 **appropriately spread across the state;**

87 **(a) Determine the need for the creation of additional centers for**
88 **diagnostic excellence in designated sectors of the state, which could**
89 **provide clinical services, including assessment, diagnoses, and**
90 **treatment of patients;**

91 **(b) Plan for effectively evaluating regional service areas**
92 **throughout the state and their capacity, including outlining personnel**
93 **and skills that exist within the service area, other capabilities that**
94 **exist, and resource needs that may be unmet;**

95 **(c) Assess the need for additional behavioral intervention**
96 **capabilities and, as necessary, the means for expanding those**
97 **capabilities in a regional service area;**

98 **(d) Develop recommendations for expanding these services in**
99 **conjunction with hospitals after considering the resources that exist in**
100 **terms of specialty clinics and hospitals, and hospital inpatient care**
101 **capabilities;**

102 **(2) Conduct an assessment of the need for coordinated, enhanced**
103 **and targeted special education capabilities within each region of the**
104 **state;**

105 **(3) Develop a recommendation for enlisting appropriate**
106 **universities and colleges to ensure support and collaboration in**
107 **developing certification or degree programs for students specializing**
108 **in autism spectrum disorder intervention. This may include degree**
109 **programs in education, special education, social work, and psychology;**
110 **and**

111 **(4) Other responsibilities may include but not be limited to:**

112 **(a) Provide recommendations regarding training programs and**
113 **the content of training programs being developed;**

114 **(b) Recommend individuals to participate in a committee of**
115 **major stakeholders charged with developing screening, diagnostic,**
116 **assessment, and treatment standards for Missouri;**

117 **(c) Participate in recommending a panel of qualified**
118 **professionals and experts to review existing models of evidence-based**
119 **educational practices for adaptation specific to Missouri;**

120 **(d) Examine the barriers to accurate information of the**
121 **prevalence of individuals with autism spectrum disorder across the**
122 **state and recommend a process for accurate reporting of demographic**
123 **data;**

124 **(e) Explore the need for the creation of interagency councils and**
125 **evaluation of current councils to ensure a comprehensive, coordinated**
126 **system of care for all individuals with autism spectrum disorder;**

127 **(f) Study or explore other developmental delay disorders and**
128 **genetic conditions known to be associated with autism, including**
129 **fragile X syndrome; Sotos syndrome; Angelman syndrome; and tuberous**
130 **sclerosis.**

633.225. 1. There is hereby established in the department of
2 mental health within the division of mental retardation and
3 developmental disabilities, an "Office of Autism Services". The office of
4 autism services, under the supervision of the director of the division of
5 mental retardation and developmental disabilities, shall provide
6 leadership in program development for children and adults with autism
7 spectrum disorders, to include establishment of program standards and
8 coordination of program capacity.

9 2. For purposes of this section, the term "autism spectrum
10 disorder" shall be defined as in standard diagnostic criteria for
11 pervasive developmental disorder, to include: autistic disorder;
12 Asperger's syndrome; pervasive developmental disorder-not otherwise
13 specified; childhood disintegrative disorder; and Rett's syndrome.

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Glossary

AAP-MO	Missouri chapter American Academy of Pediatrics	KU	University of Kansas
ABA	Applied Behavior Analysis	MAC	Missouri Autism Consultant
ADDM	Autism and Developmental Disabilities Monitoring	MAP	Missouri Autism Project
APSEMO	The Association for Persons in Supported Employment in Missouri	MARA	Missouri Autism Research Agenda
ASDs	Autism Spectrum Disorders	MARRA	Missouri Autism Research and Response Agenda
ATN	Autism Treatment Network	MFH	Missouri Foundation for Health
CCHD	Center for Child Health and Development	MHD	Missouri HealthNet Division
CDC	Centers for Disease Control and Prevention	MO-AHEAD	Missouri affiliate chapter of the Association on Higher Education and Disability
CEC	Council for Exceptional Children	MO-CASE	Missouri Council of Administrators of Special Education
CMS	Centers for Medicare and Medicaid Services	MODDRC	Missouri Developmental Disability Resource Center
DCN	Department Client Number	MO-FEAT	Missouri Families for Effective Autism Treatment
DDD	Division of Developmental Disabilities	MO-STEP	Missouri Standards for Teacher Education Programs
DESE	Department of Elementary and Secondary Education	MSBA	Missouri School Boards' Association
DHE	Department of Higher Education	MTN	Missouri Telehealth Network
DMH	Department of Mental Health	MU	University of Missouri
DSS	Department of Social Services	OAS	Office of Autism Services
DVR	Division of Vocational Rehabilitation	P-20 Council	Preschool to Age 20
EXCEL	Expanding College for Exceptional Learners	PSPC	Professional Standards and Practice Committee of the CEC
FY	Fiscal Year	RSMo	Revised Statutes of Missouri
HRSA	Health Resources and Services Administration	SELN	State Employment Leadership Network
IACC	Interagency Autism Coordinating Committee	SPED	Special Education
IAN	Interactive Autism Network	TACE	Technical Assistance and Continuing Education
IDAC	In-District Autism Consultant	THRIVE	Transformation, Health, Responsibility, Independence, Vocation, Education
IDEA	Individuals with Disabilities in Education Act		



OFFICE OF AUTISM SERVICES
DIVISION OF DEVELOPMENTAL DISABILITIES
MISSOURI DEPARTMENT OF MENTAL HEALTH

800-207-9329

www.dmh.mo.gov/dd/autism/