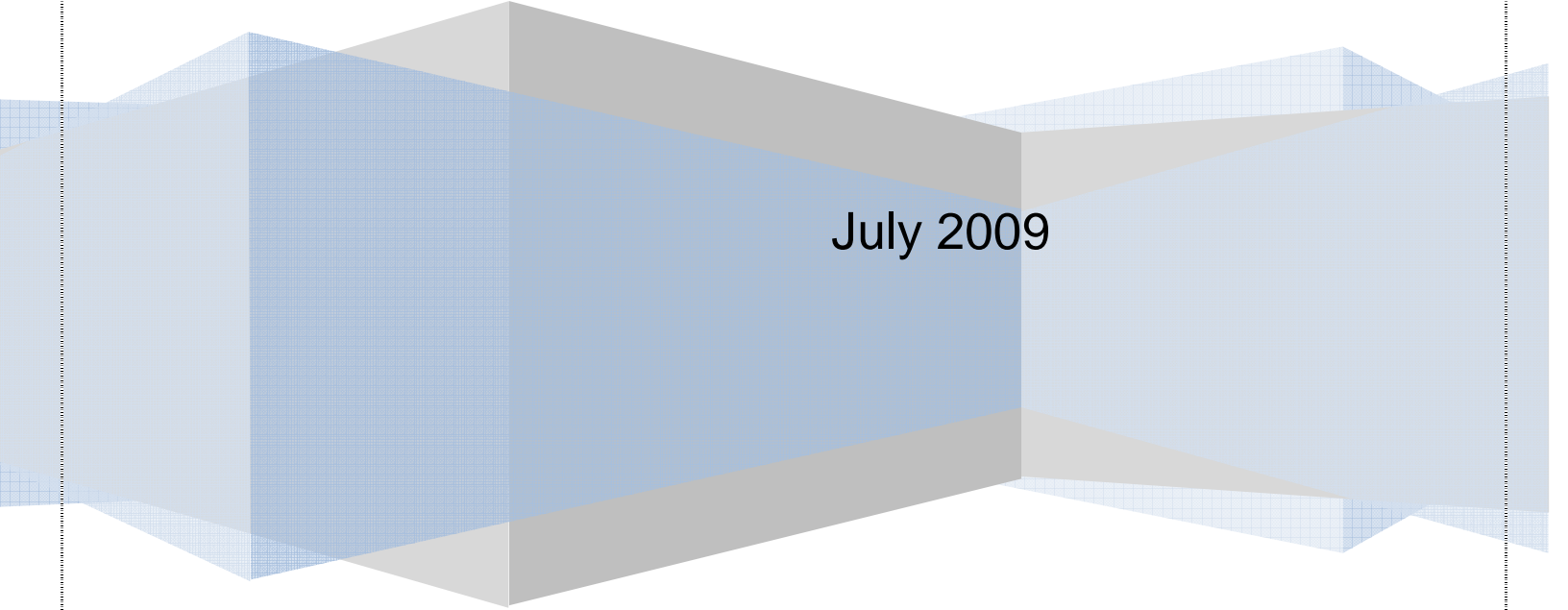


# **“Framework for the Future”**

## **A Status Report Submitted on Behalf of the Missouri Commission on Autism Spectrum Disorders**

Office of Autism Services  
Division of Developmental Disabilities  
Department of Mental Health

July 2009



## Table of Contents

Background and Purpose.....	3
Acknowledgement.....	3
What is Autism? .....	4
Looking Back.....	4
Documenting the Need.....	5
Prevalence and Incidence.....	5
Individual and Family Impact.....	6
Statutory Role of the Missouri Commission on Autism Spectrum Disorders.....	7
How Will the Commission approach Statewide, Comprehensive Planning?.....	9
Access to Services.....	10
Recommendations on Record.....	11
State Agency Descriptors and Data.....	12
Some Valuable State and National Resources.....	16
Examples of Autism Initiatives in Missouri.....	16
Missouri Autism Guidelines Initiative.....	16
Missouri Rapid Response Initiative.....	16
Navigating Autism Services: A Community Guide for Missouri.....	17
Conclusion and Next Steps.....	17
Appendices.....	19
References.....	27

## **“Framework for the Future”**

Submitted on Behalf of the

### **Missouri Commission on Autism Spectrum Disorders**

#### **Background and Purpose of the Report**

In the 2008 legislative session, Missouri’s General Assembly passed Senate Bill 768 authorizing the creation of 2 entities: the Missouri Commission on Autism Spectrum Disorders and the Office of Autism Services.

Senate Bill 768, now Missouri Revised Statute 633.200 – 210, requires the Commission to make recommendations forming a “comprehensive statewide plan for an integrated system of training, treatment and services for people of all ages with autism spectrum disorder.” At the most recent meeting of the Commission in May 2009, the Commissioners authorized a status report to be submitted as a first step in the planning and reporting process required by law. The status report, “Framework for the Future,” has been reviewed by the present Commission and is offered to

- 1) educate and inform readers about autism and the system of care in Missouri; and
- 2) illuminate the role of Missouri’s Commission on Autism Spectrum Disorders.

The Office of Autism Services within the Division of Developmental Disabilities provides administrative and technical assistance to the Commission. The creation of both the Commission and the Office of Autism Services were foremost recommendations in Missouri’s 2007 Blue Ribbon Panel Report.

#### **Acknowledgement**

The system of care in Missouri for persons with autism and other related developmental disabilities reflects the vast amount of time and energy expended by those who have gone before us. The Missouri Planning Council and various state agencies have initiated strategic planning to improve the system of care. Missouri’s Autism Project remains a unique response on behalf of individuals and families living with autism. Missouri’s Autism Centers add diagnostic expertise and regional capacity to support people with autism. The various home and community-based waivers offer services with funding leveraged from federal appropriations. Many concerned citizens, government officials, legislators, and service providers have joined with the autism community so that people with autism can achieve their full potential. The Commissioners recognize and credit the individuals and family members who are living with autism--they share their personal stories to inform, educate and stimulate system change.

## What is Autism?

There are a number of sources that address the question, “What is Autism?” For purposes of this report, the definition of autism comes from the Centers for Disease Control:

Autism spectrum disorders are a group of developmental disabilities defined by significant impairments in social interaction and communication and the presence of unusual behaviors and interests. Many people with ASDs also have unusual ways of learning, paying attention, or reacting to different sensations. The thinking and learning abilities of people with ASDs can vary – from gifted to severely challenged. ASD begins before the age of 3 and lasts throughout a person's life. It occurs in all racial, ethnic, and socioeconomic groups and is four times more likely to occur in boys than girls.

Most people agree that there is no one cause or cure for autism. However, it is accepted that autism is treatable, and people who have autism can often lead meaningful, productive lives.

Research shows that early screening, diagnosis, and treatment can greatly improve a child's development, and has a life-long, positive impact. The evidence supporting this point is ample and includes the National Institute of Child Health and Human Development Autism Overview:

Research shows that early diagnosis and interventions delivered early in life, such as in the preschool period, are more likely to result in major positive effects on later skills and symptoms...Because a young child's brain is still forming, early intervention gives children the best start possible and best chance of developing their full potential. Even so, no matter when a person is diagnosed with autism, it's never too late to benefit from treatment. ***People of all ages with ASDs at all levels of ability generally respond positively to well-designed interventions.***<sup>1</sup> (Emphasis added)

Missouri's Commission on Autism Spectrum Disorders aims to address and build upon a system of care that supports individuals with autism in their homes, schools and communities, achieving their fullest potential throughout their lives.

Note: In this report, the term “autism” is used to refer to a spectrum of disorders as defined 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. The term “system of care” is broadly used to define an array of medical, educational, and habilitative interventions delivered within Missouri's service structure.

## Looking Back...

There are a number of existing documents analyzing the system of care in Missouri. In 1990, family forums hosted across Missouri's eleven regional office geographical areas were the catalyst for the formation of an Autism Resource Center at the Institute for Human Development, University of Missouri-Kansas City, funded in conjunction with the Missouri Planning Council. This Autism Resource Center was charged with three objectives: a) provide training for families and for staff of the Division of DD; b) coordinate the first autism conference for families, staff, educators and service providers; and c) draft a state plan for autism that would identify service areas, actions steps, and funding considerations. Subsequently, the Autism Resource Center published its 1990 state plan, “Autism in Missouri: Bridging the

Gaps.”<sup>2</sup> Other efforts to chronicle autism-specific data, needs, and system improvements are as follows:

1. “System Breakthrough for Excellence: Report for the Steering Committee,” August 2003, hosted by the Division of Mental Retardation and Developmental Disabilities. The System Breakthrough for Excellence was a system re-design project designed to create a new service road map that would best serve children and adults enrolled with the Division of Developmental Disabilities.<sup>3</sup> The re-design effort included one workgroup focused solely on the needs of people with autism.
2. “The Missouri Autism Research Agenda,” July 2003, presented by the Missouri Educational and Public Policy Symposium on Autism.<sup>4</sup> The MARA acronym was amended to “Missouri’s Autism Research and Response Agenda” or “MARRA,” reflecting the desire to engage individuals with autism and their family members. The intent of MARRA was to establish a framework under which collaborative partnerships between stakeholders, research institutions, and service providers would enhance the lives of people with autism and their families.
3. “Missouri Autism Project Registry: Final Project Report and Recommendations, June 30, 2005,” J. E. Farmer, Ph.D., J.H. Miles, M.D., Ph.D. and G. Demiris, Ph.D, University of Missouri-Columbia. This report followed the MARRA initiative and defined the functions of a proposed registry to link registry data with other state agency data and to provide Missouri-specific information about autism to families, health care providers and educators.<sup>5</sup>
4. “The Blue Ribbon Panel Report on Autism”, December 2007. Blue Ribbon Panel members were appointed by President Pro Tem Michael R. Gibbons in April 2007.<sup>6</sup> The report was written after the panel heard testimony from individuals with autism, family members, healthcare professionals, educators and state agency representatives. This charge for the panel was to define the state of autism in Missouri and to make recommendations that would enhance the lives of persons with autism.
5. “Autism Program Summary,” submitted by Office of Autism Services, Division of Developmental Disabilities, July 2007-June 2008. This summary was written to benchmark data and to highlight programs funded or supported by the Division of Developmental Disabilities. See [www.dmh.mo.gov/mrdd/new/autism09.htm](http://www.dmh.mo.gov/mrdd/new/autism09.htm) for the full report.
6. Recommendations for Policy & Practice in Missouri,” Missouri School Boards’ Association Autism Task Force, March 2009.<sup>7</sup> The Missouri School Board Association convened an Autism Task Force to examine early intervention services, promote improved services within public schools and state agencies, and to improve collaboration among public and private agencies.

Many of the Autism Resource Center’s recommendations resurfaced in the reports and strategic plans that followed its publication in 1990.

## **Documenting the Need**

### Prevalence and Incidence

Data from the Centers for Disease Control’s Autism and Developmental Disabilities Monitoring (ADDM) Network found that that autism occurred in as many as 1 in 150 eight-year-old children. This 2007 data was based on multiple monitoring sites within the United States. At the same time, the CDC cautioned that the prevalence estimate should not be applied or generalized

across the nation. The 2008 population estimate for Missouri from the Census Data Center is approximately 5.9 million people (retrieved from <http://mcdc2.missouri.edu/about.shtml>).

The authors of the 1990 report, "Autism in Missouri," estimated autism prevalence within a range from 2,200 to 11,000 for Missouri residents. The report included 1987 data from the Division of Mental Retardation and Developmental Disabilities that showed only 133 individuals with autism enrolled with the Division. (Note: The Division of MRDD is now known as the "Division of Developmental Disabilities.")

An ongoing issue is the inability to accurately predict how many Missourians have autism. The MARRA report identified at least 15 different databases in Missouri related to children and adults with autism. A later report, the "Missouri Autism Project Registry," (June 2005) noted that various state agencies, universities, service providers, and healthcare clinics maintain information that would be of great benefit to researchers and policy-makers. While Missouri has not integrated the various databases, the process to do so has been studied and relationships built on state and national levels that could move this type of initiative forward.

The Executive Summary from the 2003 MARRA report chronicles a 344% growth in autism diagnoses for youth between the ages of 6-21 during the period 1993 to 2001 (U.S. Dept. of Ed., 2002). At that time, the MARRA report noted that 327 of Missouri's 525 public school districts served children with ASD.

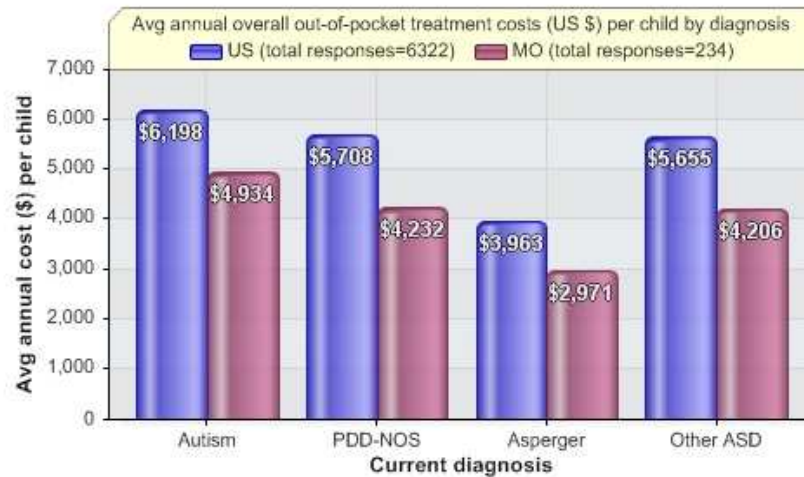
As clarified by the Centers for Disease Control website, there is a difference between estimates of prevalence and incidence of autism. Prevalence refers to existing cases identified within a defined group; incidence attempts to quantify new diagnoses of autism within a defined group over a period of time. One reason it is important to study trends in prevalence and incidence is so that public health and education policy can be assessed in terms of capacity and responsiveness.

### Individual and Family Impact

When re-designing a system of care, the planners must be aware of how the lack of a comprehensive, integrated system affects individuals and families. The planners must know the difficulty that individuals and families face in locating, selecting and paying for supports and services in the absence of an integrated system. The barriers to services are significant and exact a financial, physical and emotional toll on families and caregivers.

A recent source of autism-specific data and research is the Interactive Autism Network, or IAN. IAN is a voluntary healthcare registry that collects important data for researchers as well as data that is useful for administrators and public policy makers. IAN's primary goal is to accelerate the pace of autism research that will lead to advancements in the understanding and treatment of autism.

IAN attempts to quantify one impact of autism by reporting average, out-of-pocket treatment expenses incurred by families who have a child with autism:



Avg annual overall out-of-pocket treatment costs (US \$) per child by diagnosis." Chart. Kennedy Krieger Institute. Interactive Autism Network StateStats. Retrieved June 23, 2009  
[http://www.iancommunity.org/cs/for\\_researchers/ian\\_statestats](http://www.iancommunity.org/cs/for_researchers/ian_statestats), Data current as of 23 June, 2009.

The above chart reflects 234 responses from Missourians who enrolled in the IAN registry and answered the questionnaire regarding out-of-pocket treatment expenses. The average out-of-pocket treatment costs per child with an autism diagnosis was about \$5,000 annually compared to over \$6,000 nationally (n = 6,322). This data does not capture the variances when families may spend many more thousands of dollars for specialized treatment for their child. What is not reflected in the data is the many families that cannot pay for treatment or intervention programs and whose children go without treatment.

According to a 2006 study by Michael Ganz, a professor at Harvard School of Public Health, the cost to care for a person with autism throughout the lifespan was estimated at \$3.2 million.<sup>8</sup> Each year, the cost to society to care for people who have autism was estimated to be at least \$35 billion.

A 2008 national survey conducted by Easter Seals' entitled "Living with Autism Study" yields insight into the stressors facing individuals and families living with autism.<sup>9</sup> Over 2,500 surveys were collected from 1) parents with children age 30 or younger without special needs and 2) parents with children age 30 or younger with autism. Comparing the 2 groups, the study reports what families are thinking about health care, finances and long-term planning:

- 1) Findings show that only 18% of parents of children with autism feel their children will have health insurance that adequately covers their needs. This compares to 42% of parents with typically developing children.
- 2) Parents of children with autism express much stronger financial concerns for their families than typical parents. Findings show that 74% of parents of children with autism fear their children will not have enough financial support after the parents die, while only 18% of typical parents share this fear.
- 3) Only 29% of parents of children with autism believe their children will always have a place to live compared to 60% of parents of typically developing children.

Looking at Missouri-specific information, researchers Sharpe and Baker from the University of Missouri-Columbia interviewed Missouri families about the financial impact of autism. In their 2007 article, “Financial Issues Associated with Having a Child with Autism,” they reported that expenses to treat autism can be crushing resulting in negative consequences such as one parent leaving a job; reducing cash flow such that bills cannot be paid; cashing out family savings or retirement accounts; and forcing families into bankruptcy due to loss of employment income or treatment costs.<sup>10</sup>

It is commonly accepted that with earlier identification and earlier intervention, the cost of supports is mitigated and the likelihood of people with autism enjoying a meaningful, productive life is much, much greater.

### **Statutory Role of Missouri’s “Commission on Autism Spectrum Disorders”**

The Commission’s responsibilities are all-encompassing and will require many hours of dedication and cooperation among all parties – those serving on the Commission and the constituencies represented by members of the Commission. The result will be a strategic plan reflecting up-to-date information and action steps designed to improve the quality of life for Missourians who have autism.

Chapter 633.200 of the Revised Statutes of Missouri lists a number of responsibilities and activities for the Commission to consider:

633.200.2 The Commission **shall advise and make recommendations to the governor, general assembly, and relevant state agencies** regarding matters concerning all state levels of autism spectrum disorder services, including healthcare, education, and other adult and adolescent services.

633.200.5 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.

633.200.6 In preparing the state plan, the commission shall specifically perform the following responsibilities and report on them accordingly, in conjunction with state agencies and the Office of Autism Services.

633.200.6(1) 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) (a) Determine the need for the creation of additional centers for diagnostic excellence in designated sectors of the state, which could provide clinical services, including assessment, diagnoses, and treatment of patients.

(b) 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.

(c) Assess the need for additional behavioral intervention capabilities and, as necessary, the means for expanding those capabilities in a regional service area.

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

633.200.6(2) Conduct an assessment of the need for coordinated, enhanced and targeted special education capabilities within each region of the state;

633.200.6(3) 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. This may include degree programs in education, special education, social work, and psychology.

Other responsibilities may include but not be limited to:

633.200.6(4)(a) Provide recommendations regarding training programs and the content of training programs being developed.

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

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

(d) Examine the barriers to accurate information of the prevalence of individuals with autism spectrum disorders and recommend a process for accurate reporting of demographic data.

(e) 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.

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

#### Office of Autism Services

Immediately following the statutory section authorizing the Commission is Chapter 663.210.1, RSMo., establishing the "Office of Autism Services" and assigning its role 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." In addition, the OAS provides technical, facilitative and administrative assistance to the Commission.

#### **How will the Commission approach statewide, comprehensive planning?**

In the fall of 2008, appointments were made to the "Missouri Commission on Autism Spectrum Disorders." The Commission met in October and December 2008 and speedily adopted guiding principles, a protocol for communication, and its "Framework for the Future," a document intended to serve as a touchstone for the Commission's planning in the coming months. With just a few changes in membership, the Commission met again in May 2009 agreeing to a revised framework with four areas of concentration:

1. Individual and Family Supports;
2. Healthcare;

3. Education; and
4. Workforce Development.

While serving as a touchstone for the Commission, the Framework also reinforces important areas of consensus within the Commission:

- The Commission is committed to addressing areas of improvement in access and services for persons of all ages who have autism, with particular attention paid to the transitions in persons' lives beginning with the infant-toddler years and progressing through early childhood, elementary and secondary education, post-secondary education, and adulthood.
- In the planning process, the Commission's subcommittees will address five essential elements: screening, diagnosis, and assessment; access to service delivery; cross-system collaboration; capacity building across all systems including training; and outcome measures.

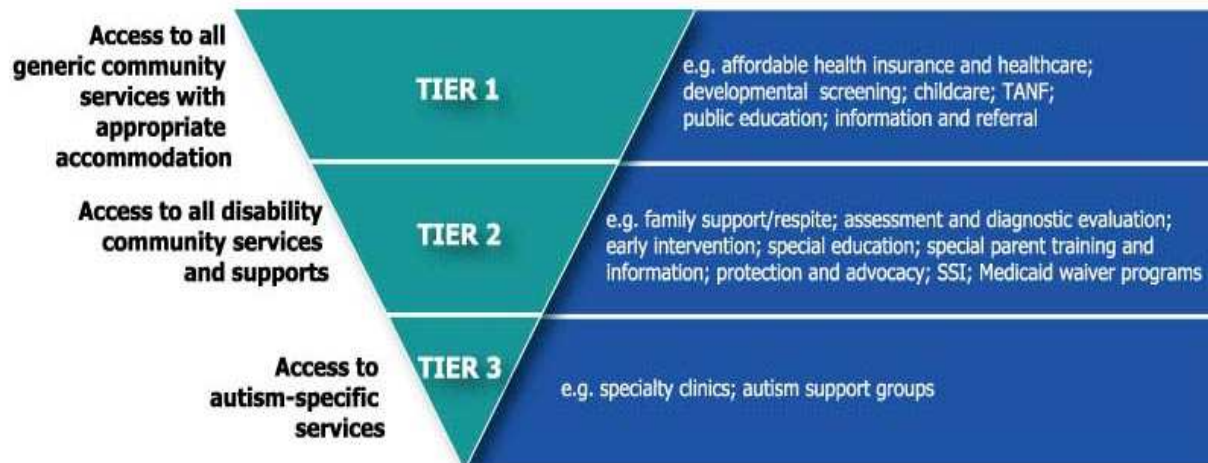
Each Commissioner has elected to serve on one of four subcommittees formed to address the areas of concentration. First, each subcommittee will further define its area of concentration to reduce duplication of effort. For example, the education and healthcare groups will need to decide which group will address the outreach and education for physicians who want a better understanding of the complexities of autism.

Next, the subcommittees will record specific goals, paying close attention to the requirements of the enabling legislation. It is anticipated that other stakeholders and interested parties will be invited to meet with the subcommittee members to offer information, research or data. For instance, an employment specialist working for the Division of Developmental Disabilities is assigned to the Workforce Development subcommittee and will talk about current employment initiatives within the State of Missouri on behalf of people who have disabilities, national statistics on employment of persons with disabilities, and employment models for consideration.

The subcommittees will provide regular updates of their work to the Commission during quarterly meetings scheduled throughout 2009 and 2010. The subcommittees will meet face-to-face or via teleconferences maximizing technology to conserve travel time. Each subcommittee will complete worksheets recording the goals, action steps, indicators of success and potential public or private partners needed to act upon the goals.

#### Access to Services

On a federal level, the Interagency Autism Coordinating Committee (IACC) was created in 2007 to coordinate efforts within the Department of Health and Human Services concerning all matters related to autism. The IACC has released a number of reports, including its "Autism Spectrum Disorders Services Roadmap." According to the Roadmap, a basic premise is that all individuals can live, work and play in their communities with varying levels of accommodation. This premise is expressed in the following 3-tiered model:



The three tiers define access to types of services. Some services are generic, some can be made available with an accommodation, and some are highly specialized. This three-tiered model is important to consider as the system of care is being examined by Missouri's Commission on Autism.

#### Recommendations on Record

The comprehensive nature of the 1990 report, "Autism in Missouri," and its recommendations are worthy of review particularly in light of their similarity to more recent recommendations:

- Increase interagency collaboration and cooperation;
- Facilitate accurate identification of autism through an autism registry;
- Increase access to services for children birth to age 5;
- Look for flexible educational services for school-aged children and youth;
- Expand and enhance community-based residential and employment options;
- Identify gaps in services;
- Create regional resource centers to provide autism-specific training and consultation to families, educators, service providers and various professionals;
- Fund an Autism Resource Center to provide an array of assistance to families;
- Emphasize ongoing communication between local schools, state schools and adult service providers;
- Develop and provide comprehensive parent training;
- Develop and provide training for professionals focusing on "best practices" to increase professional expertise in autism;
- Increase public awareness, education and advocacy;
- Allocate state funds or grants for research on effective treatments;
- Fund exemplary demonstration projects on autism-related services; and
- Establish an annual review of the recommendations.

In the 2003 "Missouri's Autism Research and Response Agenda," the MARRA group noted a discouraging lack of high-quality data on incidence, prevalence, and the effectiveness of specific interventions and treatments. They proposed a model wherein research would guide and inform the development of public policy.

Some comprehensive questions posed by MARRA:

1. What is the body of knowledge regarding autism in Missouri?
2. How many people are affected by autism? How many children are within each diagnostic category? Who is missing, and why?
3. What resources such as professionals, services, supports, funding, research and guidance are there in Missouri?
4. What is the professional and community capacity to meet the needs of Missourians with autism?
5. What services are youth receiving while in school?
6. What would information technology add to the diagnosis and treatment of autism?
7. What is a profile of effective or promising practices?
8. How much training and what type of training will make effective educators, health care professionals, service coordinators, social workers and direct support staff?
9. What is the satisfaction level with the process of services and supports?

In 2003, the “System Breakthrough for Excellence” project devoted one of eight workgroups to explore and report on autism. Among other suggestions, this group insisted that service coordinators receive autism-specific training and subsequently carry specialized caseloads to optimize service planning for people with autism.

Each of the reports listed in the section, “Looking Back,” lists valuable recommendations for consideration by the Commission and its sub-committees. Prioritizing the recommendations will be one step, with consideration of what resources are necessary for implementation.

The Commission will want to consider how its work and progress is made available to people with autism, their families and caregivers. One avenue to explore is utilizing Missouri’s Autism Project and its grass-roots level parent advisory committees for feedback. Methods for communication and timeframes for input will need to be established between the Commission and the parent committees to promote an effective exchange of information.

### State Agency Descriptors and Data

A number of state agencies are represented on the Commission and have submitted information or will soon be presenting information; a brief review of some agencies’ information follows. It is likely the Commissioners will be reviewing more in-depth data from state agencies to further develop recommendations and action steps.

#### Department of Elementary and Secondary Education

The Department of Elementary and Secondary Education (DESE) provides services to some 917,301 students PK-12 in 523 school districts across Missouri. It is the administrative arm of the State Board of Education and works with educators, legislators, government agencies and citizens to maintain a strong public education system. There are six divisions in the department whose fiscal year 2010 budget is projected to be almost 5.5 billion dollars gathered primarily from general revenue, federal funding, Proposition C revenues, gaming dollars, and other sources, with most funding flowing directly to school districts. Data from the DESE provides some insight into the increasing number of school-age children with autism.

The special education child count, collected annually on December 1, is an unduplicated count of students with disabilities by primary disability category. The data indicates an increase in the autism child count of 397.5% from 1998-99 to 2008-09. The increase in the autism child count from 2007-08 to 2008-09 was 12.3%, and the average annual increase over the past five years was 15.6%. The total number of students reported in the primary disability category of autism in grades Kindergarten through 12 was 5,776 in 2008-09, reported by a total of 394 local education agencies such as school districts, charter schools and state board operated programs.

In looking at very young children served by DESE in its statewide First Steps program, the following numbers reflect children with autism and children receiving Applied Behavior Analysis services:

Children in First Steps identified by the autism code	66
Children in First Steps currently receiving "ABA" services	88

The DESE is the designated lead agency for Missouri's First Steps program, which is reserved for children, birth to age 3, who have delayed development or diagnosed conditions that are associated with developmental disabilities. The numbers are current as of June 2009.

Division of Developmental Disabilities

The Division of Developmental Disabilities is under the purview of the Department of Mental Health which has two other divisions, Comprehensive Psychiatric Services and Alcohol and Drug Abuse. The Department's primary roles are prevention, treatment, and promotion of public understanding of persons with mental illnesses, developmental disabilities, and addictions.

The Division of DD has about 29,000 people enrolled for services. People who are determined eligible for services are assigned a service coordinator who assists in designing the plan for supports on behalf of the person who needs services. As of June 2009, over 6,400 people enrolled with the Division of DD have an autism diagnosis.

The Division's current data reflects an overall increase in the enrollment of people who have an autism diagnosis:

Enrollment of people with an autism diagnosis:

Age	05/06 – 04/07	FY 2008	FY 2009*	% Increase FY2008-2009
Birth – 3**	194	245	87	-64%
4-18	3806	4290	4588	+7%
19-Adult	1497	1827	2142	+17%
<b>TOTAL</b>	<b>5497</b>	<b>6362</b>	<b>6817</b>	<b>+7%</b>

\*through 06/16/09

\*\* after FY2009, service coordination for this age group is primarily provided by the First Steps program

Expenditures on behalf of persons with autism who are enrolled in Medicaid Home and Community-Based waivers:

Dates	05/06-04/07	FY 2008	FY 2009	% Increase
-------	-------------	---------	---------	------------

				<b>FY 2008-2009</b>
All Ages	\$ 41,659,350	\$ 52,861,484	\$ 58,790,364	+11.2%

The Division provides or funds a wide array of services and supports to individuals with developmental disabilities, including in-home services such as speech, physical, occupational or behavior therapies. Families may also receive crisis intervention services and respite care. Other services such as adaptive equipment and environmental modifications are designed to enable an individual to live safely in his family home or choose a group home or apartment. Additional information is available in the written report provided to the Commission in May 2009.

Department of Social Services -- Missouri HealthNet Division

The Department of Social Services is organized under four program divisions: Children’s Division, Family Support Division, MO HealthNet Division, and Youth Services. The MO HealthNet Division has the responsibility to purchase and monitor health care services for low income and vulnerable Missouri citizens. Eligibility determination is a fairly complex review of a number of criteria such as a person’s age, disability, resources, and income. Eligibility for MO HealthNet benefits is done by the Family Support Division. This is a key benefit because a large percentage of people receiving services through the state’s various home and community-based waivers must first be determined eligible for MO HealthNet benefits.

People enrolled with MO HealthNet who have an autism diagnosis are eligible for medically necessary services from qualified providers. According to information from this department, MO HealthNet covered services for 6,986 people with an autism diagnosis in the 2008 fiscal year (July 2007 – June 2008):

1. Total people with an autism diagnosis 6,986
2. People 20 years of age or younger
  - a. Fee-for-service 4,176
  - b. Managed care 1,230
  - c. Total people through age 20 with an autism diagnosis 5,406
  - d. Total expenditures for this group \$31,549,756
3. People 21 years of age and older
  - a. Fee-for-service 1,580
  - b. Managed care (none)
  - c. Total expenditures for this group of people \$26,130,705
4. Total annual expenditures on behalf of people with autism \$57,680,461

In addition to a long list of mandatory services and certain optional services procured by MO HealthNet, this Division administers 4 Home and Community-Based Waivers that support people with developmental disabilities and autism; the Division of Developmental Disabilities operates the waivers. These 4 waivers are key collaborative ventures for both MO HealthNet and the Division of DD.

Additional information about the Department of Social Services can be found at the Department’s website <http://www.dss.mo.gov/>. A home and community-based waiver fact sheet can be found at <http://www.dmh.mo.gov/mrdd/progs/waiver/factsheet.htm>.

## Department of Insurance, Financial Institutions, and Professional Registration

This state department regulates the insurance markets in Missouri, including the prior approval of insurance policies before they are offered for sale and ongoing review of health insurance policies to ensure compliance with state law. The department operates no programs requiring special enrollment and no programs specifically for persons with autism. Its fiscal year 2008 budget approximated \$39 million.

Missouri's insurance laws are found in the Revised Statutes of Missouri, Chapters 383, 354, 374 – 376, and 379. The department reports that over 1.7 million people in Missouri are policyholders in insurance plans that would be subject to legislation requiring coverage for certain autism-related therapies.

The department has a toll free consumer hotline, 1-800-726-7390, as well as a website that can be accessed to report a complaint or make an inquiry.

## Department of Health and Senior Services

This department has three divisions: Community and Public Health, Senior and Disability Services, and Regulation and Licensure. Services offered through its divisions include

- Home health services
- Private duty nursing
- Personal care service
- Advanced personal care service
- Case management (through contracts with local public health agencies)

While the department does not have dedicated funding or exclusive services for persons with autism, people with autism can receive services when they meet the eligibility requirements. The number of people who have autism and receive services is not known.

## Department of Higher Education

The Coordinating Board for Higher Education (CBHE) has statutory authority to design a coordinated plan for higher education that is responsive to the state's needs, population and enrollment trends, and institutional specialization. The CBHE is also authorized to recommend development, consolidation, or elimination of academic programs and to collect data and perform analyses to inform public policy. The Missouri Department of Higher Education (MDHE) is the administrative arm of the CBHE.

The mission of the CBHE and MDHE is to work collaboratively with the state's institutions of higher education to support a diverse system of affordable, accessible, high-quality educational institutions that demonstrate student learning and development, encourage and support innovation, foster civic engagement, enhance the cultural life of Missourians, and contribute to economic growth.

The focus of higher education in developing a framework for the future will be on teacher education--increasing the number of teachers certified in special education, increasing the number of continuing education opportunities, and reviewing opportunities for loan forgiveness, grants, or scholarships, especially for teachers in this field.

During the 2007-08 academic year, Missouri colleges and universities awarded 314 special education teaching degrees—163 at the baccalaureate level and 151 graduate degrees.

### **Some Valuable State and National Resources**

In developing its “Framework,” the Commission identified important resources available in Missouri. Sources of information are too numerous to mention but some are noteworthy:

- The Interagency Autism Coordinating Committee, a federal government advisory panel connected with the National Institutes of Health, has issued a host of documents specific to autism. In 2005, the Services subcommittee issued its “Autism Spectrum Disorders Services Roadmap” intended to provide a national blueprint in regard to existing systems of care, development of new services, and coordination across systems. The reports can be viewed at <http://iacc.hhs.gov/reports/>.
- Other states have passed legislation or created autism-specific offices or bureaus. Some of these offices have developed lengthy reviews of service structures that may offer insight to Missouri’s Commissioners. Acknowledging that each state’s system of care is unique, a search of the more mature processes or structures in place may be helpful.
- The workforce development subcommittee may want to review *Rehabilitation of individuals with Autism Spectrum Disorders*, George Washington University, 2007.<sup>11</sup> This monograph discusses successful employment strategies as well as barriers to employment for persons with autism. A 2008 publication from the University of Massachusetts, *Supporting Individuals with Autism Spectrum Disorders: Quality Employment Practices*, also offers insight and lists ten preliminary questions an employment specialist and potential employee should answer as they develop the job search.<sup>12</sup> Also worth reviewing is a very recent report from the University of Missouri Health System entitled, “*Adult Autism and Employment: A Guide for Vocational Rehabilitation Professionals*,” <http://www.dps.missouri.edu>.

### **Examples of Autism Initiatives in Missouri**

#### **Missouri Autism Guidelines Initiative**

In December 2008 the Missouri Commission on Autism Spectrum Disorders was presented with a proposal to develop a standard of practice in Missouri for screening, diagnosing and assessing autism. This proposal, now formalized as the “Missouri Autism Guidelines Initiative,” (MAGI) is sponsored by a public/private partnership between the Thompson Foundation and the Division of Developmental Disabilities. The MAGI is comprised of more than 40 people tasked to develop Missouri’s guidelines for screening, diagnosing and assessing autism. Members of the Autism Commission recommended potential members for the MAGI, submitting names of parents, healthcare professionals, and therapists to MAGI’s sponsors. The recommendations were made in alignment with the Commission’s official responsibilities in the enabling legislation RSMo. 633.2006(4)(b). The guidelines on screening, diagnosis and assessment are projected to be available as early as January 2010.

## Missouri Rapid Response Initiative

This project will improve access to comprehensive and coordinated care for children and youth with autism across Missouri. It focuses on building medical homes, establishing strong family/professional partnerships, and developing programs that encourage successful youth transition to adulthood. These activities will be accomplished through a variety of strategies. For instance, the project funds enhanced care coordination and family supports at diagnostic centers across the state. In addition, it supports improvements in youth, parent and professional training, and it aims to strengthen local communities so that they are better prepared to meet the needs of persons with autism. Some partners in the Rapid Response include the University of Missouri-Columbia Thompson Center; Division of Developmental Disabilities; Bureau of Special Health Care Needs; University of Missouri Extension; University of Missouri-Kansas City, Institute for Human Development; Missouri Families for Effective Autism Treatment; Department of Elementary and Secondary Education, and Family Voices. It is funded by the federal Maternal and Child Health Bureau, Health Resources and Services Administration.

### Navigating Autism Services: A Community Guide for Missouri

Recently published, this guide is the result of a parent-professional collaboration which aimed to capture basic information for families who have recently learned of an autism diagnosis, or who may be experiencing a transition from one program to another, e.g. from early childhood services to elementary school. A decade ago, the *Missouri Autism Resource Guide* was published jointly by the Departments of Mental Health, Elementary and Secondary Education, and the University of Missouri-Columbia. Representatives from these departments re-grouped in 2008 and were joined by two parent advocacy entities. The group determined that Missourians needed a guide with basic information about services and how to access those services.

A new partnership between Missouri Families for Effective Autism Treatment and the Office of Autism Services resulted in the publication, *Navigating Autism Services: A Community Guide for Missouri*. The community guide is available in print and can be downloaded from a number of websites including the Division of Developmental Disabilities' site: <http://www.dmh.mo.gov/mrdd/new/manual/navigationguide09.pdf>.

### Conclusion and Next Steps

On the national level, it will be essential to follow healthcare reform legislation as well as specific legislation such as the Autism Treatment Acceleration Act. President Barack Obama has promised to increase funding for autism research, treatment and support. In addition, both President Obama and Vice President Joseph Biden support funding the Combating Autism Act. This is a dynamic period that holds much promise for the autism community as well as others with related developmental disabilities.

Missouri faces challenges that are similar to other states:

- Continuing collaboration at the individual, local and state level;
- Balancing diagnostic, assessment and evaluative services with direct services offered in the home, school or community;

- Developing standards and services that are responsive, cost-effective, and evidence-based; and
- Continuing the momentum with sufficient human and financial capital.

There is support in Missouri for new legislation that specifically addresses the need to have health insurance coverage for autism spectrum disorders and autism-related therapies. It is likely the 2010 legislative session will see a bill outlining health insurance coverage for autism-related therapies.

What are we likely to see from Missouri's Commission on Autism Spectrum Disorders? The subcommittees' deliberations may prompt development of additional inter-agency agreements or foster more public-private partnerships. Legislation may be proposed to implement certain strategies or system improvements. As research continues to inform practice, it will be necessary for the Commission to remain abreast of research findings, promote best practices, and **increase access to services that offer citizens with autism a chance to live their lives to their fullest potential.** (Emphasis added)

For more information on Missouri's Commission on Autism Spectrum Disorders or this report, please contact the Office of Autism Services or Division of Developmental Disabilities. All Commission meetings are open to the public; the public is invited to attend.

Bernard Simons, Director  
Division of Developmental Disabilities  
Department of Mental Health  
573-751-4054

Julia Kaufmann, Director  
Office of Autism Services  
Division of Developmental Disabilities  
573-526-3848

**Missouri Commission on Autism Spectrum Disorders  
Roster of Commissioners  
June 2009**

**STATE AGENCY DESIGNEES**

Bernard Simons  
Mental Health

Heidi Atkins Lieberman  
Elementary/Secondary Education

Gary Harbison  
Health and Senior Services

Sandy Rempe  
Public Safety

Dr. Robert Stein  
Higher Education

Dr. Ian McCaslin  
Social Services

Molly White  
Insurance, Financial Institutions  
and Professional Registration

**APPOINTEES**

Dr. Janet E. Farmer  
Institution of higher learning  
Columbia, Missouri

Connie L. Hebert  
Institution of higher learning  
Cape Girardeau, Missouri

Phyllis Wolfram  
Special Education Program  
Ozark, Missouri

Anne Roux  
Speech/Language pathologist  
Ballwin, Missouri

Dr. John F. Mantovani  
Diagnostician  
St. Louis, Missouri

Paula F. Baker  
Mental health provider  
Joplin, Missouri

Dr. Michele G. Kilo  
Primary care physician  
Kansas City, Missouri

Rebecca Blackwell  
Private provider  
Webster Groves, Missouri

Vicki McCarrell  
County developmental disabilities board  
Boonville, Missouri

Dr. David P. Crowe  
Parent representative  
Cape Girardeau, Missouri

Lee Bascom  
Parent representative  
St. Louis, Missouri

Tiffany L. Daniels  
Constituent Representative  
Nixa, Missouri

Jean-Paul Bovee  
Constituent Representative  
Kansas City MO 64114

**LEGISLATIVE REPRESENTATIVES**

Honorable Scott T. Rupp  
Senate Majority

Honorable Jeff Smith  
Senate Minority

Honorable Dwight Scharnhorst  
House Majority

Honorable Sue Schoemehl  
House Minority

**Missouri Commission on Autism Spectrum Disorders  
Roster of Commissioners  
June 2009**

**DEPARTMENT OF MENTAL HEALTH STAFF**

Keith Schafer, Director  
Department of Mental Health

Bernard Simons, Director  
Division of DD

Julia Kaufmann, Director  
Office of Autism Services  
Division of DD

Kit Glover, Coordinator  
Office of Autism Services  
Division of DD

Monica Hoy  
Assistant to the Department Director  
Mental Health Commission Liaison  
Department of Mental Health

Dana Opie, Office Support  
Office of Autism Services  
Division of DD

# *Missouri Revised Statutes*

## **Chapter 633** **Mental Retardation and Developmental Disabilities** **Section 633.200**

Effective August 28, 2008

### **Commission established, members, duties.**

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 commission\* 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 agencies regarding matters concerning all state levels of autism spectrum disorder services, including health care, education, and other adult and adolescent services.

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

(1) Four members of the general assembly, with two members from the senate and two members from the house of representatives. The president pro tem of the senate shall appoint one member from the senate and the minority leader of the senate shall appoint one member from the senate. The speaker of the house shall appoint one member from the house of representatives and the minority leader of the house shall appoint one member from the house of representatives;

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

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

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

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

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

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

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

- (9) Two representatives from different institutions of higher learning located in Missouri;
- (10) An individual employed as a director of special education at a school district located in Missouri;
- (11) A speech and language pathologist;
- (12) A diagnostician;
- (13) A mental health provider;
- (14) A primary care physician;
- (15) Two parents of individuals with autism spectrum disorder, including one parent of an individual under the age of eighteen and one parent of an individual over the age of eighteen;
- (16) Two individuals with autism spectrum disorder;
- (17) A representative from an independent private provider or nonprofit provider or organization;
- (18) A member of a county developmental disability board.

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

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

5. 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. By July 1, 2009, the commission shall issue preliminary findings and recommendations to the general assembly.

6. In preparing the state plan, the commission shall specifically perform the following responsibilities and report on them accordingly, in conjunction with state agencies and the office of autism services:

(1) 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:

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

(b) 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;

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

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

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

(3) 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. This may include degree programs in education, special education, social work, and psychology; and

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

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

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

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

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

(e) 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;

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

(L. 2008 S.B. 768)

\*Word "committee" appears in original rolls.

# *Missouri Revised Statutes*

## **Chapter 633 Mental Retardation and Developmental Disabilities Section 633.210**

Effective August 28, 2008

### **Office of autism services established, duties--autism spectrum disorder defined.**

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

2. 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.

(L. 2008 S.B. 768 § 633.225)

# MISSOURI COMMISSION on AUTISM SPECTRUM DISORDERS

## “Framework for the Future” 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 Committees

Steering Committee\*  
Individual and Family Supports  
Healthcare  
Education  
Workforce Development

\*comprised of workgroup leadership and others

### Guidance for Committee Work

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

- 1) the person who has autism, and
- 2) persons within the natural environment who require supports in order to best care for the person with autism

- Screening, Diagnosis, & 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)** noted 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)
- 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 Committee Work per SB768\*

### All Committees:

- **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 comprehensive, coordinated system care for individuals with ASD.

### **Individual and Family Supports (community integration, child care and respite, long term care for individuals)**

- shall assess the need for additional behavior intervention capabilities and means for expanding such in regional service areas.

### Healthcare

- Shall determine need for creation of additional centers for diagnostic excellence.
- Shall develop recommendation for expanding services with hospitals after review of specialty clinic/hospitals and inpatient care.
- 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 assessment for coordinated, enhanced and targeted special education capabilities within each region.
- Shall develop recommendations for enlisting universities and colleges to ensure support collaboration in developing certification or degree programs for students specializing in ASD intervention (may include degree programs in education, special education, social work, psychology).
- May provide recommendations on training programs and content of such being developed.
- May recommend a panel of qualified professionals and experts to review existing models of evidence-based education practices.

### Workforce Development

- **Employment**

\*Notes: 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 committee.

## References

- <sup>1</sup> “Autism Overview: What we Know,” 2005. Eunice Kennedy Shriver National Institute of Child Health and Human Development, National Institutes of Health.
- <sup>2</sup> “Autism in Missouri: Bridging the Gaps, A State Plan for Autism,” 1990. The Institute for Human Development, University of Missouri-Kansas City, Autism Resource Center, in conjunction with the Advisory Committee on Autism to the Missouri Planning Council for Developmental Disabilities.
- <sup>3</sup> “System Breakthrough for Excellence,” 2003, Report for the Division of Mental Retardation and Developmental Disabilities’ Steering Committee.
- <sup>4</sup> “The Missouri Autism Research Agenda,” 2003, The Missouri Educational and Public Policy Symposium. <http://www.dmh.mo.gov/mrdd/progs/autism/mara.pdf>
- <sup>5</sup> Missouri Autism Project Registry: Final Project Report and Recommendations, June 30, 2005. J.E. Farmer, J.H. Miles, and G. Demir. A collaborative project facilitated by the Departments of Health Psychology, Child Health, and Health Management and Informatics, University of Missouri-Columbia.
- <sup>6</sup> Missouri’s Blue Ribbon Panel Report on Autism, December 2007. <http://www.dmh.mo.gov/mrdd/progs/autism/autismlueribbon.htm>
- <sup>7</sup> “Recommendations for Policy and Practice in Missouri,” March 2009, Missouri School Boards’ Association Autism Task Force. <http://www.msbanet.org/news/article.aspx/3844>
- <sup>8</sup> “Autism Has High Costs to U.S. Society,” press release April 25, 2006; M. Ganz, Harvard School of Public Health.
- <sup>9</sup> Easter Seals’ “Living with Autism Study.” June 2008, Easter Seals, MassMutual Financial Group, and the Autism Society of America.
- <sup>10</sup> Sharpe, Deanna L., & Baker, Dana L. 2007. Financial Issues Associated with Having a Child with Autism. *Journal of Family and Economic Issues*, 28, 247-264.
- <sup>11</sup> Dew, D. W., & Alan, G. M. (Eds.). (2007). *Rehabilitation of individuals with autism spectrum disorders* (Institute on Rehabilitation Issues Monograph No. 32). Washington, DC: The George Washington University, Center for Rehabilitation Counseling Research and Education.
- <sup>12</sup> University of Massachusetts, “Supporting Individuals with autism Spectrum Disorders: Quality Employment Practices.” 2008.