

EXECUTIVE SUMMARY

PRELIMINARY REPORT of the KANSAS AUTISM TASK FORCE to the LEGISLATIVE EDUCATIONAL PLANNING COMMITTEE December 2007

Background

The 2007 Legislature created the Kansas Autism Task Force for the purpose of studying the issues related to the needs of persons with autism in Kansas and making recommendation to address those needs.

Autism is a biologically based, neurodevelopmental disability with a strong genetic basis that is characterized by repetitive behaviors and impaired communication, social interaction and sensory processing. Autism is one of a group of disorders known as autism spectrum disorders (ASDs). With varying degrees of severity, ASDs interfere with an affected individual's ability to learn and to establish meaningful relationships with others. An individual with an ASD may appear to be simply socially awkward. More severely affected individuals may be incapable of speech or meaningful social interaction, and completely dependent upon assisted-living supports.

The prevalence of ASDs in Kansas, and nationwide, is increasing in epidemic proportions. The Centers for Disease Control currently report the prevalence of ASDs as 1 in 150. Ten years ago, the prevalence was approximately 1 in 10,000. In Kansas, from 1997 to 2004, the number of children with an ASD as reported under Part B of Individuals with Disabilities Education Act (IDEA) increased by 471 percent.

A recent report from the Harvard School of Public Health estimated the direct and indirect costs of ASDs to the United States to total \$35 billion per year. This may be a conservative estimate.

The study of optimal treatment approaches for ASDs is ongoing, however, it generally is accepted that while no one treatment is effective for every individual, virtually all individuals with an ADS improve with **early and intensive evidence-based intervention**. While the cost of this approach for individuals with an ASD will vary, most research-based programs average approximately \$50,000 per child per year. However, cost-benefit analysis has shown that the net effect of not providing three years of early intensive evidence-based intervention to a child with an ASD is a cost to the community of \$4,400,000 per individual through age 55.

Factors that confound access to appropriate treatment for individuals with ASDs in Kansas include disparity in the availability and distribution of qualified service providers across the state, and the expense of early, intensive, evidence-based intervention.

A Vision for Autism Services in Kansas

All children in Kansas will receive screening for developmental delays within the first year of life by the primary care physician, and for an ASD in the second year of life as recommended by the Centers of Disease Control and the American Academy of Pediatrics.

All Kansas children with a positive ASD screen will be enrolled in a program of evidence-based early intervention. At the same time, they will be referred for diagnostic assessment by a trained professional which will be completed within six months.

Evidence-based, data-driven intervention services will be readily and consistently available for all Kansans diagnosed with an ASD regardless of age, culture, socio-economic level, or geographic location. Children under the age of 8 will receive at least 25 hours a week of systematic evidence-based intervention for a minimum of three years. The intensity of intervention services or specific techniques, or both, will be guided by a living document entitled “*Best Practices in Autism Intervention for Kansas.*”

An **adequate number of qualified personnel** will be available throughout the state of Kansas.

Funding shall no longer be a barrier to early identification, definitive diagnosis, and interventions which reflect Best Practice for individuals with ASD in Kansas

All Kansans will have ready access to a **centralized source of information** regarding ASDs, including “Best Practice” recommendations and availability of state and local resources.

Kansas will maintain a mandatory **autism registry** that assures individual privacy. The information collected would allow more equitable allocation of resources and further understanding of ASDs.

The Barriers

- Lack of specific training for pediatricians, family-practice physicians and other primary care providers, as well as Tiny-K and school district personnel, to identify potential autism spectrum disorders (ASDs) in children
- Long wait times for diagnostic consultations
- Lack of accurate and localized information for parents
- Current lack of understanding about best practices and concerns about cost reduce the receptivity of service providers across multiple service settings to providing intensive support services
- The long waiting list for developmental disability services (3300+) and the inadequacy of the rates to recruit and retain quality direct-support professionals
- Too few qualified personnel (e.g. behavior analysts) to implement evidence-based interventions
- A current Tiny-K funding formula based on total served that makes no allowance for the high cost of early intervention services that have emerged as “Best Practice.”

- Catastrophic Aid as the only mechanism local school districts have for accessing funding for high-cost services (the Department of Education has recommended substantially increasing the threshold for accessing that funding.)
- Current available funding for the Autism Waiver limited to 25 children
- Inconsistent health insurance coverage for both the diagnosis and treatment of individuals with ASDs
- Geographic and socioeconomic considerations limit statewide access to Internet technology.

Our Recommendations

- Make training in the use of autism screening tools for primary-care providers widely available.
- Make awareness training for Tiny-K and school district personnel in the characteristics of ASDs widely available.
- Increase the use of telemedicine in diagnostic assessments in rural areas.
- Produce a *Best Practices in Autism Intervention for Kansas Handbook* that identifies best practices for individuals with an ASD and provides comprehensive guidelines for the implementation of evidence-based interventions.
- Ensure that trained professionals providing services to Kansans with an ASD implement the interventions that are recommended as “Best Practice.”
- Approve 2007 House Bill 2327 to provide financial incentives for students pursuing an applied behavioral science degree with an emphasis in autism spectrum disorders.
- Create a specific funding mechanism in the Tiny-K program to support the local providers who must provide high-cost intensive support services when they are identified in a child’s ISP.
- Increase (not reduce) the ability of local school districts to access state education funds to support the high-cost, intensive services of children with ASD identified in their IEPs.
- Expand Autism Waiver funding in fiscal year 2009 to serve 100 children.
- Introduce a state health insurance mandate specific to ASDs.
- Implement the recommendation of the Joint House/Senate Budget Committee in November, 2006 to fully fund the Developmental Disability waiting list and raise rates substantially over a three-year period.

Respectfully submitted,
The Kansas Autism Task Force

December 2007