



## Blue Ribbon Panel on Autism

President Pro Tem Michael R. Gibbons  
Senator Scott T. Rupp

December 18, 2007

STATE OF MISSOURI

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## MISSOURI SENATE

JEFFERSON CITY

## SCOTT T. RUPP

2ND DISTRICT

To Whom It May Concern:

I wanted to personally thank each panel member for their service and President Pro Tem Michael R. Gibbons for creating the Blue Ribbon Panel on Autism. The panelists represented varying view points and provided a depth of insight into each hearing we had on several issues pertaining to autism in Missouri.

I also want to extend my deepest thanks and gratitude to each person who testified before the Blue Ribbon Panel during our five hearings across the state. I understand that for many it was difficult to share their failures and successes with the Blue Ribbon Panel, but the input from the public has formed the basis of the recommendations contained in this report.

While the Blue Ribbon Panel members did differ on several issues in creating these recommendations, we were able to put forward recommendations that represented the majority of the Blue Ribbon Panel and reflected the testimony we heard in our public hearings. Each individual recommendation is not the viewpoint of each individual member or organization they represent on the panel. The best job possible was done to incorporate all viewpoints on the issues to ensure a workable recommendation.

Again, my most sincere thanks to the Blue Ribbon Panel, our staff, our wonderful volunteers and most importantly, the members of the general public that spoke out on their experiences with autism. I know that I will forever be changed after having been given this experience to chair this panel, and I look forward to personally working towards the implementation of these recommendations in Missouri.

Sincerely,

A handwritten signature in black ink, appearing to read 'Scott T. Rupp'.

Senator Scott T. Rupp

## Introduction

The Blue Ribbon Panel consisted of sixteen members and was established to assist policymakers in providing a better system for individuals and their families affected by Autism Spectrum Disorders. 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. The Blue Ribbon Panel heard over 60 hours of testimony in 5 cities (Jefferson City, Cape Girardeau, Springfield, St. Louis, and Kansas City) from numerous experts, families, and individuals with ASD. The Blue Ribbon Panel also accepted and received written testimony from Missouri citizens through mail, email, and fax.

The Blue Ribbon Panel was 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 Blue Ribbon Panel provided findings and made appropriate recommendations from a systems perspective. The Blue Ribbon Panel heard testimony and made recommendations on the following:

- Identification of agencies within state and federal government that provide services to individuals and families living with Autism Spectrum Disorders (ASD) and review of the coherence, effectiveness, collaboration, and efficiency within each agency.
- Screening and identification, diagnosis, treatment, transitions, and supports throughout the lifespan.
- Adequacy of coverage including local, state, and federal sources, and private insurance to assist families through the lifespan of services.
- Training standards and ongoing professional development for professionals and paraprofessionals.
- Development of protocols ensuring that Missouri positions itself as the national leader in best practices in treatment, training, research, and family supports in autism.
- Establishment of a commission would be vital to the implementation of many of the Blue Ribbon Panel’s recommendations and important to the improvement of public and private partnerships for individuals with ASD.

It remains for all parties involved to craft a mechanism by which mutual interests are served. To that end, Missouri’s Blue Ribbon Panel presents its recommendations in the interest of a comprehensive, coordinated system of care.

# **The State of Autism in Missouri**

## **Introduction**

The Blue Ribbon Panel on Autism was appointed by President Pro Tem Michael R. Gibbons in 2007 and chaired by Senator Scott T. Rupp to address the growing concerns about Autism Spectrum Disorders (ASD) in our state. The goal of the Blue Ribbon Panel was to ensure that people with ASD are included in their communities and receive appropriate, timely, and necessary services throughout the lifespan and to make recommendations to further those goals.

The Blue Ribbon Panel conducted hearings in Jefferson City, Cape Girardeau, Springfield, St. Louis, and Kansas City to listen to testimony from experts and members of the public. Parents, individuals with ASD, healthcare providers, educators, social service professionals, state and regulatory agencies, and others all contributed their time and expertise to the Blue Ribbon Panel through testimony at the hearings and by submitting written testimony. Their knowledge and assistance was essential in assessing current gaps and systemic impediments in services and identifying priorities for future actions to improve the system of care for individuals with ASD.

## **Autism Spectrum Disorders**

Autism is a complex neurobiological brain disorder that presents varying degrees of impairment in communication skills, social interactions, and restricted, repetitive, and stereotyped patterns of behavior, among other behavioral and physiological symptoms. Although symptoms can sometimes be recognizable at 18 months or even earlier, many individuals are not diagnosed with autism until a much later age. Early identification can lead to early treatment, which has proven most effective. Appropriate diagnosis, intervention, and treatment supported by autism-specific research, teaching, and training are critical to maximize the potential for Missouri individuals with ASD.

Autism is one of a spectrum of related disorders that carry names such as Asperger's Syndrome, Pervasive Developmental Disorder - NOS, Rett's Syndrome, and Childhood Disintegrative Disorder. The current conventional custom is to label this array of disorders as Autism Spectrum Disorders (ASD). In addition to the ASD behavioral diagnosis, physicians have found more than 30 genetic disorders that can be associated with ASDs. Currently, 15% of children diagnosed behaviorally with an ASD can also be diagnosed with a specific genetic disorder. Common genetic disorders that are commonly associated with autism include Fragile X Syndrome and Tuberous Sclerosis.

Many people who testified view the data as indicating an epidemic of ASD. While there is debate about how much of the increase results from increased recognition versus increased prevalence, there is no disagreement that there are significantly

larger numbers of people who need services to treat and cope with ASD. While Missouri lacks an adequate database for information about people with ASD in this state, no indicators suggest that the rates of incidence are statistically different from national data. Such estimates indicate that 1 in every 150 children across all racial, ethnic, and socioeconomic backgrounds is diagnosed with ASD. ASD is more prevalent in males where approximately 1 in 90 is diagnosed.

### **Missouri as a National Leader—The Foundation and the Future**

Missourians have a strong foundation upon which to base and build the Blue Ribbon Panel recommendations to strive to be a national leader in autism in the future.

Missouri began the provision of services for individuals with ASD in the early 1970's. In 1991, the first regional Parent Advisory Council was formed. This local consortium of twenty counties and parents was designed to support families who needed services for their children with ASD. The Missouri Autism Project was born and now encompasses all counties in Missouri, has authority in statute and regulation, and enjoys a specific appropriation in Missouri's budget. With the creation of the Project, a community provider—Judevine—built a network of offices and staff to assist families and individuals who live with autism. There are now five Autism Projects in Missouri, and all Department of Mental Health Regional Centers have a direct line of referral to an autism project for all clients with an ASD diagnosis or displaying ASD characteristics. Projects include the Central Missouri Autism Project, Southeast Missouri Autism Project, Northwest Missouri Autism Project, Southwest Missouri Autism Project, and Eastern Missouri Autism Project.

Less than ten years after the creation of the Missouri Autism Project, a Senate sub-committee hosted a hearing on the state of autism. This sub-committee became the basis for Missouri's Autism Research and Response agenda, or MARRA. The intent of MARRA was not to capture a one-time effort but to establish a framework under which collaborative partnerships between stakeholders, research institutions, and service providers could enhance the lives of people with ASD and their families.

To date, the presence of strong state and university partnerships through MARRA influenced the recent endowment of the Thompson Center for Autism and Neurodevelopmental Disorders at the University of Missouri-Columbia. The relationships developed within MARRA also have fortified collaboration between public and private universities to further autism research.

A specific recommendation of MARRA was to create a statewide voluntary autism registry. Late in 2006, Missouri joined forces with the Kennedy Krieger Institute to accelerate autism research in Missouri. As noted by Dr. Janet Farmer, the MU Thompson Center had already begun work with the Missouri Division of Mental Retardation and Developmental Disabilities to create a statewide voluntary autism registry. The Missouri Autism Project Registry will enable families to sign up and provide information, such as when their family member was diagnosed, when

treatments and strategies were tried and what progress was made. It also will allow them to submit their names for consideration for research projects. This project will be linked to the Interactive Autism Network (IAN), building a model of how states can integrate IAN into their systems of care, and expanding opportunities for ASD research in Missouri.

In these instances and others noted within this report, Missouri has demonstrated that a proactive stance is the best response to the public health crisis created by the increased identification of Missourians with ASD.

The budget that Governor Blunt signed for Fiscal Year 2008, included his recommendation of \$3.9 million in additional state funding to focus on improvements to ASD treatment and diagnosis. This significant increase for ASD funding more than doubles current state spending to aid families faced with ASD. The state budget provided:

- \$500,000 to create an intensive day treatment program at the Ozark Center in Joplin, the first of its kind in Missouri;
- \$2.4 million to reduce the waitlist for ASD diagnosis and treatment by expanding staff and training;
- \$1 million for Missouri's Autism Projects.

The \$1 million increase for Missouri's Autism Projects was equally divided among the state's five regional areas. The money is targeted to allow regions to eliminate or address waitlists of children in line for ASD assessments or services.

### **Organizing Structure of the Blue Ribbon Panel's Findings**

Two unifying concepts were repeatedly reinforced to the Blue Ribbon Panel. The first is the complexity of ASD and its overall effects. The second is that ASD manifests uniquely in every individual diagnosed. The multitude of testimony from parents and individuals with ASD, in conjunction with testimony from experts, emphasized the complexity of ASD; furthermore, ASD resists being reduced to a simple definition or classification. The lack of a statewide database increases the difficulty of reaching a consensus on treatments and therapies.

The Blue Ribbon Panel developed recommendations and grouped them into five categories: Comprehensive, Coordinated System of Care; Adult Services; Healthcare and Developmental Supports; Education; and Training. While some issues could be addressed under multiple categories, the Blue Ribbon Panel has attempted to eliminate any overlap by placing issues wholly within one category. The following is a description of how the Blue Ribbon Panel sees the current state of autism in Missouri and forms the starting point for its recommendations.

## **Comprehensive, Coordinated System of Care**

Testimony indicated the importance of establishing a comprehensive, coordinated system of care to increase accessibility and availability of services for individuals with ASD. One recurring theme in testimony was the need for a commission to study and oversee the delivery of ASD-specific services. The following provides background information for the subsequent recommendations.

**Multiple Agencies:** Families are often confused when state programs that assist individuals with ASD are administered by multiple state or local agencies; this coordination of services is often seen as excessively bureaucratic. Testimony indicated that great sources of frustration were the coordination of services between First Steps and local school districts as well as between the Department of Elementary and Secondary Education and the Department of Mental Health.

**Data:** Data collection is insufficient at all levels of service for individuals with ASD. Missouri does not have sufficient data collected for accurately estimating Missouri's overall ASD population. As in all aspects of ASD, there is a significant lack of data on which to base changes in policy, formation of new services, and development of best practices for providers of all types. The Missouri Rapid Response Initiative is one effort to begin collecting and organizing relevant data to help enhance further public policy development. It is one example of the important goal of collaboration between state agencies.

Missouri's participation in national databases such as Interactive Autism Network (IAN) has only recently occurred. There continues to be some reluctance for participants because of privacy concerns about the use of such data. However, data collection and analysis is a critical need that permeates every aspect of our understanding of ASD and its treatments. We do not currently have sufficient data collected to accurately characterize Missouri's ASD population and to assist in research or treatment.

**Information and Direction:** Availability of information to assist individuals and their families who have received a formal diagnosis or screened to be at risk is not well-coordinated. The effectiveness of agencies that provide information to families depends heavily on multiple factors. One of these is the agency itself that is contacted. Another is the training or preparation of the individual agency employee who handles the inquiry. In addition, there is insufficient publicity and awareness of the services available to families.

**Addressing the Need:** There are numerous entities and agencies doing effective work in the area of ASD, including, but not limited to, the Judevine

Center; the Thompson Center; Children's Mercy Hospital; Cardinal Glennon Hospital; Rivendale; Ozark Center; the Department of Mental Health (including the Division of Mental Retardation and Developmental Disabilities); the Department of Elementary and Secondary Education, including First Steps, Project ACCESS, Missouri Parents Act (MPACT); Parents as Teachers (PAT); Missouri Autism Research and Response Agenda (MARRA); Missouri Department of Higher Education (DHE); Missouri Medicaid (MO HealthNet); local SB40 boards; Department of Health and Senior Services; the State Interagency Coordinating Council; Missouri Families for Autism Treatment (MO-FEAT) as well as numerous local agencies, service providers, pediatricians, and private agencies across the state.

### **Adult Services**

Testimony indicated that the supply and quantity of adult services is insufficient to meet demand. However, many adults in Missouri do receive services. Nevertheless, whether it is in supported employment, residential placement, sheltered workshops, respite care or crisis intervention, the number of service agencies with personnel who are properly trained in the unique aspects of ASD is limited. Other areas not adequately covered are marriage issues, parenting issues, homeownership and socialization issues for individuals with ASD. Not all individuals live in group homes or residential placements. Most of the services for adults are administered through the Regional Centers of the Department of Mental Health and often in partnership with the local SB40 boards.

Testimony offered several views of the current state of adult services:

**Respite Services:** Respite services for the families that include an individual with moderate to severe ASD are limited. The training for such providers has been insufficient.

**Waiting Lists:** Habilitation centers, sheltered workshops and residential care facilities often move individuals with ASD to the bottom of waiting lists because of the difficulties presented and the insufficient availability of training for their staff members. Many providers do not have the resources or training to adequately address the needs of individuals with ASD.

**Crisis Intervention:** Crisis intervention is sparsely available due to funding constraints. Hospitals, emergency rooms, law enforcement agencies, mental health providers, psychiatric hospitals and other such institutions are generally insufficiently prepared to handle the crisis needs of individuals with ASD and their families. Testimony indicated that this seems to apply to both the immediate intervention as well as the plan for returning the patient to his or her normal environment.

**Employment Assistance:** The assistance for individuals with ASD pursuing employment generally is provided under systems designed for all developmentally disabled individuals. However, many individuals with ASD have unique needs, which the current support systems are often inadequately prepared to address.

**Data:** As in all aspects of ASD, there is a significant lack of data on which to base changes in policy, formation of new services, and development of best practices for providers of all types.

**Case Management:** The case management process does not sufficiently recognize the elements and characteristics that make ASD cases unique. This is likely due to a lack of adequate data to provide direction to case managers, the limited range of adult services, and limited training for providers and case managers.

**Adults with Aging Parents or Long-Term Care Options:** Parents of individuals with ASD express great concern about what will happen to their children when they are no longer able to keep them in their home. Testimony indicated concerns in all areas of the state, but particularly in rural areas, where residential care facilities and other service providers are already extended beyond capacity. Many individuals with ASD are high-functioning and do not need residential care or workshops. Support for individuals with ASD within their own homes and within the community need to be explored.

Fundamentally, there is a lack of availability of ASD-specific services for adults. Because much of the focus has been on allocating resources to early identification and intervention, adults with ASD have often been given a lower priority by providers.

### **Healthcare and Developmental Supports**

The first opportunity to identify children with ASD often occurs in the health and mental healthcare systems. Both systems consist of public and private providers, private insurance, public funding streams, and state and local agencies. Both federal and state statutes govern this system. Testimony indicated that availability of services varies greatly across the different regions of Missouri.

For ASD, the state administers federal and state programs and provides services to people who need public assistance, primarily through the Department of Mental Health and the Division of Mental Retardation and Developmental Disabilities. The Department of Mental Health and the Division of Mental Retardation and Developmental Disabilities administer their programs through eleven regional centers. The Division is responsible for ensuring the accessibility of mental retardation and developmental disabilities prevention, evaluation, care, habilitation and rehabilitation. In addition to services handled by the Department of Mental

Health and the Division, local SB 40 boards provide residential, adult day care, respite, and a variety of other services for developmentally disabled children and adults, funded through local taxes.

While testimony revealed great gaps in our knowledge and understanding of the defining symptoms, causes, treatments and complexity of ASD, there were some broadly supported characterizations of the current health and mental healthcare systems in Missouri:

**Physicians:** Some parents who had concerns about their child's development testified that their physician suggested a "wait and see" approach to identify whether the behavior was simply a part of normal child development rather than conduct any tests or assessments. In addition, new parents have not been advised about ASD or about its early signs, red flags, frequency of occurrence, or the issues surrounding thimerosal and vaccinations. There is a concern that medical school curricula may not sufficiently address ASD detection, diagnosis, or treatment.

**Nature and Characteristics of ASD:** Controversy exists over whether ASD is a neurological disorder, a developmental disorder or a more complex condition involving many systems of the body. Other physiological conditions that affect individuals with ASD, such as gastric and intestinal disorders, sleep disorders, incontinence, and food or medicine allergies are often completely disconnected from other ASD therapies such as speech, occupational, or behavioral.

**Best Practice Guidelines:** Testimony indicated the need for the establishment of best practice guidelines in healthcare and related professions. Best practice guidelines could be used to identify helpful treatments and to scientifically support the appropriate use of various methods of intervention and treatment.

**Diagnosis:** ASD diagnosis is complex. It often involves extended observation of behavior as well as the administration of physical and psychological tests by healthcare professionals. Typically, there is a waiting list of several months to see healthcare professionals who can establish a credible diagnosis. With early diagnosis being the critical factor for successful intervention, the capacity for diagnoses and development of multi-disciplinary behavioral treatment plans is insufficient.

The Centers for Diagnostic Excellence provide such training and diagnosis, but the overall demand is well in excess of the supply. In addition, medical school and nursing school curricula may not contain sufficient ASD-specific training.

Parent training is limited and distributed unevenly across the state. Successful

interventions and treatments require parents to understand what services are available, what to expect as their child with ASD develops, and how to be an effective team member working with the case manager and the Individualized Education Program (IEP) team.

Finally, there is an obvious shortage of properly prepared physicians, pediatricians, pediatric psychologists, speech therapists, occupational therapists, behavioral therapists, researchers, pediatric neurologists, nutritionists, paraprofessionals, implementers, and other professionals. In addition, there are only a limited number of institutions involved in training new entrants into these professions. This shortage exists statewide but is more pronounced in rural areas, which causes parents to drive long distances for services and places additional stress on families.

**Data:** The Missouri Autism Research and Response Agenda (MARRA) is one effort to begin collecting and organizing relevant data and to help enhance further public policy development. It is one example of the important goal of collaboration between state agencies.

**After Diagnosis:** After receiving a diagnosis, the individual with ASD should begin treatment interventions. However, the training and capacity of the case manager or the First Steps Coordinator might determine the type, quality, and quantity of services an individual might receive. As a result, services for an individual with ASD can vary widely. Due to inadequate data systems, the matching of therapies or interventions to the specific needs of an individual is frequently based on what services are available rather than using the best practices currently known. There continues to be differences between medical specialists and others regarding approaches to treatment.

**Financing of Services:**

Many different entities are responsible for sharing the cost for ASD services and treatment.

*Private Pay*

Parents often pay out of pocket or significantly supplement other payment methods to receive needed services, resulting in the depletion or exhaustion of family resources, both financial and personal.

*Local, State, Federal Funding*

For those eligible, services derived from the federal Individuals with Disabilities Education Act (IDEA) and Medicaid (MO HealthNet) can provide significant assistance. Specific waivers allow for broadening the use of MO HealthNet funding for those who are eligible. Students who are eligible for IDEA can access special education funding until high school graduation or age 21, whichever comes first. For eligible individuals with developmental disabilities, services and funding can

be paid through the Department of Mental Health and often through the local SB 40 boards. In addition to private pay and government supported programs, payment for some services can come from private or employer medical insurance plans that will be addressed in the Healthcare and Developmental Supports section.

#### *Health Insurance*

Private health insurance rarely covers the needs of various treatments for individuals with ASD, because it is deemed a preexisting condition. Insurers have classified ASD as a behavioral disorder based on their standard classifications of coverage and claims. Their structure is designed as a means to return an individual to a condition that is roughly equivalent to a “baseline” that existed prior to an incident or identifiable change that created a detrimental outcome. Because ASD usually begins to affect a child’s behavior during his or her very early years, private insurers often state that a baseline for such a child is difficult to establish. Accordingly, there is no pre-existing baseline to which to return the child.

Insurers do not have effective systems for evaluating and covering multi-disciplinary diagnoses of ASD because such diagnoses depend on the services of non-medical and medical professionals, even though such multi-disciplinary diagnoses may be the current best practice. This may lead to a denial of any coverage for a diagnosis. In addition, the consequences of limited coverage or no coverage extend far beyond the individual family. Professionals who are interested in this field must look at positions available and the earnings potential when compared with other options.

Missouri does not currently have any statutory requirements for insurers that relate specifically to individuals with ASD. However, general non-discrimination statutes and mental health parity statutes do apply. Some services, particularly the obvious medical services, are covered by insurance in many policies. Additionally, some insurers cover a specific number of treatments for certain prescribed interventions but none cover the bulk of the cost of a full course of treatment and intervention required for individuals with ASD. Testimony indicated that many other states have ASD-specific related statutes that require specific actions by insurers.

### **Education**

Public education in Missouri is provided and governed through a system of local school districts. The Missouri Constitution identifies public education as the first priority of state government after the payment of just debts and specifies that at least 25% of state revenues must be allocated to educating our children. While state

statutes confer most of the power over public education to the local school districts, the constitution provides for a state board of education to supervise public instruction. The state board uses the Department of Elementary and Secondary Education to carry out this mandate. The scope of services provided through local school districts has expanded over time and through many federal and state mandates to include broad responsibility for students with all kinds of special needs.

Local school districts vary widely in size and in the capacity to address the needs of all children and the complex requirements of statutory mandates. Such variability leads to differences in the quantity and quality of services provided from district to district. Based on expert testimony and public testimony, the following is a description of the characteristics of Missouri public education regarding ASD:

**Services Widely Varied:** Most local school districts are working diligently to develop and implement appropriate services for students with ASD. However, the current state of programs for students with ASD varies widely. Testimony indicated great levels of concern that some school districts lack sufficient staff that is adequately trained to provide an appropriate education for students with ASD.

**First Steps:** The First Steps program is funded as Part C of the federal Individuals with Disabilities Education Act (IDEA) and is administered through the Department of Elementary and Secondary Education, Department of Mental Health, and a network of First Steps Coordinators. First Steps provides various services for children up to age three with certain developmental disabilities and developmental delays. Testimony focused on the shortage of trained providers in rural areas and on the transition from First Steps to the local school district at age three.

**Parents As Teachers (PAT):** The Parents as Teachers program was created to help new parents develop early childhood parenting skills and understand child development. This organization could help parent educators play an important role in the early identification of ASD.

**Best Practice Guidelines:** There are currently no best practice guidelines to help bring consistency in the therapies and methodologies used by local school districts. However, the lack of such guidelines is a symptom of a larger problem – the absence of a database and statewide data collection system to help classify the specific issues faced by each individual child. The database could also be used to identify helpful treatments and to scientifically support the appropriate use of various methods of intervention, treatment, and teaching.

**Teacher Education:** While teacher education curricula and professional development programs address many special education needs, ASD-specific training is relatively rare. Professional educators with ASD-specific training

are in short supply to meet the rising demand for ASD-specific services; the shortage is particularly critical in rural areas of the state.

**Individualized Education Programs:** Students with disabilities are eligible to have the school district prepare an Individualized Education Program (IEP). An IEP addresses a particular student's educational needs, establishes short and long-term educational goals, and identifies any supports needed to reach these goals. To develop an IEP, the school district assembles an IEP team, usually consisting of various school officials, teachers, and parents.

Difficulties may arise when an IEP contains goals, therapies, and methodologies different from what the child had received under First Steps or when the school district does not believe that the services from First Steps are relevant to the current education program. Mediation and other options are available, but may require additional resources and time. School districts often disagree about the specific strategies, educational placement, and degree of related services that the child should receive.

**Eligibility:** All public education programs for special education students contain eligibility criteria. IDEA Part B allows school districts to determine eligibility of students for services. Although students may already have received a formal medical diagnosis of ASD, some districts insist on performing their own assessment to determine eligibility for services, which is often labeled an "educational diagnosis." Some parents and providers testified that they view the educational diagnosis as a bureaucratic method for the school district to deny services to some children.

**Program Conflicts:** For students with ASD with more severe behavioral issues, parents testified that some school districts have failed to address and consider a student's neurological and mental health status, and have employed methods intended for students whose behaviors are not the result of a disorder like ASD. Such methods include isolation or suspension from school under the criteria established by the Safe Schools Act.

## **Training**

Testimony indicated a need for increased training across all levels for all parties involved in the delivery of services for individuals with ASD – teachers, providers, family members, and organizations.

**System Training:** Service coordinators, case managers, and service providers all expressed the need for more ASD-specific training. Project ACCESS, Judevine, the University of Missouri-Thompson Center, and the other Centers for Diagnostic Excellence provide such training, but the overall demand is well in excess of the supply. In addition, medical school and nursing school curricula may not contain sufficient ASD-specific training.

**Parent Training:** Training opportunities for parents are in high demand and are often limited in some regions of the state. Some of the Missouri Autism Projects and Judevine offer various levels of parent training on a variety of ASD topics to meet individual family needs. This includes a three-week intensive parent training course that includes the individual with ASD and the family member as well as less-intensive day trainings. MPACT offers education-related training to assist families with understanding the IEP process and IDEA regulations. Successful interventions and treatment requires parents to understand what services are available, what to expect as their child with ASD develops, and how to be an effective team member working with the case manager and the Individualized Education Program (IEP) team.

Public testimony reflected the need for increased training opportunities for families, in all areas-related to ASD, including behavioral techniques, treatment options, and in the area of education.

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

The Blue Ribbon Panel identified what is currently functioning well and what gaps exist that could be addressed. The Blue Ribbon Panel prepared the following recommendations that address priority areas where change is critically needed, based on testimony heard and the expertise and insight derived from Panel members' professional and personal experiences with ASD.

### **COMPREHENSIVE, COORDINATED SYSTEM OF CARE**

Testimony presented to the Blue Ribbon Panel made the case for the allocation of additional resources in Missouri to provide healthcare, educational services, and other adult and adolescent services for the ASD community. Testimony also emphasized the need for better distribution of healthcare and related resources throughout Missouri and the lack of trained experts in certain healthcare and related professions. Also, extensive testimony was heard about the need for families and parents of individuals with ASD to have a better understanding of the complex regulations surrounding early childhood education, and the development of individualized education programs.

What was clear from the testimony was the need for the coordinated development of qualified resources. This coordinated development needs to be guided by a state plan for ASD.

#### ***A. Creation Of The Missouri Commission On Autism Spectrum Disorders***

##### **RECOMMENDATION #1**

**The Blue Ribbon Panel recommends that the General Assembly create the Missouri Commission on Autism Spectrum Disorders. The Commission would advise and make recommendations to the Governor, General Assembly, and relevant state agencies regarding matters concerning all ASD services, including healthcare, education, and other adult and adolescent services.**

**The Commission would be specifically charged with 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 would consist of members, including but not limited to: members of the General Assembly; representatives from the Department of Mental Health; Department of Elementary and Secondary Education, including representatives from First Steps, Division of Vocational Rehabilitation, and Early Childhood; Department of Health and Senior Services; Department of Public Safety; Coordinating Board for Higher Education; Department of Social Services, including the Children's Division; Department of Insurance, Financial Institutions, and Professional Registration;

institutions of higher learning located in Missouri; a special education director; a speech and language pathologist; a diagnostician; a mental health provider; independent private providers, and non-profit providers and/or organizations; a primary care physician; parents of individuals with ASD that encompass the entire life spectrum; and individuals with ASD.

The members of the Commission shall consist of a broad representation of Missouri's citizens, both urban and rural, who are concerned with the health and quality of life for individuals with ASD. Staff from the Department of Mental Health will provide administrative support to the Commission.

***In preparing the state plan a comprehensive, coordinated system of care for ASD in Missouri, the Commission should 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 coordinated system of care delivery across the state to address the increased and increasing presence of ASD and ensure that resources are created, well-utilized, and appropriately spread across the state;*
- 2. 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;*
- 3. 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;*
- 4. Assess the need for additional behavioral intervention capabilities and, as necessary, the means for expanding those capabilities in a regional service area;*
- 5. 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;*
- 6. Conduct an assessment of the need for coordinated, enhanced and targeted special education capabilities within each region of the state;*
- 7. 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. This may include degree programs in education, special education, social work, and psychology;*
- 8. Provide recommendations regarding training programs and the content of training programs being developed;*
- 9. Recommend individuals to participate in a committee of major stakeholders charged with developing screening, diagnostic, assessment, and treatment standards for Missouri;*
- 10. Participate in recommending a panel of qualified professionals and experts to review existing models of evidence-based educational practices for adaptation specific to Missouri;*
- 11. Examine the barriers to accurate information of the prevalence of individuals with ASD across the state and recommend a process for accurate reporting of demographic data;*

12. *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 ASD.*

## **RECOMMENDATION #2**

**The Blue Ribbon Panel recommends that all relevant state agencies deliver a report to the Missouri Commission on Autism Spectrum Disorders that describes the manner in which funds are allocated among various governmental agencies for services used by individuals with ASD.**

Based on that review, the relevant state agencies should include recommendations in the report for changes in the delivery of such services and recommendations for possible efficiencies that could be achieved through such changes. The report should also address gaps in funding sources that may prohibit families and individuals with ASD from having access to evidence-based best practices.

### ***C. Outreach to Families – Assistance to Families for a Comprehensive, Coordinated System of Care***

For the creation of a comprehensive, coordinated system of care to be effective, it is essential that policies cover the lifespan of individuals with ASD. Although many excellent services are available for individuals with ASD and their families, these services can be difficult to access. In many instances, people are simply not aware of the available services and supports or of alternative options that could result in faster and better services and supports. They also may not know the proper procedures for gaining a position on a waiting list. As a result, an individual with ASD may fail to obtain a spot on a waiting list, or alternatively, may be placed on a waiting list for an inadequate or inappropriate service or support.

The Blue Ribbon Panel acknowledges that the Division of Mental Retardation and Developmental Disabilities currently has an Office of Autism Services (OAS), which is unable to operate at its full potential to provide services and outreach to families because it is only staffed part-time.

## **RECOMMENDATION #3**

**The Blue Ribbon Panel recommends that the Office of Autism Services, through appropriate funding to the Division of Mental Retardation and Developmental Disabilities, be staffed with a full-time person and an appropriate number of program staff to carry out the responsibilities assigned to it in legislation.**

**The Blue Ribbon Panel recommends that the Department of Mental Health's Office of Autism Services coordinate with other relevant state agencies, universities, non-profits, and providers to make information easily accessible and to actively reach out to families to make them aware of the process to obtain services and supports for individuals with ASD and their families throughout the**

**lifespan. This includes promoting, enhancing, and publicizing public and private 1-800 numbers, which can assist families with individuals with ASD before and after a diagnosis. This would serve as a resource to parents to assist in navigating the various systems services and treatment.**

**The Office of Autism Services, in conjunction with state agencies, would also be responsible for assessing, on an annual basis, and reporting to the Governor, the General Assembly, and the Commission, progress made with respect to the implementation of a state plan.**

*D. Data – Obtaining an accurate assessment on the number of individuals with ASD in Missouri and services provided*

#### **RECOMMENDATION #4**

**The Blue Ribbon Panel recommends that the Department of Elementary and Secondary Education solicit proposals to design a data collection system to support analysis of ASD intervention across the lifespan (evidence-based therapies or teaching practices) and costs of serving children with ASD organized by appropriate classifications.**

It is recommended that the data collection system be created for all students with ASD using the state-wide identification number and be submitted to the Department of Elementary and Secondary Education. Access to the data should be granted to appropriate public school personnel, qualified researchers in the field, and individuals specifically authorized by statute or rule.

#### **RECOMMENDATION #5**

**The Blue Ribbon Panel recommends that Missouri continue its partnership with IAN and allow further completion of IAN (when appropriations are made available). Recommended steps include, but are not limited to:**

- Disseminate information about IAN to parents statewide and encourage voluntary enrollment.
- Establish a method for routine access to the IAN Missouri-specific statistics (IAN-Missouri).
- Examine other aspects of the IAN-Missouri dataset, especially prevalence, parental reports of treatment use and treatment efficacy, and regional patterns of access to care in Missouri to allow for a comparison of Missouri data with national data.
- Define methods for integrating IAN with other Missouri state databases, including the cross-agency Children’s Data Warehouse, if and when it is developed.

- Establish a Scientific and Privacy Advisory Council for the IAN-Missouri registry.
- Continue MARRA meetings with Missouri researchers to discuss options for use of IAN-Missouri to accelerate the pace of ASD research and treatment. More specifically, a Missouri-specific survey should be developed to answer questions pertinent to the state and the researchers.

### **ADULT SERVICES**

The state of Missouri needs to develop a lifelong comprehensive, coordinated system of care for individuals with ASD. Testimony indicated that differences exist between merely serving individuals diagnosed with ASD and providing ASD-specific services. More simply, just because an individual with ASD receives a service does not mean that the service is “ASD-specific.” To ensure that treatment is “ASD-specific,” particular training of service providers must be required on an initial basis and on an ongoing basis. Training must have core competencies that include an emphasis on communication, social interaction, behavior analysis, dealing with challenging behavior and crisis intervention strategies. Successful treatment requires focusing on the individual manifestation of ASD in the individual being treated.

It is important to provide a seamless transition from school to work after graduation as well as a transition from a school-based program to the community. Local school districts should consider developing transition plans for students with ASD.

Testimony indicated that there are concerns with insufficient time and planning prior to the federal mandate age of sixteen. If a student is to graduate at age eighteen, the transition plan needs to focus on the student’s goals for transition after graduation. Services and supports must be smooth and not be disruptive and should maximize independence for individuals with ASD. The goal is to achieve the least restrictive environment while focusing on the individual’s strengths and interests. If an individual is not able to secure a paid position in the work force, he or she should be able, with supports, to work and to continue to develop work skills.

Early diagnosis and early intervention are critical. While such emphasis may positively impact the outcomes for an individual with ASD, and his or her family, it does not negate the need for a lifetime of services. ASD is a lifelong disorder. A statewide commitment of resources is needed along with increased access and availability of such services.

#### ***A. Respite and Crisis Intervention***

Like many people with chronic health conditions and disabilities, individuals with ASD are especially vulnerable during emergencies. There is a lack of individual support available to adolescents and adults with ASD who live at home. Individual

support services may include home and residential respite, off-site day habilitation, recreation, or community integration opportunities.

In addition, police or other emergency responders might not be familiar with how to handle a crisis involving an individual with ASD. As a result, they might inadvertently escalate crisis behavior in the attempt to intervene in crisis situations and may risk injury to all parties involved.

The Department of Mental Health currently provides residential support for individuals with ASD in crisis or who are no longer able to reside with their natural family. Testimony indicated that the current system could better serve individuals with ASD and their families. Many of the current residential providers have difficulties providing appropriate services in the residential setting due to a lack of staff training and existing funding mechanisms.

### **RECOMMENDATION #6**

**The Blue Ribbon Panel recommends that the Department of Mental Health continue development of supports available to individuals with ASD in or outside of their homes. Additionally, the Department of Mental Health should focus on respite, crisis intervention teams, and residential service categories. The Department of Mental Health should evaluate the need for respite services capacity to be expanded.**

**It is also recommended that the Department of Mental Health evaluate existing supportive placements for individuals with ASD and explore residential supports that are appropriate.**

**The Blue Ribbon Panel recommends that each regional center support a crisis team that can respond to behavioral emergencies within the home for families and service providers that support adults with ASD (when appropriations are made available).**

#### ***B. Employment***

Individuals with ASD range in employment ability from those who benefit primarily from sheltered workshops and other forms of supported employment to those who may be successfully employed in competitive settings with some specialized training. Supports must be individualized to help each individual with ASD achieve his or her potential in employment.

The Division of Vocational Rehabilitation, as the coordinating agency for funding and supports in the area of employment, must individualize the planning process to ensure the necessary supports and services.

### **RECOMMENDATION #7**

**The Blue Ribbon Panel recommends 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. The counselor shall provide ASD consultation services to other staff in the region.**

### **RECOMMENDATION #8**

**The Blue Ribbon Panel recommends that the Division of Vocational Rehabilitation collaborate with institutions of higher education to identify providers for the purpose of providing supports to individuals with ASD who are attending such institutions.**

### **RECOMMENDATION #9**

**The Blue Ribbon Panel recommends that the Division of Vocational Rehabilitation develop an Innovation and Expansion (I & E) grant, in collaboration with a university within Missouri to target best case practices specific to clients with ASD, and disseminate this information to Division of Vocational Rehabilitation counselors and providers in each office and region, via trainings and meetings.**

It is recommended that the Division of Vocational Rehabilitation develop viable alternatives to serve individuals on the more severe end of the autism spectrum when supported employment is not an option. The Blue Ribbon Panel recommends that the Division of Vocational Rehabilitation develop alternative evaluation methods and allow providers access to them when evaluating clients with ASD.

The Blue Ribbon Panel recommends that the Division of Vocational Rehabilitation examine best practices used by other states and implement pilot projects to meet the unique employment considerations of individuals with ASD and consider the contrast between rural and urban settings and the differences in employment options, including job development, sheltered, supported and competitive employment.

### **RECOMMENDATION #10**

**The Blue Ribbon Panel recommends that the Division of Vocational Rehabilitation, serving as the lead agency, and other relevant state agencies, collaborate to identify funding and to identify providers to enable the development of social skills and interview skills that are necessary to the successful employment for high-functioning individuals with ASD.**

It is critical to recognize and address the needs of high-functioning individuals, who might be initially successful in obtaining employment, but might have difficulty

maintaining it or might miss opportunities because of difficulties with social skills, personal care, personal management, communication, or behavioral issues.

#### **RECOMMENDATION #11**

**The Blue Ribbon Panel recommends that the Department of Mental Health consider the costs and benefits associated with funding for “follow-up” services for individuals with ASD so that access to supported employment is available. The Department of Mental Health should, in partnership with other funding sources whenever possible, allocate resources for “follow-up” services in employment.**

#### **RECOMMENDATION #12**

**The Blue Ribbon Panel recommends that the Department of Economic Development study the fiscal impact of a tax credit for businesses that employ individuals with ASD.**

#### ***C. Long-Term Support and Planning***

ASD presents lifelong implications for education, social development, and community adjustment. Supports are needed for individuals with ASD, their families, professionals, and providers to ensure that services, options, and opportunities are available throughout their lifespan. When individuals have access to appropriate services and supports, they have greater opportunities to live independent, healthy, and productive lives.

Testimony indicated that referrals for necessary supports and services often do not happen until the age of eighteen or the year of high school graduation, whichever comes first. When this occurs, individuals with ASD are often placed on waiting lists due to funding constraints for services. Without structures and supports, behavioral challenges are often exacerbated and can result in crisis in the form of self-injury, danger to self or others, or property destruction.

Moreover, assessments by the Division of Vocational Rehabilitation, if left until the last year of school and or just prior to graduation, may yield results that determine an individual to be ineligible for employment. By involving needed supports early in the transition planning process, individuals with ASD, their families, and the system of supports designed to facilitate transition will be better able to determine the needs of the individual and the capacity of the system to provide resources on an ongoing basis.

#### **RECOMMENDATION #13**

**The Blue Ribbon Panel recommends that local school districts inform parents of the importance of having a service coordinator from the Department of Mental**

**Health present at the IEP meeting that takes place around the fourteenth birthday of a child with ASD. The Department of Mental Health can begin to develop transition goals for the child, and determine which state agencies should be contacted while fostering stronger relationships with the child and his or her family. The child's family or legal guardian would have the right to exclude this individual from the IEP meeting.**

#### **RECOMMENDATION #14**

**The Blue Ribbon Panel recommends that upon entering services with the Department of Mental Health, the family must provide the Department of Mental Health with a written long-term service plan for individuals with ASD.**

### **HEALTHCARE AND DEVELOPMENTAL SUPPORTS**

Healthcare is often the first opportunity to identify and treat children with ASD. Issues in healthcare such as screening, diagnosis, treatment, and medical coverage can have a profound impact on the course that will be taken with the child throughout his or her life.

#### ***A. Screening***

Public testimony emphasized the importance of more comprehensive and effective screening. Physicians, in particular, called for widespread adoption of a screening tool throughout Missouri to aid in the early detection of ASD. Screenings are essential for the early detection of any developmental disorder.

In April 2007, the Missouri State Medical Association issued a resolution that supported the education of Missourians to improve the awareness and understanding of ASD. In that resolution, they urged physicians to include autism screenings in all well-child visits for children no later than 18 months of age. On October 29, 2007, the American Academy of Pediatrics called for screening all children for autism at 18 and 24 months of age.

Today, through efforts related to a pilot program developed by Missouri Rapid Response Initiative, a collaborative effort is underway to increase development screenings for children with ASD and other development concerns, provide family members with education and supports during the diagnostic process, and decrease the wait time for diagnostic and early intervention services. Rapid Response team members are collaborating with numerous agencies serving children ages 0 to 5 to implement the use of the Modified Checklist for Autism in Toddlers (M-CHAT) as a standard protocol.

## **RECOMMENDATION #15**

**The Blue Ribbon Panel recommends that a universal screening protocol be adopted for ASD to be utilized by physicians, pediatricians, healthcare providers, and child-serving agencies in Missouri.**

**The Blue Ribbon Panel recommends that the Centers for Diagnostic Excellence work in partnership with agencies involved in the care of young children to promote effective training in the use of recommended early ASD screening tools. This will promote uniformity as well as consistency of screening tools for these individuals, as well as First Steps service coordinators, Parents as Teachers staff, and other entities routinely seeing children at early ages.**

**The M-CHAT is a generally accepted protocol that can be utilized at well-child examinations for children age 18 months to 24 months and in other appropriate settings. In addition, other healthcare professionals, First Steps service coordinators, Parents as Teachers staff, and other entities that routinely see children at early ages can adopt a screening tool such as the M-CHAT for use throughout Missouri.**

### ***B. Medical Diagnosis***

Several physicians testified that ASD is a neurologically-based disorder, as opposed to a mental health illness. This distinction is important, particularly in dealing with insurance companies that categorize ASD as a mental health illness. Other states, such as Oregon, Georgia, and Tennessee have incorporated such language in legislation.

## **RECOMMENDATION #16**

**The Blue Ribbon Panel recommends that Missouri designate ASD as a medical diagnosis, specifically a neurologically-based disorder.**

**Autism Spectrum Disorders should be defined to include:**

- **Autism**
- **Asperger's Syndrome**
- **Childhood Disintegrative Disorder**
- **Rett's Syndrome**
- **Pervasive Development Disorder – NOS**

### ***C. Evidence-Based Standards***

In the area of diagnosis, there was concern about the differing standards of practice that exist in order to make the diagnosis. Many third parties, such as insurance

companies, are skeptical about the increased incidence of diagnoses of ASD and the lack of standards.

The development of standards will help to fortify healthcare professionals and establish a basis for future training programs. The standards can be used by school districts in understanding the challenges that are presented in the educational process. The standards can be utilized to inform the public, and they can be given to parent.

Recently, the state of California developed a document entitled Autism Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis, and Assessment. This document represents evidence-based standards that were developed by trained professionals in the field in that state, and ultimately were legislated by the state of California to ensure uniform performance standards and to improve public understanding of the challenges presented.

In addition to standards for screening, diagnosis, and assessment, standards of treatment need to be addressed. Treatment possibilities, and lack thereof, for autism and ASD remain an area of concern, and one that is sorely lacking in evidence-based research and support.

#### **RECOMMENDATION #17**

**The Blue Ribbon Panel recommends that there be established a committee of major stakeholders, to adopt screening, diagnosis, assessment, and treatment standards for Missouri. The Missouri Commission on Autism Spectrum Disorders and Office of Autism Services should be utilized to recommend participants in this group.**

**The Blue Ribbon Panel supports the identification, research, and evaluation of current evidence-based integrative therapies as well as emerging treatment protocols. Autism programs associated with research centers should be encouraged to be at the forefront of this endeavor, with existing Institutional Review Boards (IRBs) monitoring the safety and efficacy of studies. This should include treatments that are emerging evidence-based therapies.**

#### ***D. Analyzing the existing MRDD program and service packages***

Testimony focused on the importance of services for individuals with ASD. Specific attention was paid to the three Home and Community-Based Waivers administered by the Department of Mental Health through the Division of Mental Retardation and Developmental Disabilities. The three waiver programs allow reimbursement for services not otherwise covered by MO HealthNet. These services are specifically designed for people who have developmental disabilities, including ASD. The three waiver programs are the Comprehensive Waiver, Community Support Waiver, and the Missouri Children's Waiver (known as the Sara Lopez Waiver).

Testimony centered on expansion or inclusion of behavioral therapies or Applied Behavioral Analysis, an autism-specific waiver, or an evaluation of services under the new provisions of the Deficit Reduction Act.

### **RECOMMENDATION #18**

**The Blue Ribbon Panel recommends that the Department of Mental Health establish a task force composed of individuals from the private sector and state government to determine the need for expansion of waiver programs. The task force should be comprised of representatives from relevant state agencies, private sector (including physicians and a clinical psychologist focused on providing services to individuals with ASD), parents of individuals with ASD across the lifespan (involved in pursuing educational and healthcare services), and other appropriate agencies and individuals. In order to maximize this opportunity on a timely basis, the task force should provide recommendations to the Department of Mental Health in time for FY 2010 budget recommendations.**

The task force should be commissioned to complete the following initiatives:

- Study the existing service provision under the three Medicaid waivers that allow expanded services for people with developmental disabilities. Determine the service gaps that exist for individuals with ASD and make recommendations about possible service expansion under the existing waivers, to include services such as Applied Behavioral Analysis, other intensive behavioral support, family training services, and other services that would improve the care of individuals diagnosed with ASD.
- Study the options for casting a wider net of coverage for individuals with ASD—specifically, review the provisions of the family opportunity provisions of the Deficit Reduction Act to determine the ability to extend appropriate benefits to a larger population of individuals with ASD and determine their fiscal impact.
- In the process of reviewing opportunities for service expansion and casting a wider net for individuals with ASD, the task force should analyze the activities of other states to ascertain what has been most beneficial.

#### ***E. Health Insurance Coverage***

Autism is a complex neurobiological disorder, and is the fastest growing developmental disability in the United States. Early intervention is critical to gain maximum benefits in existing therapies. Most private health insurance plans do not provide coverage for Applied Behavioral Analysis (ABA), extensive therapies including occupational speech and physical therapies, and other ASD-related services.

Several states have passed ASD insurance legislation that specifically require private insurance companies to provide coverage for behavioral treatments, intensive therapies, respite care, and other services, thus creating a public/private partnership for the provision of care. By improving outcomes for individuals with ASD, mandated private insurance coverage will decrease the lifetime costs of treating and providing services, and will result in an overall cost savings in the long term. Without passage of legislation requiring private health insurance coverage for ASD, the costs associated with ASD will continue not only to affect families, but will have far-reaching social implications as well.

Because significant capacity issues exist regarding treatment for individuals with ASD, there are often concerns about qualifications of some providers who enter this arena. It is important in order to assure quality of services, and to meet insurance eligibility criteria that standards for personnel who provide services to individuals with ASD exist within the state of Missouri.

### **RECOMMENDATION #19**

**The Blue Ribbon Panel recommends that the state of Missouri pass legislation requiring private insurance companies to provide coverage for required services for people diagnosed with ASD. A cap should be placed on private insurance coverage for these services and should be commensurate with spending limits placed on these services in other states that have passed similar legislation.**

In that regard, the following specifics are recommended:

- The coverage requirements should not apply to individuals covered under individual insurance policies, or to small employers (having 50 or less employees).
- For purposes of private insurance coverage, ASD should be considered a neurobiological disorder as stipulated by the medical profession as opposed to a mental disorder.
- Individuals with a medical diagnosis of ASD encompassing the aforementioned disorders would be covered if the diagnosis was provided by an appropriate physician or psychologist.
- Basic medical coverage should not be excluded or denied based on an individual's ASD.
- Services covered by private insurance carriers, in addition to typical medical coverage, could include the following services to deal with developmental disabilities: Applied Behavioral Analysis; behavioral therapy and behavioral training, including parent training; occupational therapy; speech therapy; physical therapy; medications; nutritional supplements; evaluation and assessment services; communication devices; habilitation services.

For purposes of insurance policies that are included, ASD will be defined to include:

- Pervasive Developmental Disorder
- Asperger's Syndrome
- Childhood Disintegrative Disorder
- Rett's Syndrome
- Autism

#### ***F. Missouri's Rapid Response Initiative***

One way to encourage the use of effective, early screening for children who may have an ASD is to determine the feasibility of expanding the Mid-Missouri Autism Rapid Response initiative statewide. The Rapid Response pilot is a collaborative, community-based program focusing on earlier diagnosis and support for parents. The pilot has been successful in addressing its three primary aims: decreasing wait times for diagnosis and interventions; providing family members with education and supports during the diagnostic process and immediately thereafter; and increasing the number of children who are routinely screened for Autism Spectrum Disorders.

Through local agency participation, development of information brochures, training on the M-CHAT screen, and development of training curricula, the pilot has provided a tangible response to a specific need for children and families in mid-Missouri.

#### **RECOMMENDATION #20**

**The Blue Ribbon Panel recommends that Missouri determine the feasibility of expanding the current Rapid Response Model Program statewide.**

#### **EDUCATION**

Testimony focused on the need for a statewide strategy for addressing the issues governing the provision of special education and related services for students with ASD.

Testimony indicated the need for standards regarding the effective educational assessment and intervention for students diagnosed with ASD. Educational experts and parents expressed concern about the different standards of practice that individual schools and school districts use to determine educational eligibility and to choose appropriate interventions and methodologies. The development of evidence-based best practice guidelines would serve as a resource for educational professionals when making educational intervention and methodology decisions.

#### ***A. Best Practice Guidelines***

The Blue Ribbon Panel is aware that other states are undertaking projects that are coordinated with a national effort to identify best practices for ASD interventions (e.g., *California Legislative Blue Ribbon Commission on Autism Task Force on Education and Professional Development: Summary of Possible Solutions*). Missouri should collaborate and play a leadership role in the formation of these national guidelines. All state agencies should be actively involved in the definition, evaluation, dissemination and implementation of national guidelines that are appropriate for Missouri.

### **RECOMMENDATION #21**

**The Blue Ribbon Panel recommends that the state of Missouri develop and implement best practice guidelines for educational assessments and interventions. Evidence-based best practice guidelines for effective educational assessment and interventions for ASD should be developed and disseminated broadly to act as a resource for Missouri school districts.**

#### ***B. Missouri's Implementation of the Individuals with Disabilities Education Improvement Act***

In Missouri, there are two ways for a child to be eligible for services under the federal IDEA. First, a child can have characteristics of a particular disorder, such as ASD, that grants automatic eligibility. Second, children can be eligible for early intervention services between the ages of birth and 36 months by having a developmental delay, defined as functioning at half the developmental level that would be expected for a child developing within normal limits and of equal age. The Blue Ribbon Panel heard numerous concerns about this requirement, including the perception of how it limits high-functioning individuals with ASD, who need the social and communicative services that are not otherwise available to them.

### **RECOMMENDATION #22**

**The Blue Ribbon Panel recommends that the Department of Elementary and Secondary Education, the Department of Mental Health, local school districts, Parents as Teachers, First Steps, and other appropriate local and state entities refine the eligibility criteria and the evaluation process for participation in First Steps to ensure enhanced participation and the opportunity for enhanced early intervention. Missouri should be aggressive in giving maximum intervention at the earliest opportunity for individuals with ASD.**

#### ***C. The First IEP: Transition from IDEA Part C to B and Addressing Parental Concerns***

One of the greatest concerns of some experts and many, if not all, parents who testified was the transition process from IDEA Part C to Part B. Several clinical personnel indicated the importance of allowing First Steps providers to be involved

in the transition process and, in some way, to contribute to the creation of the student's IEP.

Many parents and legal guardians of children moving into Part B are unaware of their rights in the IEP process. Many also cannot afford legal counsel to help them understand their rights. Consequently, parents and legal guardians are forced to make decisions with a lack of information regarding their options and the consequences of their choices to their child. Numerous parents testified that they were intimidated by the IEP process and were often times unaware of their rights.

### **RECOMMENDATION #23**

**The Blue Ribbon Panel recommends that the school district provide parents with a Parent's Bill of Rights on the IEP process. Participants in the IEP process should be required to sign off on the discussion at the end of each meeting, acknowledging what was discussed and what goals were set, regardless of agreement or disagreement. Additionally, school districts should be encouraged to define the programs for ages 3 to 5 at high levels of intervention so that costly interventions (such as a full time paraprofessional) will be less needed from age 5 to 21.**

### **RECOMMENDATION #24**

**The Blue Ribbon Panel recommends that the Missouri State Plan be amended to require the First Steps case manager or provider of the parent's or legal guardian's choice to accompany a child transitioning from IDEA Part C to Part B to the IEP meeting and transition meeting. The First Steps designee should also accompany the child with ASD to the child's new early childhood facility and help the child to become more skilled and as comfortable as possible there. The parent or legal guardian should have the right to exclude such an individual if they so desire.**

#### ***D. Early Identification & Intervention***

Available research and studies demonstrate that early intervention leads to better outcomes for individuals with ASD.

### **RECOMMENDATION #25**

**The Blue Ribbon Panel recommends that each Regional Professional Development Center have an autism specialist who is familiar with the latest information on best practices, interventions, studies, and data collection to assist school districts and parents with training and the IEP process. Such specialists would provide information about available resources and programs and interact, where applicable, with Project ACCESS.**

### *E. Educational Opportunities*

Many parents expressed extreme dissatisfaction that they are unable to move their child to a different school district if they have encountered problems in their own school district.

#### **RECOMMENDATION #26**

**The Blue Ribbon Panel recommends that the General Assembly amend the charter school law to eliminate the geographical limitation on charter schools. In the expanded area, the statute would allow the establishment of charter schools having the education of ASD students as a primary mission. The statute should encourage a good mix of ASD students with their neuro-typical peers to attend the school. Attendance in such schools should be allowed for students regardless of their residence location.**

#### **RECOMMENDATION #27**

**The Blue Ribbon Panel recommends that the State of Missouri promote or establish a system of early childhood centers that focus on the needs of students age 3 to 5 who have ASD or other special needs when such services are not available at the local district level. Each center that chooses to participate would serve a consortium of school districts as a way to make maximum use of limited resources and qualified staff. The state should provide incentives to include an effective transition from First Steps and to ensure the inclusion of neuro-typical students.**

#### **RECOMMENDATION #28**

**The Blue Ribbon Panel recommends that Missouri allow equivalent funding to follow the student to the provider of the parent's choosing. Having options for treatments or services empowers parents and encourages the General Assembly to explore models of choice in educational services. The General Assembly should investigate the merits of ASD scholarships, open enrollment for students with ASD, public and private partnerships, and any other educational opportunities for students with ASD, students with developmental disabilities, or students with developmental delays.**

### *F. Educational Diagnosis*

While it is clear that the evaluation of children conducted by educators is not done to “diagnose” the child, but rather to see if and how the diagnosis of ASD adversely impacts the child’s education, there is considerable misunderstanding created by the requirement to “make an educational diagnosis.”

Public education programs for special education students require students to meet eligibility criteria to qualify for services. Some children come to the school district seeking services with a medical diagnosis of ASD. Under IDEA, the school district is to consider the medical diagnosis and determine whether that diagnosis requires any educational intervention or supports. Testimony indicated a perception problem and semantics issue involving this process. Although the school district is not to dispute that a medical diagnosis has been made, many special educators and school districts use the term “educational diagnosis” to describe the process by which they determine whether educational intervention is required. In this way, it appears to parents that the school district is conducting its own diagnosis of the child and is making a different decision than the multi-disciplinary diagnosis team previously reached.

### **RECOMMENDATION #29**

**The Blue Ribbon Panel recommends that the General Assembly and the Governor urge the Missouri congressional delegation to change the existing IDEA law to allow automatic eligibility for children who have received a medical diagnosis of ASD.**

### **RECOMMENDATION #30**

**The Blue Ribbon Panel recommends that the term “educational diagnosis” be eliminated in addition to any distinction made between a medical diagnosis and an “educational diagnosis.” A medical diagnosis, if one has been completed, should be allowed to establish eligibility for services. A school-level evaluation should only be completed to help define the program or if no medical diagnosis has been done. It is recommended that schools establish the requirement to include traditionally medical or therapeutic interventions for students with ASD because such treatments are normally precursors to reasonable educational activities.**

### ***G. Collection and Analysis of Data on Missourians with ASD***

As expressed through public testimony, there was a strong desire to create an environment for service providers that is coordinated and efficient. Many individuals who testified to the Blue Ribbon Panel recommended a statewide effort to collect and analyze data regarding Missourians with ASD.

When service providers discover techniques that work with individuals with ASD, either educational or otherwise, similarly situated providers should know about them. To that end, the Blue Ribbon Panel heard testimony about the need to collect data on the techniques and services provided to Missourians with ASD over an extended period to identify what works in Missouri. With such a study in hand, Missouri will have an evidence-based analysis of various techniques that can be shared with the community of service providers to individuals with ASD.

## **RECOMMENDATION #31**

**The Blue Ribbon Panel recommends that the Department of Elementary and Secondary Education conduct a study in which it collaborates with state and private universities in Missouri to follow the group of children (with parental consent) who transition from Part C to Part B of IDEA beginning in the fall of 2008. It is recommended that the study be conducted over a period of time commencing upon entry into Part B and ending upon completion of fifth grade by the child. Additionally, it is recommended that the Department of Elementary and Secondary Education provide annual updates regarding transition between Part C to Part B of IDEA to the Office of Autism Services and the Commission on Autism Spectrum Disorders.**

The State of Missouri can collaborate with top flight state and private educational institutions and the research community to analyze the success or failures of services provided to individuals with ASD.

The state and private universities that agree to participate in such a study would be selected so that there is an appropriate level of geographic and population based diversity. The privacy of the individuals participating in the study could be maintained by tracking the individuals by their student identification number as issued by the Department of Elementary and Secondary Education, or in some other fashion if necessary.

## **TRAINING**

Many experts described the need to enhance training capabilities as related to numerous disciplines involved in the field of neuro-developmental disorders within Missouri. Testimony indicated the need for increased training for all parties that are involved with ASD.

### ***A. Comprehensive, Coordinated Training***

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. Ongoing training for professionals (across multiple disciplines) and paraprofessionals working with individuals with ASD is needed. ASD training should be tailored to address the distinct differences and responsibilities of each professional group as well as parents and individuals with ASD. Physicians and other healthcare providers, educators, childcare providers, parents, first responders, and emergency preparedness planners must all receive appropriate training.

While teacher education curricula and professional development programs address many special education needs, ASD-specific training is relatively rare. More services and supports are needed for the aging autism population. Older adults with ASD are

entitled to community support, including help from those agencies that serve the needs of all senior citizens. They have unique needs for residential placements, long-term planning, and medical care.

### **RECOMMENDATION #32**

**The Blue Ribbon Panel recommends that all relevant state agencies explore the need for training on the issues of aging, changing behavioral needs, and physical growth for families and individuals with ASD throughout the lifespan. The Blue Ribbon Panel recommends that existing training be expanded and the creation of additional training opportunities.**

**The Blue Ribbon Panel recommends that the three Centers for Diagnostic Excellence coordinate and enhance their initiatives for training individuals involved with ASD. Additionally, training should be provided to Parents as Teachers and First Steps Coordinators in the methods of early ASD screening, and additional training opportunities be provided to train paraprofessionals through Project ACCESS or the Regional Professional Development Centers.**

#### ***B. Respite and Crisis Intervention***

Testimony indicated that there is a severe lack of training for agencies that provide crisis and respite services for individuals with ASD. As a result, few agencies are able to provide necessary services, particularly in rural areas. Testimony suggested the need to examine pay differentials, which could have the effect of encouraging more agencies to provide such services.

### **RECOMMENDATION #33**

**The Blue Ribbon Panel recommends that the Department of Mental Health study the impact of training for providers of services with individuals with ASD. All providers who support people with ASD should demonstrate, at a minimum, specialized training for those who will provide direct support and their supervisors. Training should be evidence-based and should include, but not be limited to, information regarding ASD, how to deal with challenging behavior, crisis intervention strategies and strategies for support across environments and across all relevant state agencies, particularly with adults and adolescents in a non-school setting.**

### **RECOMMENDATION # 34**

**The Blue Ribbon Panel recommends that the Department of Mental Health evaluate pay differentials and the costs associated with initial training and ongoing training for direct care workers while in training and rate differentials for providers who specialize in supporting people with ASD.**

### **RECOMMENDATION #35**

**The Blue Ribbon Panel recommends that the Department of Mental Health reinstate crisis teams through each regional center. Each crisis team member should undergo competency-based training, at least annually, on strategies for crisis intervention, dealing with ASD as well as related disorders with behavior and communication challenges.**

**There should be a comprehensive, coordinated system of care when responding to crisis in adults with ASD to prevent future crises involving the need for law enforcement or hospitalization.**

#### ***C. Training to Address Growth and Development of Children and Families***

As children with ASD age, they often demonstrate challenging behavior. Parents report difficulty with changing their expectations appropriately to anticipate and meet this need effectively. Parent training could be specialized for families of adolescents and adults with ASD and could focus on how to target such subjects as setting age-appropriate expectations, supporting the individual with goal setting, providing skills for independent living, and providing strategies for de-escalating challenging behavior.

### **RECOMMENDATION #36**

**The Blue Ribbon Panel recommends that additional curricula be added to the teacher education programs at the university and college level that is specific to ASD and to the management of behavior problems encountered with ASD.**

## **Timeline for Recommendations**

All of the recommendations are of equal importance. The Blue Ribbon Panel chose to establish a time identifying when certain recommendations should be implemented – either in the short-term or in the long-term – rather than attempt to prioritize the recommendations in terms of importance. This timeline does not diminish or decrease the importance of any specific recommendation.

### ***Short-Term Recommendations***

#### **RECOMMENDATION #1**

The Blue Ribbon Panel recommends that the General Assembly create the Missouri Commission on Autism Spectrum Disorders. The Commission would advise and make recommendations to the Governor, General Assembly, and relevant state agencies regarding matters concerning all state levels of ASD services, including healthcare, education, and other adult and adolescent services.

The Commission would be specifically charged with 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.

#### **RECOMMENDATION #3**

The Blue Ribbon Panel recommends that the Office of Autism Services, through appropriate funding to the Division of Mental Retardation and Developmental Disabilities, be staffed with a full-time person and an appropriate number of program staff to carry out the responsibilities assigned to it in legislation.

The Blue Ribbon Panel recommends that the Department of Mental Health's Office of Autism Services coordinate with other relevant state agencies, universities, non-profits, and providers to make information easily accessible and to actively reach out to families to make them aware of the process to obtain services and supports for individuals with ASD and their families throughout the lifespan. This includes promoting, enhancing, and publicizing public and private 1-800 numbers, which can assist families with individuals with ASD before and after a diagnosis. This would serve as a resource to parents to assist in navigating the various systems services and treatment.

#### **RECOMMENDATION #8**

The Blue Ribbon Panel recommends that the Division of Vocational Rehabilitation collaborate with institutions of higher education to identify providers for the purpose of providing supports to individuals with ASD who are attending such institutions.

### **RECOMMENDATION #10**

The Blue Ribbon Panel recommends that the Division of Vocational Rehabilitation, serving as the lead agency, and other relevant state agencies, collaborate to identify funding and to identify providers to enable the development of social skills and interview skills that are necessary to the successful employment for high-functioning individuals with ASD.

### **RECOMMENDATION #14**

The Blue Ribbon Panel recommends that upon entering services with the Department of Mental Health, the family must provide the Department of Mental Health with a written long-term service plan for individuals with ASD.

### **RECOMMENDATION #15**

The Blue Ribbon Panel recommends that a universal screening protocol be adopted for ASD to be utilized by physicians, pediatricians, healthcare providers, and child-serving agencies in Missouri.

The Blue Ribbon Panel recommends that the Centers for Diagnostic Excellence work in partnership with agencies involved in the care of young children to promote effective training in the use of recommended early ASD screening tools. This will promote uniformity as well as consistency of screening tools for these individuals, as well as First Steps service coordinators, Parents as Teachers staff, and other entities routinely seeing children at early ages.

### **RECOMMENDATION #18**

The Blue Ribbon Panel recommends that the Department of Mental Health establish a task force composed of individuals from the private sector and state government to determine the need for expansion of waiver programs. The task force should be comprised of representatives from relevant state agencies, private sector (including physicians and a clinical psychologist focused on providing services to individuals with ASD), parents of individuals with ASD across the lifespan (involved in pursuing educational and healthcare services), and other appropriate agencies and individuals. In order to maximize this opportunity on a timely basis, the task force should provide recommendations to the Department of Mental Health in time for FY 2010 budget recommendations.

### **RECOMMENDATION #20**

The Blue Ribbon Panel recommends that Missouri determine the feasibility of expanding the current Rapid Response Model Program statewide.

### **RECOMMENDATION #21**

The Blue Ribbon Panel recommends that the state of Missouri develop and implement best practice guidelines for educational assessments and interventions. Evidence-based best practice guidelines for effective educational assessment and interventions for ASD should be developed and disseminated broadly to act as a resource for Missouri school districts.

### **RECOMMENDATION #24**

The Blue Ribbon Panel recommends that the Missouri State Plan be amended to require the First Steps case manager or provider of the parent's or legal guardian's choice to accompany a child transitioning from IDEA Part C to Part B to the IEP meeting and transition meeting. The First Steps designee should also accompany the child with ASD to the child's new early childhood facility and help the child to become more skilled and as comfortable as possible there. The parent or legal guardian should have the right to exclude such an individual if they so desire.

### **RECOMMENDATION #29**

The Blue Ribbon Panel recommends that the General Assembly and the Governor urge the Missouri congressional delegation to change the existing IDEA law to allow automatic eligibility for children who have received a medical diagnosis of ASD.

## ***Long-Term Recommendations***

### **RECOMMENDATION #2**

The Blue Ribbon Panel recommends that all relevant state agencies deliver a report to the Missouri Commission on Autism Spectrum Disorders that describes the manner in which funds are allocated among various governmental agencies for services used by individuals with ASD.

### **RECOMMENDATION #4**

The Blue Ribbon Panel recommends that the Department of Elementary and Secondary Education solicit proposals to design a data collection system to support analysis of ASD intervention across the lifespan (evidence-based therapies or teaching practices) and costs of serving children with ASD organized by appropriate classifications.

#### **RECOMMENDATION #5**

The Blue Ribbon Panel recommends that Missouri continue its partnership with IAN and allow further completion of IAN (when appropriations are made available).

#### **RECOMMENDATION #6**

The Blue Ribbon Panel recommends that the Department of Mental Health continue development of supports available to individuals with ASD in or outside of their homes. Additionally, the Department of Mental Health should focus on respite, crisis intervention teams, and residential service categories. The Department of Mental Health should evaluate the need for respite services capacity to be expanded.

#### **RECOMMENDATION #7**

The Blue Ribbon Panel recommends 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. The counselor shall provide ASD consultation services to other staff in the region.

#### **RECOMMENDATION #9**

The Blue Ribbon Panel recommends that the Division of Vocational Rehabilitation develop an Innovation and Expansion (I & E) grant, in collaboration with a university within Missouri to target best case practices specific to clients with ASD, and disseminate this information to Division of Vocational Rehabilitation counselors and providers in each office and region, via trainings and meetings.

#### **RECOMMENDATION #11**

The Blue Ribbon Panel recommends that the Department of Mental Health consider the costs and benefits associated with funding for “follow-up” services for individuals with ASD so that access to supported employment is available. The Department of Mental Health should, in partnership with other funding sources whenever possible, allocate resources for “follow-up” services in employment.

#### **RECOMMENDATION #12**

The Blue Ribbon Panel recommends that the Department of Economic Development study the fiscal impact of a tax credit for businesses that employ individuals with ASD.

### **RECOMMENDATION #13**

The Blue Ribbon Panel recommends that local school districts inform parents of the importance of having a service coordinator from the Department of Mental Health present at the IEP meeting that takes place around the fourteenth birthday of a child with ASD. The Department of Mental Health can begin to develop transition goals for the child, and determine which state agencies should be contacted while fostering stronger relationships with the child and his or her family. The child's family or legal guardian would have the right to exclude this individual from the IEP meeting.

### **RECOMMENDATION #16**

The Blue Ribbon Panel recommends that Missouri designate ASD as a medical diagnosis, specifically a neurologically-based disorder.

### **RECOMMENDATION #17**

The Blue Ribbon Panel recommends that there be established a committee of major stakeholders, to adopt screening, diagnosis, assessment, and treatment standards for Missouri. The Missouri Commission on Autism Spectrum Disorders and Office of Autism Services should be utilized to recommend participants in this group.

### **RECOMMENDATION #19**

The Blue Ribbon Panel recommends that the state of Missouri pass legislation requiring private insurance companies to provide coverage for required services for people diagnosed with ASD. A cap should be placed on private insurance coverage for these services and should be commensurate with spending limits placed on these services in other states that have passed similar legislation.

### **RECOMMENDATION #22**

The Blue Ribbon Panel recommends that the Department of Elementary and Secondary Education, the Department of Mental Health, local school districts, Parents as Teachers, First Steps, and other appropriate local and state entities refine the eligibility criteria and the evaluation process for participation in First Steps to ensure enhanced participation and the opportunity for enhanced early intervention. Missouri should be aggressive in giving maximum intervention at the earliest opportunity for individuals with ASD.

### **RECOMMENDATION #23**

The Blue Ribbon Panel recommends that the school district provide parents with a Parent's Bill of Rights on the IEP process. Participants in the IEP process should be required to sign off on the discussion at the end of each meeting, acknowledging what was discussed and what goals were set, regardless of agreement or

disagreement. Additionally, school districts should be encouraged to define the programs for ages 3 to 5 at high levels of intervention so that costly interventions (such as a full time paraprofessional) will be less needed from age 5 to 21.

#### **RECOMMENDATION #25**

The Blue Ribbon Panel recommends that each Regional Professional Development Center have an autism specialist who is familiar with the latest information on best practices, interventions, studies, and data collection to assist school districts and parents with training and the IEP process. Such specialists would provide information about available resources and program and interact, where applicable, with Project ACCESS.

#### **RECOMMENDATION #26**

The Blue Ribbon Panel recommends that the General Assembly amend the charter school law to eliminate the geographical limitation on charter schools. In the expanded area, the statute would allow the establishment of charter schools having the education of ASD students as a primary mission. The statute should encourage a good mix of ASD students with their neuro-typical peers to attend the school. Attendance in such schools should be allowed for students regardless of their residence location.

#### **RECOMMENDATION #27**

The Blue Ribbon Panel recommends that the State of Missouri promote or establish a system of early childhood centers that focus on the needs of students age 3 to 5 who have ASD or other special needs when such services are not available at the local district level. Each center that chooses to participate would serve a consortium of school districts as a way to make maximum use of limited resources and qualified staff. The state should provide incentives to include an effective transition from First Steps and to ensure the inclusion of neuro-typical students.

#### **RECOMMENDATION #28**

The Blue Ribbon Panel recommends that Missouri allow equivalent funding to follow the student to the provider of the parent's choosing. Having options for treatments or services empowers parents and encourages the General Assembly to explore models of choice in educational services. The General Assembly should investigate the merits of ASD scholarships, open enrollment for students with ASD, public and private partnerships, and any other educational opportunities for students with ASD, students with developmental disabilities, or students with developmental delays.

### **RECOMMENDATION #30**

The Blue Ribbon Panel recommends that the term “educational diagnosis” be eliminated in addition to any distinction made between a medical diagnosis and an “educational diagnosis.” A medical diagnosis, if one has been completed, should be allowed to establish eligibility for services. A school-level evaluation should only be completed to help define the program or if no medical diagnosis has been done. It is recommended that schools establish the requirement to include traditionally medical or therapeutic interventions for students with ASD because such treatments are normally precursors to reasonable educational activities.

### **RECOMMENDATION #31**

The Blue Ribbon Panel recommends that the Department of Elementary and Secondary Education conduct a study in which it collaborates with state and private universities in Missouri to follow the group of children (with parental consent) who transition from Part C to Part B of IDEA beginning in the fall of 2008. It is recommended that the study be conducted over a period of time commencing upon entry into Part B and ending upon completion of fifth grade by the child. Additionally, it is recommended that the Department of Elementary and Secondary Education provide annual updates regarding transition between Part C to Part B of IDEA to the Office of Autism Services and the Commission on Autism Spectrum Disorders.

### **RECOMMENDATION #32**

The Blue Ribbon Panel recommends that all relevant state agencies explore the need for training on the issues of aging, changing behavioral needs, and physical growth for families and individuals with ASD throughout the lifespan. The Blue Ribbon Panel recommends that existing training be expanded and the creation of additional training opportunities.

The Blue Ribbon Panel recommends that the three Centers for Diagnostic Excellence coordinate and enhance their initiatives for training individuals involved with ASD. Additionally, training should be provided to Parents as Teachers and First Steps Coordinators in the methods of early ASD screening, and additional training opportunities be provided to train paraprofessionals through Project ACCESS or the Regional Professional Development Centers.

### **RECOMMENDATION #33**

The Blue Ribbon Panel recommends that the Department of Mental Health study the impact of training for providers of services with individuals with ASD. All providers who support people with ASD should demonstrate, at a minimum, specialized training for those who will provide direct support and their supervisors. Training should be evidence-based and should include, but not be limited to, information

regarding ASD, how to deal with challenging behavior, crisis intervention strategies and strategies for support across environments and across all relevant state agencies, particularly with adults and adolescents in a non-school setting.

**RECOMMENDATION # 34**

The Blue Ribbon Panel recommends that the Department of Mental Health evaluate pay differentials and the costs associated with initial training and ongoing training for direct care workers while in training and rate differentials for providers who specialize in supporting people with ASD.

**RECOMMENDATION #35**

The Blue Ribbon Panel recommends that the Department of Mental Health reinstate crisis teams through each regional center. Each crisis team member should undergo competency-based training, at least annually, on strategies for crisis intervention, dealing with ASD as well as related disorders with behavior and communication challenges.

**RECOMMENDATION #36**

The Blue Ribbon Panel recommends that additional curricula be added to the teacher education programs at the university and college level that is specific to ASD and to the management of behavior problems encountered with ASD.

## **Biographies of Blue Ribbon Panel on Autism Members**

The above report consists of contributions from a diverse group of individuals whose mandated purpose was to explore the state of ASD in Missouri. The Blue Ribbon Panel on Autism must gratefully acknowledge those who came before us and whose tireless efforts laid the foundation upon which the Panel's recommendations will rest. We appreciate the dedication and vision of all the people who are committed to building a better, more responsive system of care in Missouri for families and individuals with ASD.

### **Senator Scott T. Rupp (Chairman)**

Senator Scott T. Rupp has twice been elected to represent northwest St. Charles County in the Missouri House of Representatives (2002 and 2004) and was elected in 2006 to represent portions of St. Charles and Lincoln Counties in the Missouri Senate.

Senator Rupp serves on the following committees: Appropriations, Education, Pensions, Veterans' Affairs and General Laws (Vice-Chair), Transportation, (Vice-Chair), Joint Committee on Education, Joint Committee on Public Employee Retirement, Joint Committee on Transportation Oversight, and the Children's Services Commission.

Senator Rupp is also an investment representative in Missouri and founded Rupp & Associates, an investment firm where he holds the series 6, 63 & 7 general securities licenses. He also started a mortgage brokerage called Educational Financing Company, which specializes in loans for parents of college bound students. He is the Vice President of Business Development for UMB Bank in O'Fallon, Missouri, specializing in commercial lending.

### **Ron Ashworth (Vice-Chairman)**

Ronald B. Ashworth is currently the board chairman and was the former president and chief executive officer of the Sisters of Mercy Health System. Ashworth served as president and CEO from July 1999-2007 and had previously held the position of executive vice president and chief operating officer for five years. He has been a member of the Mercy Board of Directors since the organization's founding in 1986.

### **Senator Jolie Justus**

Senator Jolie Justus was elected to the Missouri State Senate in 2006. Senator Justus serves on the following committees: Financial and Governmental Organizations and Elections; Judiciary and Civil and Criminal Jurisprudence; Rules, Joint Rules, Resolutions and Ethics; Seniors, Families and Public Health; Joint Committee on Legislative Research; Children's Services; and Court Automation. She was also one of two senators appointed to the President Pro Tem's Blue Ribbon Panel on Autism.

Senator Justus graduated from Southwest Missouri State University in Springfield with a Bachelor of Science in Communications. She went on to earn her juris doctorate, with distinction, from University of Missouri - Kansas City School of Law. Senator Justus is also the Director of Pro Bono Services for the law firm of Shook, Hardy & Bacon LLP.

### **Julie Roscoe**

Julie Roscoe is the Deputy Director of Family and Community Relations of Judevine Center and has worked there for 20 years.

### **Randy Sanders**

Randy Sanders is the Program Coordinator for the Francis Howell School District and a parent of a child with autism.

### **Bill Bolster**

Bill Bolster has been an attorney with Lewis, Rice, & Fingersh, L.C. since 2000 and is a parent of a child with autism. His areas of practice are commercial real estate and securities. He graduated from Georgetown University and obtained his juris doctorate from St. Louis University School of Law.

### **Tom Davis**

Tom Davis is the President CEO of Meyer Companies Inc., a former MO State Board of Education Member, and a grandparent of a child with autism. He is Vice President of the Jackson County SB-40 Board and a member of the Thompson Center Foundation Board. He graduated cum laude from Missouri University College of Engineering and did additional study at UMKC, MU and Worcester College, Oxford. He is a published poet and essayist and an active volunteer in many civic and charitable causes.

### **Robin Russell**

Robin Russell is a member of the Autism Alliance of Kansas City and a parent of a child with autism.

### **Dr. Steve Kanne**

Stephen Kanne, PhD, ABPP, is the Associate Director of the Thompson Center for Autism and Neurodevelopmental Disorders. Dr. Kanne is an Assistant Professor in the Department of Health Psychology. He received his bachelor's degree and his doctoral degree in clinical psychology from Washington University in Saint Louis. He completed a clinical internship at the University of California, San Diego, followed by a post-doctoral fellowship in Pediatric Neuropsychology at the University of Missouri-Columbia. He then joined the staff at Saint Louis Children's

Hospital as a Pediatric Neuropsychologist, where he worked for the next 5 years. Dr. Kanne joined the MU faculty in December 2005.

Dr. Kanne's clinical activities involve providing general outpatient pediatric neuropsychological services. He also specializes in the assessment of children suspected of having an Autism Spectrum Disorder at the Thompson Center for Autism and Neurodevelopmental Disorders. His current research interests focus on children with Autism Spectrum Disorders, targeting questions of assessment, diagnostic accuracy, and gaining a fundamental understanding of the disorder. Dr. Kanne is also actively involved in an interdisciplinary training program for professionals who work with children with special healthcare needs. He has published in the areas of cognitive neuropsychology, history of neuropsychology, and pediatric traumatic brain injury. Dr. Kanne is board certified in clinical neuropsychology.

### **Dr. Laurie Fowler**

Dr. Fowler graduated from medical school at the University of Missouri-Columbia. After finishing a residency in Pediatrics, she became one of two people in the country selected for an Allergy and Rhinology fellowship, sponsored by the American Academy of Otolaryngic Allergy. After completion of her fellowship, she was asked by the University of Missouri to stay on as an Assistant Professor in the Division of Otolaryngology, as well as the Department of Child Health.

Dr. Fowler eventually took over the allergy clinic responsibilities full time and worked there several years before she left the University in December 2002. During her tenure at the University of Missouri, Dr. Fowler shared her expertise with colleagues, giving lectures at national meetings of the American Academy of Otolaryngic Allergy, as well as serving on the board of directors for the American In-Vitro Allergy and Immunology Society. In February 2005, Dr. Fowler opened her Columbia, Missouri practice. Dr. Fowler is highly regarded for her work in both pediatric and adult allergy management, as well as for her understanding of food allergies.

### **Mamie Benson**

Mamie Benson is a member of the SE Project Parent Advisory Committee and a parent of a child with autism.

### **Shawn Williams**

Shawn Williams is a member of the SW Project Parent Advisory Committee, detective with the Springfield Police Department, and a parent of a child with autism.

### **Nikki Straw**

Nikki Straw is the Chairperson of the Southwest Project Parent Advisory Committee, Chairperson of the Statewide Autism Parent Advisory Council, and a parent of a child with autism.

### **Dr. Cindy Dowis**

Dr. Cindy L. Dowis is the Director of Special Education in Kirksville, Missouri. Her doctorate degree was in Administration with an emphasis on special education. She has four degrees from the University of Missouri-Columbia. She has worked in Blue Springs, Department of Defense Schools in Athens, Greece, Columbia Public Schools, Camdenton, and Kirksville. She is an advocate for children with disabilities and strongly believes in best practices. She has served on a variety of committees and has been recognized as the Outstanding Teacher of the Year.

### **Heidi Atkins Lieberman**

Heidi Atkins Lieberman was selected in March of 2007 to lead the Missouri Department of Elementary and Secondary Education's Division of Special Education. As assistant commissioner, her responsibilities include contributing to policy development, supervising the state-operated special education schools and reviewing and advising on federal programs, plans and guidelines in the division. She had previously served as the division's legal counsel for 16 years. Atkins Lieberman received her law degree from the University of Arkansas in 1984.

### **Julia Kaufmann**

Julia Kaufmann, M.S., is with the State of Missouri's Division of Mental Retardation and Developmental Disabilities. She began her career with the Division in northeastern Missouri at the Hannibal Regional Center and later served as the Director of the Hannibal and Kirksville Regional Centers. She has served as the Division's point person for a re-design project, "System Breakthrough for Excellence," and attended the Missouri Results Initiative "Change Agent Academy." Presently, she provides oversight for autism, children's services, and the regional offices in the central corridor of Missouri.