

**The
Missouri
Educational
And
Public Policy Symposium
On
Autism**

Presents

**“The Missouri Autism Research Agenda”
2003**

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DRAFT

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Executive Summary

On May 6, 2002, a symposium was held in Jefferson City to address the State's need for direction in developing public policy to address more comprehensively and appropriately the needs of children with autism, their families, and the agencies that provide services. The symposium was convened as an outcome of hearings held by the Missouri Senate Joint Committee on Autism, sponsored by Senators Rosanne Bentley and Sydney Johnson. Dr. Anne Deaton, Director, Missouri Division of MRDD, Department of Mental Health organized the symposium, facilitated by Mr. Alan Baumgartner, Mental Health Commission and Dr. Barton Wechsler, UMC.

Symposium participants included representatives from the Missouri Autism Advisory Committee; the Department of Mental Health; Missouri State Senate; the Department of Social Services; the Department of Health and Senior Services; the Department of Elementary and Secondary Education; the Coordinating Board for Higher Education; University of Missouri, Columbia; University of Missouri, Kansas City; St. Louis University; Southwest Missouri State University; University of Missouri, St. Louis; and Washington University. In addition to these table participants, scores of individuals sat in the audience throughout the daylong proceedings.

Participants urged symposium members to move Missouri forward by focusing on collaborative research efforts and coordinated dissemination of information regarding existing and future services throughout the State. The medical and educational communities were urged to combine existing and future data bases in an effort to examine more closely and systematically the research on autism, both factors contributing to the condition and the effects of interventions. The hope of this effort is to offer a guide for research, and shape public policy to enhance the lives of people with ASD and their families. This document represents a first step in Missouri's effort to achieve that outcome.

Autism Spectrum Disorder (ASD), includes autistic disorder, Aspergers disorder, and pervasive developmental disorder—not otherwise specified (PDD-NOS), is one fast growing minority groups within the disability community in the United States with a 644% increase (336 in 1993 and 1,589 in 2001) in youth between the ages of 6-21 with ASD from 1993 to 2001 (U.S. Dept of Ed., 2002). Within Missouri there has been a 344% increase in youth between the ages of 6-21 from 1993 to 2001 (U.S. Dept of Ed., 2002). Currently, 327 of Missouri's 525 public school districts serve children with ASD.

ASD prevalence rates from studies published before 1985 are 4 to 5 per 10,000 children for the broader autism spectrum and approximately 2 per 10 000 for the more narrowly defined condition termed *classic autism* [1-7]. Since 1985, non-US studies have reported higher rates of autism, ranging from a prevalence of 7 to 10 per 10 000 children for autistic disorder and an estimated prevalence for autism spectrum disorders 1.5 to 2.5 times higher [1, 8]. ASD is the second largest developmental disability diagnosis behind mental retardation (Autism Society of America, 2001). The adult outcomes for youth

with ASD is dismal with 94% of all adults with ASD being unemployed (Barnard et al, 2001).

The purpose of the Missouri Autism Research Agenda (MARA) is to establish a cohesive, integrated research agenda that will positively affect the lives of people with ASD and their families. This research agenda will synthesize what is currently known regarding ASD in terms of assessment/diagnosis, promising practices/supports, etc., and also provide answers to questions yet to be answered or adequately addressed in the current literature. The intent of the documents and the Missouri Autism Research Agenda is not to be a one time effort or static document but one that represents an ongoing collaborative partnership between all stakeholders with representation within a fluid document that represents the best of what we know and do to enhance the lives of people with ASD and their families.

There are currently at least 15 (See appendix B) databases that exist in Missouri that would have data regarding children and families affected by ASD, however there is not an integrated, cohesive database that can provide families, self-advocates, policy makers, state agencies, funding sources, and researchers with vital information to develop and implement public policy, procedures, pre-service and in-service training, services and supports that effect individuals with ASD and their families. There is little integrated, cohesive data internationally, nationally, regionally, or within Missouri that can provide stakeholders with rigorous scientific data around the following questions:

- What are the effects of our interventions and treatments?
- What are the short term and longitudinal differences between various treatment interventions?
- Are there quantitative and qualitative differences in the longitudinal outcomes for people with ASD and their families with interventions/treatment x versus y? What accounts for these differences?
- What is the cost benefit analysis of the various treatment/interventions options?
- What are promising practices?
- Where are the holes in support and services for Missourians with ASD and their families? If people are not being served, why? And what is happening to/for these families and people with ASD?
- What percentage of current dollars are going to outcome research? And evidence based practice?
- We currently have very limited knowledge the number of people with ASD or families receiving services and what the outcomes are?
- Can Missouri develop state standards of exemplary practice for supporting individuals with ASD and their families?

The development and implementation of a statewide database, screening protocol/effort, and the development of a cohesive, unified research agenda can propel Missouri to address the needs for Missourians with ASD, their families, and all other stakeholders. Furthermore, this research agenda can support Missouri in becoming a National and International leader in research, practice, supports/services, and public

policy implementation. In addition, this effort is to develop a complete, integrated, accurate, and collaborative effort of all stakeholders to enhance the lives of people with ASD and their families. Furthermore, providing evidence based practices and information to people with ASD, families, educators, state agencies, and policy makers.

Several questions and comments arose from a public forum held at the National Autism Symposium in Springfield, Missouri on April 3, 2003 where there were over 50 parents, family members, state agency staff, educators, providers, and mental health commission members. They are as follows:

- Can Missouri support the development or adoption of a “standard of practice?”
- We (parents, family members, educators, etc.) need to have an accessible listing of community supports and resources-criteria for participation/eligibility, costs, funding availability, support networks, etc. Many families stated that they found out about supports later rather than earlier and didn’t get much help.
- The IEP process is very painful for families. Often the process feels more adversarial rather than one of a problem solving, collaborative interaction. “Parents don’t want to be the enemy.” How can we make it feel and be more like a team?
- Who can diagnose autism? Can districts? Pediatricians? It is often hard to get a diagnosis and yet services are often tied to getting one.
- Parents As Teachers (PAT) needs more information and training related to autism and ASD. They see lots of families and your children and need the expertise to identify which children might need to be screened and/or evaluated.
- Causes-we need more information and research about causes – particularly if there are some causes that are preventable.
- Effect of vaccines- more research is needed, better data base needed.
- Early diagnosis and having physicians use the CHAT would be a really good idea. It would help in a couple of ways. First, get kids at risk identified early and second raise the awareness of criteria for ASD and what it might look like in young kids so physicians would have a higher level of information than what they currently have.
- If CHAT screening is implemented it's important to know where to refer kids. (For example, First Steps will serve any child with a diagnosis of autism.)
- Collaboration - more should happen between universities and families to develop the data base and outcome data that would allow strong basis for getting funding for research from federal agencies or funding for services from state legislature.
- Applied agenda - need to meet the immediate need for families and children currently identified and in the system. But look ahead for what we need in the future.
- Training for law enforcement - need information in order to effectively interact with adults/adolescents with autism who may escalate or become violent if they don't understand what's happening or what they're supposed to do.

State of the State

There are many questions related to the current state of the state as it relates to ASD. With this in mind the following list represents questions that need to be answered to accurately provide an accurate reflection of the current state of the state for people with ASD and their families:

1. What is the current body of knowledge of ASD in Missouri?
2. How many people (children & adults) are affected by ASD? How many kids are within each diagnostic category? Who could be missing? Why?
3. What resources (professionals, services/supports, funding, research) are there in Missouri for ASD?
4. What is the professional and community capacity to meet the needs of Missourians with ASD?
5. What services are youth getting while in school?
6. What supports/services are youth getting in the community?
7. Who with ASD is and isn't getting service/treatment in Missouri? How does this vary statewide, regionally, locally within the state?
8. What are the outcomes of services/treatment people and families receive?
9. What would information technology add to the diagnosis and treatment of people with ASD?
10. How many positive behavior support plans are in place and/or being implemented? What are the outcomes of these plans?
11. What percentage of families receive a medical diagnosis and do not receive an educational diagnosis? How long is the wait between diagnosis and services/treatment?
12. What is a profile of effective/promising practices?
13. Are there school districts or organizations within Missouri that provide exemplary practice? Where are they? What do they provide? How are they funded?

Statewide Database

In order to enhance the quality of autism research in the state, there is a strong need for a collaborative statewide database that includes research-related information about all of the children in the state whose families are willing to participate. The state already funds a well-established autism database at the University of Missouri-Columbia that can serve as a model for the state. At the present time, this database only includes children treated at the University of Missouri-Columbia, but it could be expanded to serve as a statewide resource. The database would be developed by a consortium of autism researchers in the state, in collaboration with a research director. They would establish a common approach to data collection, monitor data entry to ensure accuracy and confidentiality, and support access to the database through project review. Such a database would greatly enhance the number of children and families who have the opportunity to contribute to research efforts, and it would also increase the likelihood of federal funding for autism research in the state.

Professional Development

Research question that relate to professional development are as follows:

1. What is the current knowledge and skill level of educators, related service providers, para-educators, etc., related to ASD, interventions, positive behavior support, etc.?
2. How much training have educators had that work with children with ASD?
3. What kind of training did these educators receive?
4. How much training and what type of training will make effective educators, health care professionals, service coordinators, social workers, direct support professionals, etc.?

Parenting and Family

1. What resources, whether information, services/support/treatment, assistance do family want and need? What do we need to be doing more of and what do we need to be doing less of?
2. What is the satisfaction level with the process of services and supports?
3. What are the affects of ASD on the financially (lost wages, promotions, etc.), emotionally, psychologically, etc.?
4. What are the affects on siblings?

Other/Implementation Issues to consider

1. How does or would HIPAA Regulations impact the development of a statewide database?
2. How could or would we go about getting the CHAT in pediatricians offices? How would we propose to implement the use of the CHAT? Who would receive the completed CHAT?
3. Funding?

Several other entities (Appendix C: state of California-Department of Developmental Services; state of New York –Health Early Intervention Program; American Academy of Neurology, Pediatrics) have developed and implemented comprehensive, integrated, proactive efforts to address the significant issues facing people with ASD, their families, policymakers, state agencies, researchers, and other stakeholders.

Appendix A

References

[1] Wing L. The definition and prevalence of autism: a review. *Eur Child Adolesc Psychiatry*. 1993;2:61-74.

[2] Gillberg C, Wing L. Autism: not an extremely rare disorder. *Acta Psychiatr Scand*. 1999;99:399-406.

[3] Lotter V. Epidemiology of autistic conditions in young children. *Soc Psychiatry*. 1966;1:124-137.

[4] Brask BH. A prevalence investigation of childhood psychosis. In: *Nordic Symposium on the Comprehensive Care of Psychotic Children*. Oslo, Norway: Barnepsykiatrisk; 1972:145-153.

[5] Wing L, Gould J. Severe impairments of social interaction and associated abnormalities in children. *J Autism Dev Disord*. 1979;9:11-29.

[6] Gillberg C. Infantile autism and other childhood psychoses in a Swedish urban region. *J Child Psychol Psychiatry*. 1984;25:35-43.

[7] Hoshino Y, Kumashiro H, Yashima Y, Tachibana R, Watanabe M. The epidemiological study of autism in Fukushima-ken. *Folia Psychiatr Neurol Jpn*. 1982;36:115-124

[8] Barnard et al, 2001, *Ignored or ineligible? The reality for adults with autism spectrum disorders*, London: National Autistic Society, p.16

Appendix B
Missouri Databases with ASD Data

Missouri Autism Project

Department of Mental Health, Division of Mental Retardation/Developmental
Disabilities; Div of Comprehensive Psychiatric Services; Division of Alcohol and
Drug Abuse

Missouri Department of Health and Senior Services, Division of Genetics' State Database

Missouri Department of Elementary and Secondary Education

Missouri Department of Elementary and Secondary Education, Division of Vocational
Rehabilitation

Department of Corrections

Child Development Unit at the University of Kansas Medical Center

Judevine Center for Autism, St. Louis, Missouri

Washington University: Missouri Twin Registry

Division of Family Services

Missouri State Autism Spectrum Disorder Project (Judy Miles, M.D., University of
Missouri)

Autism Society of American (Missouri members)

Children's Mercy Hospital (Michelle Kilo, M.D.-Kansas City, Missouri)

Appendix C

Clinical Practice Guideline: Report of the Recommendations-Autism/Pervasive Developmental Disorders Assessment and intervention for Young Children (Ages 0-3 years) New York State Department of Health Early Intervention Program

<http://www.health.state.ny.us/nysdoh/eip/autism/index.htm>

Autistic Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis and Assessment. California Department of Developmental Services, 2002.

<http://www.ddhealthinfo.org>

American Academy of Neurology- Autism Practice Guidelines: Screening and Diagnosis of Autism. (2000)

June 11, 2003