

**A Report on Early Intervention Services for
Minnesota's Children with Autism Spectrum Disorders—
Executive Summary**

**Submitted by
The Research and Training Center on Community Living
Institute on Community Integration
University of Minnesota**

**A Report on Early Intervention Services for
Minnesota’s Children with Autism Spectrum Disorders—
Executive Summary**

Introduction

This executive summary provides an overview of the activities funded by the Minnesota Department of Human Services (DHS) and conducted by the University of Minnesota’s Research and Training Center on Community Living (RTC), Institute on Community Integration concerning early intervention services for children with autism spectrum disorders. The activities focused on a stakeholder process to gather information to advance the development of and access to early intervention services and supports for children with autism spectrum disorders (ASD) and their families. To fulfill the contract obligations the RTC:

- Convened and facilitated an ASD Advisory Council of 40 Minnesotans to gather diverse perspectives related to early intervention services for children with ASD;
- Conducted key stakeholder interviews with an additional 24 Minnesotans to gather more diverse perspectives related to early intervention services for children with ASD; and
- Reviewed and summarized Minnesota and the other states’ early interventions and supports to identify funding strategies, commonalities in approaches to early interventions and effective early intervention practices.

Background The complexities of ASD often lead to diminished developmental growth and to challenging behaviors in preschool and beyond; yet these can often be alleviated by interventions provided by professionals in collaboration with families in community-based, school-based, or home-based settings. Autism spectrum disorder is the fastest growing developmental disability in the United States. It is estimated that approximately 1.5 million individuals in the U.S. have an ASD diagnosis.

Historically, ASD services and supports have been both very valuable and very costly. Estimates suggest that 35 billion dollars are spent annually on both direct and indirect services and supports for people with ASD and their families with costs expected to continue to rise. Research does suggest that the cost of lifelong supports can be significantly reduced with effective early diagnosis and appropriate intervention. If these savings can be realized, it is crucial for states to establish policies and practices that allow for the most effective early intervention services and supports to be available to as many children and their families as possible. Despite federal and state initiatives to advance our understanding and knowledge of ASD, these initiatives have also highlighted the difficulties in developing effective public policy to meet the needs of individuals with ASD and their families.

The accompanying report draws on information and data from several sources. It summarizes priorities identified by the ASD Advisory Council and by other key stakeholders in Minnesota. It also looks at national trends in funding for ASD services and common practices for screening,

A Report on Early Intervention Services for Minnesota’s Children with Autism Spectrum Disorders—Executive Summary

diagnosis, and early interventions found in recent literature or through contact with national organizations and agencies.

In addition to the introduction, the report has six sections:

- Publicly-Funded Early Intervention Services in Minnesota
- Minnesota Stakeholder Input
- Early Intervention Services in Other States
- State Insurance Mandates for ASD Early Intervention Services
- Medicaid Funded Services
- Summary of Findings and Their Implications

Publicly-Funded Early Intervention Services in Minnesota

The Minnesota Departments of Education (MDE) and Human Services (DHS) are the two primary funders of early intervention services in Minnesota. According to state data, a total of 1,561 children (5 and under) with ASD received services through MDE in 2011 and 2,012 children (5 and under) through DHS in 2010. Information is not available that tells how many children received services funded by both, and therefore the extent of overlap in these numbers is unknown.

For children served under MDE, Early Intervention Services include, but are not limited to:

- Assistive Technology
- Audiology
- Health Services
- Medical Services (limited)
- Parent Training
- Nursing
- Sign Language and Cued Speech
- Vision Services
- Psychological Services
- Social Work Services
- Transportation
- Special Instruction
- Speech/Language
- Service Coordination

In 2011, 100 children under 2 years old received special education services through Part C of the Individuals with Disabilities Education Act (IDEA); 1461 children ages 3 to 5 received special education services through Part B of IDEA.

For children served under DHS, Early Intervention Services include, but are not limited to:

- Personal Care Assistance
- Private Duty Nursing
- Intensive Residential Treatment Services
- Children Therapeutic Services and Supports
- Assertive Community Treatment
- Consumer Support Grant

In 2010, besides the 2,012 children under five who were funded through DHS, another 8,010 children aged six to 17 with ASD received support from DHS funded programs.

Minnesota Stakeholder Input

This section focuses on the data collected from the proceedings of the ASD Advisory Council and the interviews conducted with other key Minnesota stakeholders. DHS and project staff worked to ensure that diverse perspectives were gathered as a part of the stakeholder advisory process. In the end, 40 individuals were chosen to be part of the ASD Advisory Council and 24 individuals were selected to take part in an extensive scripted interview.

The Advisory Council was comprised of parents, clinicians, county workers, service providers, educators, and employees of Minnesota's Departments of Education, Health, and Employment and Economic Security. All participants had personal and/or professional experience working with children, youth, or adults with autism and their families. Many of the parents on the council also work in the field supporting individuals with ASD and/or IDD. The Advisory Council was asked to participate in a series of meetings and conference calls over the course of 11 weeks in fall, 2012. The meetings and calls were facilitated by the project staff and were also attended by DHS staff. The public was invited to attend or listen in to all sessions and there were about 10-12 guests at each meeting. Throughout the process, council members discussed the following key questions:

- What are the characteristics of effective early intervention services for children with ASD?
- What are perceived as gaps and overlaps in existing services and supports in early intervention?
- What should the State of Minnesota do to provide greater access to early intervention services and supports?

Themes Over the course of the Advisory Council activities and input opportunities, members' input focused on the following broad topical areas: a) family involvement and education; b) the development of planning using person-centered activities that are developmentally appropriate and accessible over the lifespan; c) programs accessible across the state, including in rural areas; d) programs provided by well-trained staff with appropriate supervision and oversight; e) assessment, training, and therapies that are evaluated regularly; and f) involvement of state agencies to ensure quality and compliance with policy and regulations. Members identified eight themes or expectations for quality early interventions:

1. Active Family Involvement
2. Person Centered Programming
3. Staff are Highly Trained and Qualified
4. Programs are Data Driven with Frequent, Ongoing Assessment
5. Culturally Responsive and Inclusive Programs
6. Programs Promote Skill Generalization
7. Programs are Funded, Accessible, and Coordinated
8. Programs Address Transition, Employment, Education and Other Service Needs Across the Lifespan

A Report on Early Intervention Services for Minnesota’s Children with Autism Spectrum Disorders—Executive Summary

In the final online survey, ASD Advisory Council members were asked to identify and prioritize key questions they wish to see considered in Minnesota in the future. Council member responses included general recommendations for research in the areas of efficacy of early intervention models, the efficacy of interventions across the lifespan, education, employment, and emerging co-occurring medical, nutritional and environmental issues.

Several council members identified as a priority the need for more research around the effectiveness of different therapies and the long term outcomes of children and adolescents receiving intensive ABA services as compared to those receiving non-intensive Autism services or to those who are in standard public school programs. Several council members proposed the establishment of a board of licensed professionals’ competent in both research methods and ABA to evaluate peer reviewed research and published evidence for ABA and other treatments.

Key Stakeholder Interviews In-depth, structured interviews were conducted with 24 key stakeholders to examine effective early intervention services for children with ASD. Stakeholders included parents, service providers, advocates, and volunteers at services agencies.

The protocol for these interviews was developed by University of Minnesota and Minnesota DHS staff in conjunction with the members of the ASD Advisory Council. The interview questions focused on: a) experiences providing and receiving early intervention services, b) characteristics of effective early intervention services, c) model early intervention services, d) effective practices for involving families in early intervention, e) culturally responsive early intervention services and supports, and f) policy recommendations for improving access to effective early intervention for children with ASD. Interviews were conducted by telephone.

Stakeholders described a range of experiences with early intervention services for children with ASD including the process of getting a diagnosis of ASD, accessing services, getting funding for services, finding the right service, measuring progress, training and credentials for staff, parent and family involvement, and dealing with insurance coverage issues. The report summarizes responses organized in terms of effective practices in early intervention services; comments were coded into 11 categories of effective practice in early intervention:

1. Early Means Early
2. Targeted Key Skill Areas
3. Individualized to Unique Needs
4. Specific, Structured Approach
5. Time Intensive
6. Include Staff who are Highly Trained and who Specialize in ASD
7. Data Driven with Frequent, Ongoing Assessment
8. Promote Skill Generalization
9. Include Active Family Involvement
10. Provided Across the Lifespan
11. Culturally Responsive and Inclusive

Early Intervention Services in Other States

As the prevalence of individuals diagnosed with an ASD continues to rise, states are developing initiatives to address needs by improving systems for screening and diagnosis. Several states have developed ASD task forces, councils, and commissions to research and analyze specific needs, services, and supports within the ASD community. A number of these committees have developed statewide ASD plans to address specific need areas within the state.

The majority of states have statewide ASD plans in place. The plans vary in specificity with regard to recommendations for policy and endorsement of intervention approaches and they are in various stages of implementation. Of the states that have plans, they were all developed by interagency/multiple stakeholder teams. However, the lead agency authoring or commissioning the report varied across states. (It should also be noted that the presence of state plans does not imply that the recommendations identified within the plans are being implemented.)

While it can be challenging to address the topics of funding, screening/diagnosis, and intervention separately (i.e., state autism plans often discuss funding in light of particular types of diagnostic procedures and specific interventions), it is equally challenging to garner objective meaning from the many state task forces and national policy groups that have synthesized these topics based on the unique input of their stakeholders.

A national review of statewide autism plans reveals that early screening is a significant need or gap across states. Statewide plans universally acknowledge the importance of early screening and diagnosis as a gateway to early intervention. The majority of states appear to utilize the American Academy of Pediatrics (AAP) guidelines for the screening and diagnosis of ASD as well as usage of the recommended, validated screening and diagnostic tools for ASD.

Other common content denominators across statewide ASD plans include a clear distinction among screening, diagnosis, and intervention. All states identify a significant challenge in appropriate training of pediatricians, primary care physicians, and other front-line health care practitioners in screening for ASD. Further, recruiting adequate numbers of trained assessment specialists to provide evaluation and diagnostic services to determine eligibility and support needs remains a significant challenge across states. Inadequate access to these services remains even more pronounced in culturally/linguistically diverse and rural communities.

While many states' primary efforts focused on improved screening and early intervention efforts in toddlers and young preschoolers, in some states, some providers have developed initiatives to improve identification of older preschool children on the autism spectrum. Many states also have campaigns to increase screening and improve identification of ASD with coordinated partnerships among state departments of education, human services, health, and developmental disabilities.

The review of state ASD plans revealed that the majority of states require an ASD diagnosis from a specified list of qualified professionals. Best practices in diagnosis involve a

A Report on Early Intervention Services for Minnesota's Children with Autism Spectrum Disorders—Executive Summary

comprehensive assessment including standardized tools. All states listed a challenge in the number of qualified professionals with training in neurodevelopmental disorders to complete ASD diagnostic assessments. These shortages were more dramatic in rural and low-income communities within states. Diagnostic practices that support families well allow for multi-disciplinary teams, second opinions, and disclosure of conflicts of interest (e.g. clinics that perform diagnostics and provide early intervention services). The content analysis of statewide ASD plans revealed several common themes as well universal recommendations across states. These include:

- Increased screening a clear priority
- Earlier identification a priority and a trend
- Following AAP Guidelines
- Public awareness campaigns
- Increase professional capacity
- Consistent use of screening and diagnostic tools
- Need for increased coordination
- Decreased time between failed screen, diagnosis, and early intervention
- Addressing access issues

Many state plans recommend the provision of early interventions for children with ASD but plans vary considerably in their early intervention recommendations, therapeutic modalities, intensity levels, and potential funding sources. One of the larger differences among the states is the extent to which they rely on the educational sector to provide or fund early interventions. The child's age that the educational sector bears some accountability also varies.

The various therapeutic modalities recommended or recognized in state plans include behavioral, developmental, medical, and social/communication interventions.

State Insurance Mandates for ASD Early Intervention Services

Currently, 32 states mandate private insurers to cover early intensive behavioral and developmental services for ASD, while 5 other states and the District of Columbia have statutes that may provide for coverage for ASD services. By definition, these state mandates do not impact the coverage provided by self-funded plans. A federal mandate would be required to reach self-funded plans. Among the 32 states requiring coverage there is a range of dollar (intensity) and age (duration) caps specific to behavioral intervention/therapy. For states with higher age caps, the dollar caps usually decrease with age. This section of the report provides a summary of the state-by-state requirements.

Under these mandates insurers are generally required to cover screening, diagnosis, and a variety of early intervention services (behavioral and developmental) that are prescribed as medically necessary by a medical or behavioral health professional, such as therapeutic services (occupational therapy, speech/language therapy, physical therapy), pharmacy, psychology, psychiatry, and equipment necessary in the course of intervention. Where private insurance is unavailable to families, publicly funded Medicaid waiver programs often provide the only

A Report on Early Intervention Services for Minnesota’s Children with Autism Spectrum Disorders—Executive Summary

source of health insurance funding; in some cases waiver funding covers what private insurance does not cover.

In future policy analyses, a more complete picture of the funding structure for relative cost burden of ASD services would involve the relative cost distribution between private insurers, Medicaid, school districts, and families, inclusive, if possible, of hidden costs covered by parents/families such as lost wages/productivity, costs related to their own mental health care, and costs associated with non-covered therapies (e.g., special diets).

Medicaid Funded Services

Early intensive behavioral and developmental intervention services are generally not included in state Medicaid plans. Exceptions include Florida, Washington State, Massachusetts, and Virginia. In Minnesota, Medicaid (MA) currently funds intensive interventions primarily through fee-for-service MA, as a rehabilitative mental health service under billing codes for skills training through the Children’s Therapeutic Services and Support program.

As the prevalence of ASD diagnosis continues to rise, the demand for waiver supports and services is expected to grow and will likely present significant policy challenges. State Home and Community Based Services (HCBS) programs face lengthening waitlists and funding cuts and states have the authority to limit the number of people enrolled in their waiver programs. While many states would like to increase the numbers of individuals served, declining state revenues and expanding Medicaid rolls have stifled growth.

A review of statewide ASD policy indicated a significant need for additional funding to meet the diverse needs of individuals with ASD and their families. Funding limitations were consistently cited as a primary obstacle in the provision of specialized ASD services. The report also contains a discussion of how states are utilizing waivers to meet family needs. A growing number of states reported having ASD-specific waivers for children—at the time of this report, 11 states offered ASD-specific waivers for children while others were served through ID/DD waivers that included provisions specifically for ASD.

An analysis of eligibility standards for HCBS programs provided both consistent themes and variability across states. All states established that in order to be eligible to receive services under the HCBS Waiver program, the individual would otherwise need long-term care in a nursing home, hospital or intermediate care facilities for people with developmental disabilities. Individuals with ASD also having a diagnosis of intellectual disability qualified for HCBS in each state. In terms of specific disability eligibility criteria, the majority of states used cognitive ability scores (i.e., IQ), functional limitation scores, or a combination of both to qualify for HCBS waiver services. Broad eligibility criteria such as diagnosis from a qualified professional (e.g., psychologist, physician, and psychiatrist) or “meets DSM-IV criteria for disability” was also common in the eligibility language.

Functional skill deficits were another common component of eligibility across states. The majority of states listed deficits in functional/adaptive skills (language/communication,

A Report on Early Intervention Services for Minnesota’s Children with Autism Spectrum Disorders—Executive Summary

learning, mobility, self-direction, capacity for independent living) as an aspect of eligibility. The standard across states was three or more functional needs to meet state eligibility criteria.

An analysis of ASD specific waivers revealed that specific eligibility requirements were: (a) the diagnosis of an ASD by a qualified professional (licensed psychologist or physician) and (b) Medicaid income eligibility requirements. In these programs, IQ was not specified as a component of eligibility criteria (although for 1915(c) waivers, they also had to meet institutional level-of-care criteria). Services provided in the children’s ASD waivers reveals a focus on specialized needs of children with ASD, including intensive, in-home behavioral therapy, speech therapy, occupational therapy, social skills training, and children’s respite care.

The report included three state profiles on early intervention practices from South Carolina, Missouri, and Wisconsin. These were chosen to provide illustrations of interesting services and practices.

Summary of Findings and Their Implications

The final section of the report summarizes the findings of this project across the various methodologies used to obtain information. The summary is intended to inform decision making related to early intervention services for children with ASD. It includes information gathered from stakeholders regarding early interventions for children with ASD as well as all of the other data sources and components of the stakeholder process. The summary presented the findings and implications based on these questions:

- What are helpful first steps into early intervention services?
- What are effective practices for determining that a child is in need of early intervention services?
- What are effective early intervention approaches?
- How should early intervention services be funded?
- Do we have capacity in Minnesota to provide intensive early intervention behavioral and developmental services to all children with autism?
- Do we know if early intensive behavioral and developmental intervention services delivered in Minnesota are effective for achieving desired outcomes?