

# *The Missouri Blue Ribbon Panel Report on Autism: A Guide for Families and Community*

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*(December, 2007) This family guide is produced by parent members of the Missouri Autism Coalition (MAC) and Missouri Families for Effective Autism Treatment (MO-FEAT) who served on the supporting committee to the Blue Ribbon Panel. This summary is in no way meant to replace the official senate report. It is merely a tool to help families and community members understand the report and recommendations and should only be used as such.*

**Introduction.** In April, 2007, Senator Michael Gibbons announced the formation of the Missouri Blue Ribbon Panel on Autism, made up of 16 members including two state senators, professionals from various related fields, and family members of individuals with autism. The



Panel was charged with reporting to the Missouri State Senate on the state of autism in Missouri, including their recommendations for improving state systems, structures, and policy to improve the future for people with autism in Missouri.

After holding hearings in various regions of Missouri, and receiving and reviewing written testimony, the Panel summarized their findings and recommendations for improving state systems, structures, and policy to improve the future for people with autism in Missouri. The Panel reviewed a wide variety of topics and concerns, including mental health services, education, health care, reimbursement and funding issues. They then focused the report on issues specifically related to state government and recommendations that would be considered state-level priorities. The report is meant to serve as a roadmap for the future, and includes numerous recommendations for the state of Missouri to consider implementing. No

recommendations in the report are binding, nor do they establish any changes in regulations or policy by themselves.

**Overview of the Findings.** Autism is a complex neurobiological disorder, and is the fastest growing developmental disability in the United States. Early diagnosis and early intervention are critical. However, while early intervention may positively impact the outcomes for an individual with ASD [Autism Spectrum Disorder], and his or her family, it does not negate the need for a lifetime of services. ASD is a lifelong disorder and meeting the needs of individuals with ASD is a complex undertaking. Having well-trained professionals and well-informed families and caregivers is a prerequisite to meeting those needs. A comprehensive approach to treatment is required, encompassing a broad array of services, supports, and interventions in the areas of health, education, behavior and social skills. A statewide commitment of resources is needed along with increased access to and availability of such services. When individuals have access to appropriate services and supports, they have greater opportunities to live independent, healthy, and productive lives.

# ***SUMMARY OF THE RECOMMENDATIONS***

*In December 2007, the Blue Ribbon Panel on Autism made 36 recommendations as a roadmap for improving the state of autism in Missouri, as follows. In this summary, the term “autism” refers to all disorders on the autism spectrum.*

1. Create a Missouri Commission on Autism Spectrum Disorders to help develop a comprehensive, coordinated system of care for autism spectrum disorders. The Commission should make recommendations for a state plan for autism.
2. Direct the government agencies serving people with autism to report to the Commission on use of current funding and recommendations for changes.
3. Increase staffing for the Office of Autism Services in order to increase access to information, to actively reach out to families with resources, and to monitor implementation of a state plan once formulated.
4. Develop a confidential data collection system to analyze which interventions are effective in treating autism.
5. Continue the state’s partnership with IAN (Interactive Autism Network).

## **ADULT SERVICES:**

6. Develop the supports available through the Department of Mental Health including respite, crisis intervention teams, and residential services.
7. Designate a Department of Vocational Rehabilitation counselor in each region that would specialize in serving persons with autism.
8. Provide supports for individuals with autism who are pursuing higher education.
9. Develop a grant to target best case practices for employment of persons with autism, and disseminate this information to job counselors.
10. Identify funding and providers to help develop the interviewing and social skills that are necessary for high-functioning individuals with autism to secure and maintain successful employment.
11. Consider funding “follow-up” services for individuals with autism to improve their success in supported employment.
12. Study the fiscal impact of a tax credit for businesses that employ individuals with autism.
13. Inform parents of the importance of having a service coordinator from the Department of Mental Health attend the IEP meeting at age 14, if the parent desires.
14. Inform families of the importance of having a written long-term service plan for their family member with autism.

## **HEALTHCARE AND DEVELOPMENTAL SUPPORTS:**

15. Develop a universal screening tool for autism to be used by physicians, pediatricians, healthcare providers, and child-serving agencies in Missouri.
16. Designate autism spectrum disorders as medical diagnoses, specifically as neurologically-based disorders, as opposed to mental illnesses.
17. Adopt evidence-based standards for screening, diagnosis, assessment, and treatment of autism.

18. Establish a task force to consider expanding Missouri Medicaid waiver programs to include services such as Applied Behavioral Analysis, behavioral support, family training services, and other services that would improve the care of individuals diagnosed with autism.
19. Pass legislation requiring private insurance companies to provide coverage for specific services for people diagnosed with autism spectrum disorders.
20. Explore expansion of the current Missouri Rapid Response Model Program statewide.

### **EDUCATION:**

21. Develop and implement best practice guidelines for educational assessments and interventions.
22. Refine the eligibility criteria and the evaluation process for participation in First Steps to ensure enhanced participation and the opportunity for enhanced early intervention.
23. Provide a Parent's Bill of Rights to make the IEP process easier for parents to understand and participate in. School districts should target higher levels of intervention at ages 3 to 5 years.
24. Amend the Missouri State Plan to require the First Steps coordinator or provider to attend the child's transition and IEP meetings, and to help transition the child to the early childhood program.
25. Identify an autism specialist at each Regional Professional Development Center to assist school districts and parents with training and the IEP process.
26. Establish charter schools that specialize in educating children with autism.
27. Establish a system of early childhood centers, that focus on the needs of students age 3 to 5 who have autism or other special needs, when such services are not available at the local district level.
28. Allow equivalent funding to follow a student to the provider of the parent's choosing.
29. Work to change the existing IDEA law to allow automatic eligibility for special education services for children who have a medical diagnosis of an autism spectrum disorder.
30. Eliminate the term "educational diagnosis" and any distinction made between a medical diagnosis and an "educational diagnosis." A medical diagnosis should be allowed to establish eligibility for special education services.
31. Track the outcomes of the group of children with who begin early childhood special education services in the fall of 2008 until they complete fifth grade, with parental consent.

### **TRAINING:**

32. Coordinate and enhance all autism training opportunities including trainings on early screening for autism, and trainings through Project ACCESS and the Regional Professional Development Centers.
33. Offer specialized training to all providers who support people with autism, and their supervisors.
34. Consider paying direct care workers for people with autism a higher pay rate and increased pay for additional trainings.
35. Reinstate crisis teams through each regional center with special trainings for these team members, and create a comprehensive, coordinated system for crisis care.
36. Improve teacher education training about autism spectrum disorders and the management of behavior problems.

## *Next Steps to Take for Families and Community Members*

### *Where to go to read further*

The entire Missouri Blue Ribbon Panel Report on Autism can be downloaded at [www.senate.mo.gov/autism](http://www.senate.mo.gov/autism).

### *How to get involved: Voices for Autism*

If you would like to help support Missouri legislative initiatives to improve the lives of people with autism and their families, you can sign up to be a Voice for Autism. Please send your contact information to MO-FEAT at [mo-feat@sbcglobal.net](mailto:mo-feat@sbcglobal.net) or call us at (314) 275-8880.

The report and recommendations of the Missouri Blue Ribbon Panel on Autism are only a first step on the road to improving the lives of Missourians who have autism spectrum disorders. Real change will require the support and active involvement of many Missourians. You can take the following steps to assist in this effort:

- Contact your legislator to let him or her know how autism affects your life. Invite them into your home to visit with your family. Educate them on your needs and how they could help support your family. Speak up about how these recommendations affect you and your community.
- Continue active communication with your legislators about autism-related issues in your community.
- Respond quickly to any CALLS FOR ACTION that you receive by email, and contact your legislator's office immediately to express your opinion about these issues. Your legislator will not know how important these issues are to you if you do not let make your concerns known.
- Continue to educate yourself about autism-related issues.
- Consult the Missouri Autism Coalition website to follow how the recommendations of the Blue Ribbon Panel report are being implemented ([www.missouriautism.com](http://www.missouriautism.com)).
- Talk to your family, friends, and neighbors and encourage their support in your autism advocacy efforts. It is important that our legislators hear the same message from as many people as possible.