

## **2007 Blue Ribbon Panel on Autism**

### ***Background on Autism***

Autism is a complex neurobiological disorder characterized by varying degrees of impairment in communication skills, social interactions, and restricted, repetitive and stereotyped patterns of behavior. Although symptoms can sometimes be recognizable in infancy, many individuals are not diagnosed with autism until a later age. Early identification can lead to early treatment, which has proven most effective. Appropriate diagnosis, intervention, and treatment backed by autism-specific research, teaching, and training are critical to maximize the potential for Missouri individuals with autism.

The number of children and adults diagnosed with Autism Spectrum Disorders (ASD) is increasing dramatically, thereby creating a growing and urgent concern for families, service providers, and policy-makers. Currently, more children are diagnosed with autism than AIDS, juvenile diabetes and cancer combined. Across the nation, it is estimated that 1 in 150 children are diagnosed on the autism spectrum. Autism costs the nation over \$90 billion per year; this figure is expected to double in the next decade.

### ***Blue Ribbon Panel on Autism***

The Blue Ribbon Panel shall consist of sixteen members and will be responsible for assisting policymakers in providing a better system for individuals and their families affected by Autism Spectrum Disorders. The Blue Ribbon Panel is charged with identifying issues of children, youth, and adults with autism and with making appropriate recommendations to address those identified needs. The duties of the committee shall include the following, but are not limited to:

### ***Charge***

Determine “the State of Autism” in Missouri including services, teaching, training, and research and make recommendations for improving the quality of life across the lifespan of individuals with autism and their families.

In addition, the panel is charged with providing findings and making appropriate recommendations on the following:

1. From a systems perspective:
  - (A) Identify agencies within state government which provide services to individuals and families with autism;
  - (B) Review the coherence, effectiveness, and efficiency within the agency;
  - (C) Investigate collaboration across agencies;
  - (D) Examine existing and potential state and private partnerships.
  
2. From a systems perspective :

- (A) Analyze the linkage, communication and coherence among Parents as Teachers, First Steps, Early Childhood Special Education, K-12 Education;
  - (B) Analyze the supports in transitions after high school and through adulthood;
  - (C) Examine existing and potential state and private partnerships.
- 3. From the perspective of the individuals with autism and their families:
  - (A) Evaluate the effectiveness of the systems described in one and two above;
  - (B) Determine their accessibility, affordability, and availability.
- 4. Review the phases a child and family encounter on their journey with autism beginning with the screening/identification, diagnosis, treatment, transition, and supports throughout the lifespan.
- 5. Examine the barriers to accurate identification of the prevalence of individuals with autism across the state and recommend a process for accurate reporting of demographic data.
- 6. Determine adequacy of coverage including local, state, and federal sources. Additionally, explore sharing of costs with private insurance and Medicaid to assist families through the lifespan of services.
- 7. Evaluate current training standards and ongoing professional development for professionals and paraprofessionals, including but not limited to: teachers, therapists, and/or direct support professionals.
- 8. Determine the extent to which universities in Missouri conduct autism-specific research which:
  - (A) Advances science, treatment, and hope for cure for autism;
  - (B) Considers the best science which leads to the best practice;
  - (C) Positions Missouri to be the national leader in best practices for autism research.
- 9. Determine, develop, and recommend steps necessary to position Missouri as the national leader in best practices in treatment, training, research, and family supports in autism.

**Representation on the Blue Ribbon Panel on Autism:**

Senator Scott Rupp, (R-Wentzville) (**Chairman**)  
Senator Jolie Justus, (D-Kansas City)

**St. Louis**

Ron Ashworth, President/CEO of Sisters of Mercy Health System (**Vice-Chairman**)

Julie Roscoe, Deputy Director Family and Community Relations of Judevine Center

Randy Sanders, Autism Director of Francis Howell School District, Parent  
Bill Bolster, Attorney, Parent

**Kansas City**

Tom Davis, CEO of Meyer Companies Inc., Former MO State Board of Education Member, Grandparent

Robin Russell, Autism Alliance of Kansas City, Parent

**Mid-Missouri**

Dr. Steve Kanne, Associate Director of the Thompson Center for Autism and Neurodevelopmental Disorders

Dr. Laurie Fowler, Physician

**Southeast**

Mamie Benson, SE Project Parent Advisory Committee, Parent

**Springfield**

Shawn Williams, Law Enforcement, SW Project Parent Advisory Committee, Parent

**Joplin**

Nikki Straw, Chairperson of Statewide Autism Parent Advisory Council, Parent

**Northeast**

Dr. Cindy Dowis, Director of Special Education for Kirksville School District

**Missouri-At-Large**

Heidi Atkins-Liberman, Assistant Commissioner—Special Education

Julia Kauffman, MRDD District Administrator, former Director for Autism Services

**Meetings:**

Various meetings, determined by the chairman, will be held throughout the state with parents, families, providers, and educators. The purpose of these meetings will be to listen, evaluate, and make recommendations. The panel shall issue a report, as deemed appropriate by a majority of the members of the committee, to the President Pro Tem of the Missouri Senate no later than Oct. 31<sup>st</sup>, 2007.