# A Report on Early Intervention Services for Minnesota's Children with Autism Spectrum Disorders

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

**December 31, 2012**

## Table of Contents

## Acknowledgements

**The authors wish to thank the following for their contributions to this project:**

**Advisory Council Members**
This was a time-limited group and we asked them for a lot of input in a very short amount of time. Each member contributed with intention and commitment. A list of Advisory Council members is included in Appendix C.

**Key Stakeholders**
Through a lengthy phone interview, these individuals were candid and thoughtful about their own personal experiences. They shared their stories and ideas with passion and sincerity to support Minnesotans with autism.

**Truven Health Analytics**
Truven Health Analytics conducted the data analyses presented in these reports at the request of the Minnesota Department of Human Services and the research team.

**This report was written by staff from The Research and Training Center on Community Living at the Institute on Community Integration, University of Minnesota (listed alphabetically):**

Anab Gulaid, M.P.A.
Jen Hall-Lande, Ph.D.
Amy Hewitt, Ph.D.
Barb Kleist, J.D.
Tim Moore, Ph.D.
Derek Nord, Ph.D.
Christen Opsal, M.A.
Joe Timmons, M.A.

# I. Introduction

In August, 2012, the Minnesota Department of Human Services contracted with the University of Minnesota's Research and Training Center on Community Living (RTC) to manage 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's and the other states' ASD plans and funding strategies to identify commonalities in approaches to early interventions and effective early intervention practices.

This report provides a summary of the information gathered from stakeholders and the states.

## Background

According to Autism Speaks (2012), ASD and autism are:

> both general terms for a group of complex disorders of brain development. [They] are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors… [They] can be associated with intellectual disability, difficulties in motor coordination and attention, and physical health issues such as sleep and gastrointestinal disturbances.

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. Some manifestations of these challenging behaviors come in the form of unusual or repetitive vocalizations; ritualistic behaviors; rocking or other self-stimulation; self-injury or aggression toward others; sensory responses to light, temperature, textures, and smells; and problems with eating and drinking.

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. Recent estimates from the Centers for Disease Control and Prevention indicate that one in 88 children have an ASD (2012). Since the 1990s, there has been a significant increase in the number of children diagnosed with this condition and it has been described by many states as a significant public health crisis. State educational data on ASD suggest a 10-17 % annual growth nationwide (U.S. State Educational Data, 2003; Cavagnaro, 2007). Other sources reflect even greater increases—a review of special education services conducted by Larson and Lakin (2010) report a 349.2% increase in special education ASD diagnoses between 1999 and 2008.

There is not one simple explanation for this surge in diagnosed cases. Along with increased public awareness, there are changes in diagnostic criteria and an emphasis on diagnosing the condition earlier in life but the medical and research communities seem divided on whether there are physiological reasons for the increased prevalence. Whatever the reasons for the increase, the views expressed by families and by practitioners highlight the need for improving access to high quality services and supports that extend throughout an individual's life.

Historically, ASD services and supports have been both valuable and costly. Estimates suggest that 35 billion dollars are spent annually on both direct and indirect services and on supports for people with ASD and their families (Ganz, 2007). Available yet limited research suggests that the lifetime cost of supporting an individual diagnosed with ASD ranges from $2.5 million to $4.4 million (Ganz, 2006, 2007; Jarbrink & Knapp, 2001); currently approximately 60% of these costs are estimated to be in adult services. Without modifications or changes to the current system, the significant expense associated with supporting people with ASD is expected to increase substantially in the next decade (Gerhardt, 2009).

Research does suggest that the cost of lifelong supports can be significantly reduced by as much as two-thirds with effective early diagnosis and appropriate intervention (Jarbrink & Knapp, 2001). Some early intervention cost benefit analyses have estimated the lifetime savings per individual with ASD to range from $656,000 to $1,082,000 (Ganz, 2006, 2007). If these savings can be realized, it is important 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.

ASD research and policy initiatives have increased dramatically in the past decade. In 2006, Congress passed the landmark *Combating Autism Act* (CAA) resulting in the first piece of federal legislation specific to ASD. CAA has focused on research, surveillance, public awareness, screening, and early identification; in 2011, President Obama signed legislation re-authorizing CAA. CAA and other legislation has led many states to create tasks forces, commissions, and work groups in order to better understand the challenges and needs of individuals with ASD. While these initiatives have advanced our understanding and knowledge of ASD, it has also highlighted the difficulties in developing effective public policy to meet the needs of individuals with ASD and their families.

This report draws on information and data from several sources. It summarizes priorities identified by an ASD Advisory Council and by other key stakeholders, recruited by the Minnesota Department of Human Services. It also looks at national trends in funding for ASD services and common practices for screening, diagnosis, and early interventions found in recent literature or through contact with national organizations and agencies.

## II. Publicly-Funded Early Intervention Services in Minnesota

Generally, Minnesota children with ASD are served by funding that comes from two state agencies, the Department of Education (MDE) and the Department of Human Services (DHS). What follows in this section of the report are summaries of services and supports funded by these departments and some demographic data detailing who receives these services and supports. 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.

### Minnesota Department of Education

Early intervention services are funded and implemented through the public school education system as authorized through the Individuals with Disabilities Education Act (IDEA), as amended in 2004. Part C of IDEA, *Early Intervention for Infants and Toddlers with Disabilities*, is aimed at serving children from birth through two years of age. The purpose of the services are to "enhance the development of infants and toddlers with disabilities; reduce educational costs by minimizing the need for special education through early intervention; minimize the likelihood of institutionalization, and maximize independent living; and, enhance the capacity of families to meet their child's need." Early intervention services are meant to be provided in natural environments, such as a child's home or child care setting. Interventions are to be scientifically research-based and aimed at enhancing primary caregivers' ability to promote developmental outcomes (Minnesota Department of Education, 2012).

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

Table 1 presents the number and percent of children with ASD receiving Part C services in Minnesota in 2011, from the MDE Child Count data.

**Table 1. IDEA Part C - ASD Recipients by Age & Race/Ethnicity, Child Count December 2011 (*N* = 100)**

| Race | Infants | | 1 year olds | | 2 year olds | |
|---|---|---|---|---|---|---|
| | Number | % of Total | Number | % of Total | Number | % of Total |
| American Indian/Alaska | | | | | | |
| Asian | | | 1 | 1.0% | 2 | 2.0% |
| Black | | | | | 20 | 20.0% |
| Hispanic | | | | | 6 | 6.0% |
| Multi-racial | | | | | 1 | 1.0% |
| Native Hawaiian/Pacific | | | | | | |
| White | | | 6 | 6.0% | 64 | 64.0% |
| Total | 0 | 0.0% | 7 | 7.0% | 93 | 93.0% |

In total, 100 children with ASD received services but only 7 received them prior to age 2 and none before age 1. Differences based on race exist across the early intervention age groups that most accessed services. At two years of age, those identified as black or as white constituted the highest user groups and approximately three times as many children identified as white access early intervention than children identified as black.

IDEA Part B is the section of the act that authorizes services to children and youth ages 3 to 21. Part B includes early intervention services for children from three to five years of age that have any disability and either a developmental delay or a high probability of having a developmental delay. Services are provided at no cost to parents during and beyond the typical school calendar year. Table 2 presents Part B service-usage statistics, based on 2011 Child Count results made available by MDE.

**Table 2. IDEA Part B - ASD Recipients by Age & Race/Ethnicity, Child Count December 2011 (*N* = 1,461)**

| Race | 3 year olds | | 4 year olds | | 5 year olds | |
|---|---|---|---|---|---|---|
| | Number | % of Total | Number | % of Total | Number | % of Total |
| American Indian/Alaska | 4 | 0.3% | 3 | 0.2% | 4 | 0.3% |
| Asian | 19 | 1.3% | 32 | 2.2% | 40 | 2.7% |
| Black | 50 | 3.4% | 72 | 4.9% | 84 | 5.7% |
| Hispanic | 32 | 2.2% | 40 | 2.7% | 64 | 4.4% |
| Multi-racial | 12 | 0.8% | 17 | 1.2% | 30 | 2.1% |
| Native Hawaiian/Pacific | 1 | 0.1% | 0 | 0% | 3 | 0.2% |
| White | 197 | 13.5% | 322 | 22.0% | 435 | 29.8% |
| Total | 315 | | 486 | | 660 | |

In 2011, 1,461 children with ASD received these services. Of this total, 22% of recipients were three years of age, 33% were four years of age, and 45% were five years of age.

**Minnesota Department of Human Services**

DHS has a number of data sources describing characteristics of children and adults with an ASD. The data presented here came from the Medicaid Management Information System (MMIS) and MAXIS; they include screening, assessment and residential service provider data and are from calendar year 2010. Unless otherwise noted, a person was identified as having an ASD diagnosis if they had a diagnosis code beginning with 299. The analysis of these data was conducted and the associated tables were developed by Truven Health Analytics upon request from the study team.

*Characteristics of Children with ASD Receiving Services* In 2010, 2,053 children between 0-5 years of age and 8,010 children between 6-17 years of age received services funded by DHS through Minnesota Health Care Programs (MHCP). Table 3 shows that across age groups, children identified as white represented the largest proportion of service users, followed by those identified as black or African-American. Long--Term Services and Supports (LTSS) include all Medicaid funded HCBS Waiver services and state plan services which include Personal Care Assistance (PCA), Private Duty Nursing (PDN), Intensive Residential Treatment Services (IRTS), Adult Rehabilitative Mental Health Services (ARMHS), Children Therapeutic Services and Supports (CTSS), Assertive Community Treatment (ACT), and Rule 5 services; as well as non-Medicaid funded services received through the Alternative Care program and Consumer Support Grants. Non-LTSS refers to other MHCP services and could include hospitalizations, physician services, prescription drugs, and other health care services.

| Table 3. Racial Distribution of Minnesota Health Care Programs Recipients with ASD: CY2010 | | | | |
|---|---|---|---|---|
| Race | LTSS | | Non-LTSS | |
| | Ages 0-5 N=808 | Ages 6-17 N=5163 | Ages 0-5 N=1245 | Ages 6-17 N=2847 |
| Asian | 3.5% | 3.4% | 4.6% | 4.0% |
| Black/African-American | 21.0% | 12.3% | 15.4% | 13.8% |
| Native American | 1.6% | 2.1% | 3.5% | 3.7% |
| Hawaiian/Pacific | 0.1% | 0.1% | - | 0.1% |
| Two or more | 6.3% | 3.5% | 7.1% | 4.6% |
| Unknown | 8.2% | 5.6% | 6.8% | 5.5% |
| White | 59.0% | 72.1% | 62.6% | 67.7% |

*Services Used by Children with ASD* As can be seen on Table 4, the use of Fee-For-Service (FFS) and Managed Care (MC) are approximately split for those aged zero to 5. As children age, a greater percent of children with ASD use FFS as opposed to MC.

| Table 4. Individuals with ASD in December, 2010, by Managed Care and Fee-For-Service Status | | | | | |
|---|---|---|---|---|---|
| Age Group | FFS n | FFS % | MC n | MC % | Total n |
| 0 - 5 | 1,099 | 53.6% | 953 | 46.4% | 2,052 |
| 6 - 17 | 5,769 | 72.1% | 2,235 | 27.9% | 8,004 |

Table 5 presents Personal Care Assistance (PCA) service usage and the percent of all LTSS recipients with a PCA claim. A total of 591 children age zero to five and 3,094 children age six to 17 received PCA services in 2010.

| Table 5. PCA Use in CY2010 by LTSS Recipients with ASD | | |
|---|---|---|
| Age Group | Number with PCA claim | Percent of LTSS recipients with PCA claim |
| 0 to 5 | 591 | 73.1% |
| 6 to 17 | 3,094 | 59.9% |

After combining FFS and Managed Care users, specific therapies were assessed by age group. Table 6 shows that a small percentage, ranging from 1.4% to 11.6% of children with ASD between birth and age five, used physical, occupational, or speech therapy in 2010. For those using these services, occupational therapy was used at a higher unit rate, on average. From ages 6 to 17, the percentage of children with ASD using different therapies was similar to what was observed at the younger age across physical and speech therapies. However, there were half as many children 6 to 17 using occupational therapy. Similar patterns were observed in the average unit of service use across all therapies for those 6 to 17. Therapy utilization rates and unit usage was assessed by FFS and Managed Care status, there were no observed differences.

**Table 6. Therapies Used by Individuals with ASD in CY2010**

| Age Group | Number with PT claims | Percent with PT claims | Average units of PT | Number with OT claims | Percent with OT claims | Average units of OT | Number with ST claims | Percent with ST claims | Average units of ST |
|---|---|---|---|---|---|---|---|---|---|
| 0 - 5 | 29 | 1.4% | 30.2 | 175 | 8.5% | 71.6 | 239 | 11.6% | 24.1 |
| 6 - 17 | 100 | 1.2% | 26.2 | 386 | 4.8% | 73.4 | 354 | 4.4% | 25.8 |

Notes: Fee-for-Service and Managed Care combined; Percentages based number of individuals identified in age group with ASD in 2010; PT = physical therapy, OT = occupational therapy, & ST = speech therapy.

Mental health service usage was assessed for children with ASD. Seven children's mental health service groups were defined for analysis regarding ASD usage. Additionally, three "intensity" groups were defined by the average number of hours used in a one-month period of time. The service groups were defined using a logic model provided by DHS, and the hours calculated from units paid, using conversion factors provided by DHS. The groups included Children's Therapeutic Services and Supports (CTSS) and non-CTSS services. The intensity groups were calculated by summing the total monthly hours for by all hours across the seven mutually-exclusive service groups.

The service groups included:

- CTSS Skill Training (Group 1)
- CTSS MH Behavioral Aid (Group 2)
- CTSS Psych (Group 3)
- CTSS Day Treatment (Group 4)
- Outpatient (Group 5)
- School Based Mental Health (Group 6)
- Crisis Assistance/Preschool (Group NA)

Service intensity was defined as:

- Low-intensity (< 100 hours) = All months less than 100 hours (i.e., less than 25 hours/week)
- Moderate-intensity (100-160 hours) = At least one month greater than or equal to 100 and less than and equal to 160 hours (i.e., between 25 and 40 hours week)
- High-intensity (> 160 hours) = At least one month of more than 160 total hours (i.e., 40 hours/week)

Table 7 presents demographics data for each "intensity" group. There are a few notable differences between groups. While the gender distribution is consistent across the groups, the more intensive user groups are skewed toward younger children. In addition, these more intensive groups appear to be more racially diverse. With regards to the Medical Assistance - Tax Equity Fairness and Responsibility Act (MA-TEFRA), there is a definite contrast between the low intensity and high intensity users; the former are predominantly non-TEFRA, while MI-TEFRA recipients predominate among high-intensity users. Looking at FFS and MC coverage, high intensity users are almost exclusively FFS, compared to an average of about 35% of low intensity users with at least some period of the calendar year in managed care. (The difference between MA-TEFRA and non-TEFRA is that only the child's income is counted for MA-TEFRA eligibility; non-TEFRA includes parent income for eligibility.)

**Table 7. Demographic Characteristics of Children with ASD Using Mental Health Services in CY2010 (by intensity of use per month):**

| Characteristic | < 100 hours (n) | < 100 hours (%) | 100-160 hours (n) | 100-160 hours (%) | > 160 hours (n) | > 160 hours (%) |
|---|---|---|---|---|---|---|
| **Age** | | | | | | |
| Age 0 to 5 | 530 | 12.0% | 57 | 49.1% | 33 | 35.5% |
| Age 6 to 13 | 2385 | 53.8% | 57 | 49.1% | 58 | 62.4% |
| Age 14 to 17 | 1006 | 22.7% | 2 | 1.7% | 2 | 2.2% |
| Age 18 to 20 | 513 | 11.6% | 0 | 0.0% | 0 | 0.0% |
| **Gender** | | | | | | |
| Female | 967 | 21.8% | 23 | 19.8% | 19 | 20.4% |
| Male | 3468 | 78.2% | 93 | 80.2% | 74 | 79.6% |
| **Race** | | | | | | |
| Asian | 77 | 1.7% | 8 | 6.9% | 9 | 9.7% |
| Black | 444 | 10.0% | 14 | 12.1% | 17 | 18.3% |
| Native American | 111 | 2.5% | 0 | 0.0% | 2 | 2.2% |
| Pacific Islander/ Hawaiian | 3 | 0.1% | 0 | 0.0% | 0 | 0.0% |
| Two or more | 184 | 4.1% | 3 | 2.6% | 2 | 2.2% |
| Unknown | 247 | 5.6% | 9 | 7.8% | 9 | 9.7% |
| White | 3369 | 76.0% | 82 | 70.7% | 54 | 58.1% |
| **Insurance** | | | | | | |
| TEFRA | 662 | 14.9% | 62 | 53.4% | 62 | 66.7% |

| Table 7. Demographic Characteristics of Children with ASD Using Mental Health Services in CY2010 (by intensity of use per month): | | | | | | |
|---|---|---|---|---|---|---|
| **Characteristic** | **< 100 hours (n)** | **< 100 hours (%)** | **100-160 hours (n)** | **100-160 hours (%)** | **> 160 hours (n)** | **> 160 hours (%)** |
| Non-TEFRA | 3610 | 81.4% | 53 | 45.7% | 30 | 32.3% |
| Other -Not MA | 163 | 3.7% | 1 | 0.9% | 1 | 1.1% |
| **Fee-For-Service (FFS)/Managed Care (MC)** | | | | | | |
| FFS in 2010 | 2880 | 64.9% | 108 | 93.1% | 88 | 94.6% |
| MC in 2010 | 604 | 13.6% | 1 | 0.9% | 0 | 0.0% |
| Both in 2010 | 951 | 21.4% | 7 | 6.0% | 5 | 5.4% |

Notes: TEFRA = Medical Assistance/Tax Equity Fairness and Responsibility Act; FFS = Fee-For-Service; MC = Managed Care; Both = Fee-For-Service and Managed Care in same year.

Table 8 highlights mental health service use and shows the total number of children that are under 21 years of age with ASD with at least one mental health claim, by service group, as well as the average number of monthly hours for users in each group. The table shows, for each year, that the most commonly used mental health services were CTSS Skills Training and Outpatient (non-CTSS). Average monthly hours are highest for Skills Training and Day Treatment, although the former has far more users. CTSS MH Behavioral Aid, School based MH and Crisis Assistance/Pre-school were the least used of all services. Utilization is not mutually-exclusive; children could be receiving more than one type of service in the course of a month or over the year.

| Table 8. Mental Health Service Use by Children under 21 with ASD in CY2010: Number of Users and Average Monthly Hours | | | | | | |
|---|---|---|---|---|---|---|
| **Service Group** | **Age Groups** | | | | **Total** | **Average** |
| | **0 to 5** | **6 to 13** | **14 to 17** | **18 to 20** | **Number of 2010 users*** | **Hours/month** |
| CTSS Skill Training (Group 1) | 357 | 1365 | 444 | 80 | 2246 | 26.1 |
| CTSS MH Behavioral Aid (Group 2) | 43 | 83 | 15 | 5 | 146 | 13.8 |
| CTSS Psych (Group 3) | 86 | 422 | 159 | 48 | 716 | 2.8 |
| CTSS Day Treatment (Group 4) | 128 | 213 | 79 | 13 | 434 | 31.9 |
| Outpatient (Group 5) | 258 | 1610 | 804 | 458 | 3131 | 2.0 |
| School Based MH (Group 6) | 1 | 81 | 27 | 8 | 117 | 7.2 |

**Table 8. Mental Health Service Use by Children under 21 with ASD in CY2010: Number of Users and Average Monthly Hours**

| | | | | | | |
|---|---|---|---|---|---|---|
| Crisis Assistance/Preschool (Group NA) | 2 | 29 | 22 | 1 | 54 | 1.6 |

*One user is missing age data.

Table 9 shows the average number of monthly hours in each service group, by overall intensity of use. What is clear is that CTSS Skills and Training service group is the apparent driver in terms of overall number of mental health hours. Day treatment hours also average fairly high, but as noted above, relatively fewer children receive these services. It is also notable that children in the lower intensity group received a wider array of services, while those in the highest use group appear to be primarily receiving Skills Training and Day Treatment services.

**Table 9. Average Monthly Hours of Mental Health Service Received by Children with ASD: By Service Group and Intensity (CY2010)**

| Intensity of Use | Age Group | Number of children | CTSS Skill Training Hours (Group 1) | CTSS MH Behavioral Aid Hours (Group 2) | CTSS Psych Hours (Group 3) | CTSS Day Treatment Hours (Group 4) | Outpatient Hours (Group 5) | School Based MH Hours (Group 6) | Crisis Assistance/ Preschool Hours (Group NA) |
|---|---|---|---|---|---|---|---|---|---|
| At least one month >160 hours | 0 – 5 | 33 | 133.38 | 1 | | 40.8 | 1 | | |
| | 6 - 13 | 58 | 151.43 | | 2.5 | | 0.9 | | |
| | 14 -17 | 2 | 164.25 | | 1 | 15.71 | 1 | | |
| At least one month 100-160 hours | 0 – 5 | 57 | 96.36 | 10.09 | | 49.42 | 3.22 | | 1.94 |
| | 6 - 13 | 57 | 91.9 | 15.88 | 1 | 52.83 | 1.57 | 6 | |
| | 14 -17 | 2 | 62.04 | | | | | | |
| All months less than 100 hours | 0 – 5 | 530 | 17.74 | 14.08 | 3.61 | 33.87 | 1.85 | 1.5 | |
| | 6 - 13 | 2385 | 12.1 | 14.32 | 2.62 | 33.3 | 1.97 | 6.47 | 1.17 |
| | 14 -17 | 1006 | 8.57 | 12.48 | 3.24 | 25.7 | 2.06 | 9.07 | 2.08 |
| | 18 -20 | 513 | 7.61 | 9.91 | 2.52 | 21.21 | 1.94 | 7.8 | 0.25 |

## Summary

The amount of services received by these children may meet many needs identified by families. However, these data from Education and Human Services do not reflect the number of children receiving services funded by both departments nor do they reflect the number of children who are not receiving any services.

Using recent census data (there were 352,815 children in Minnesota under five years of age based on 2009-2011 American Community Survey results) and the Centers for Disease Control estimate (1 out of 88 children have ASD), it appears there could be over 4000 children in Minnesota with ASD in this age category. (This estimate could be much smaller or larger, because the data on which the CDC relies for its national estimate shows great variability among individual autism surveillance sites.) It is not known how many children with ASD are undiagnosed or underserved, though many advocates and policy makers believe that many are. Among MHCP children, the differences in utilization of intensive services between TEFRA and managed care programs are a concern. Many children do not qualify for MHCP, and the majority of commercial insurance and self-funded plans do not cover intensive interventions for ASD. One cannot assume, though, that lack of MHCP participation *always* means a lack of ASD coverage or access. Not all children with ASD may need or benefit from intensive interventions, and commercial and self-funded programs do tend to cover other interventions commonly prescribed for children with ASD (e.g., prescription medications and allied health interventions such as physical, occupational and speech therapy). In addition, some children are receiving educational services, though educational resources may vary by school district.

## III. Minnesota Stakeholder Input

This section focuses on the data collected from the proceedings of the ASD Advisory Council and from the interviews conducted with other key Minnesota stakeholders.

### Strategies Used to Ensure Diverse Perspectives

The Minnesota Department of Human Services (DHS) and project staff worked to ensure that diverse perspectives were gathered as a part of the stakeholder advisory process. The project staff and DHS used a matrix of various perspectives to plan and assemble the Advisory Council (see Table 10). Once convened, the Council members had the opportunity to share with project staff their ideas for adding to the diversity of perspectives gathered. This process identified 41 individuals and 20 organizations and clinics, including several organizations that serve people who are Native American, Somali, Hispanic, African American, Asian/Pacific Islander, or Hmong. This process also yielded suggestions to include more practitioners with a behavior analysis or psychiatric background.

### ASD Advisory Council Results

This project included the facilitation of a short-term structured advisory group process to provide input and opinions on the characteristics of effective early intervention services for children with ASD. Ultimately, a 40-member Advisory Council was assembled by DHS. Members of this group came from two sources: 10 were asked to participate by study staff based on their involvement in ASD-related projects and policy initiatives (e.g., state ASD task force, LTSAE planning group); the other 30 were selected after DHS sent out a request to interested stakeholders to submit a Statement of Interest to join the council to support the objectives of this project. Forty-six individuals applied for these spots. The 16 applicants who were not selected were invited to participate in key stakeholder interviews (almost all agreed to that).

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. Council members were 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.

**Table 10: Stakeholder Advisory Council Membership by Stakeholder Type***

| | Metro | Out-State | Ethnic Minority |
|---|---|---|---|
| Parents | 13 | 4 | 3 |
| Clinicians | 5 | 1 | |
| Residential Service Providers | 4 | 1 | |
| Advocates | 12 | 2 | 2 |
| State or County Staff | 7 | 2 | |
| Educators | 4 | | |
| Attorneys | 2 | | |

* Note: Some participants represented more than one perspective.

*Methodology* Research team members facilitated three Advisory Council meetings: October 16, November 13, and December 11, 2012. Full council meetings were held on Tuesday afternoons in the metro area. Between meetings, two Early Intervention Workgroup conference calls were held (on October 23 and November 20) and members had the opportunity to respond to follow-up questions via three online surveys. These three strategies were used in combination to ensure that stakeholders had ample opportunity to provide input in various formats. Overall participation was good across these three methods (see Table 11 for an overview of the meeting, call, and survey participation). Each meeting and call was structured to include introductions of participants, review of the charge of the council, updates on other components of the work, and a facilitated discussion to answer "key questions" pertaining to the topic of early intervention. 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?

**Table 11: Advisory Council Participation by Stakeholder Type**

| | Meetings | | | Workgroup Calls | | Online Surveys | | |
|---|---|---|---|---|---|---|---|---|
| | 10/16 | 11/13 | 12/11 | 10/23 | 11/20 | 10/19 | 11/17 | 12/20 |
| Parents | 16 | 10 | 11 | 4 | 3 | Surveys were answered anonymously | | |
| Clinicians | 6 | 4 | 4 | 2 | 2 | | | |
| Providers | 4 | 4 | 3 | 4 | 4 | | | |
| Advocates | 13 | 9 | 11 | 2 | 1 | | | |
| State or County Staff | 9 | 7 | 8 | 5 | 5 | | | |
| Educators | 4 | 4 | 3 | 2 | 2 | | | |
| Attorneys | 2 | 2 | 2 | 2 | 2 | | | |
| Total Participants* | 36 | 24 | 29 | 20 | 16 | 27 | 12 | 17 |

***** Note: Some participants filled two or more roles.

*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. To organize member input, eight emerging themes were used as anchors and are listed in the section that follows. This section summarizes comments, conversations, and information obtained from the advisory group members.

### 1. Active Family Involvement

Council members indicated the need for family focused services. For this to occur, members indicated that families need equal access to information about the many options for children with ASD. County case managers, therapists, teachers, and other professionals require up-to-date information about treatments and interventions and about how to participate in collaborative relationships with families. Suggestions were made that information about ASD assessment and interventions be presented in the form of fact sheets describing programmatic philosophies, research base, target populations (e.g., age, level of function), staff credentials and turnover, intake and discharge procedures, geographic scope, funding options, outcomes, and diversity/ethnicity.

Council members also indicated that families need access to screening, diagnostic, psychological, sensory, and environmental services. They also need access to a variety of treatment approaches that meet the unique needs of the individual and family. Services should seek to maintain home placement by providing support to families and children and giving priority triage to children in foster care deemed high risk for out-of-home placement. These services include crisis intervention, respite care, and personal care assistance. Due to the varying service needs and the unique mix of services that children and families receive, service coordination was also identified as important. As families move from intensive to less intensive supports, members suggested that it would be beneficial to allow a period of tapering off of the services provided rather than an immediate break from services.

Council members reported that in-home services need to be flexible and responsive to the family needs. Childcare and transportation support were also identified as important by several council members because many families find it difficult to participate in services with their child with ASD due to the need to care for other children or travel limitations. Families benefit from capacity building activities that can be attained through skill training, skill development, counseling, and psychotherapy. Further support for families should be available via professional therapy and support groups, especially in rural areas.

### 2. Person-Centered Programming

Council members indicated that there is a need for a variety of programs in order to better respond to the unique needs of children with ASD. Some felt that consumer-directed options would ensure greater person-centered, individualized services. Members advocated for evidence-based programs as well as programs with a limited evidence base, such as holistic medicines and hippotherapy.

Council members indicated the need for funding agencies to be open about interventions and therapies that are individualized. Members were mixed regarding the evidence supporting different approaches. Some believed interventions and therapies should be evidence-based, evidence-informed, and/or use promising practices. Others felt options should be inclusive of familial philosophical orientations.

Others indicated that programs should be both home-based and community-based, focusing on skills used in multiple environments. Members reported that the provision of intensive services should be based on individual need, with high staff-to-child ratio as appropriate. Intervention approaches should be child-focused with coordination by an objective professional. The use of assistive technology should be considered to aid in teaching and support. Other suggestions included the need to include schools in planning and programming and a focus on activities of daily living. All activities should be guided by positive behavioral supports and target areas deemed as important by the family. This connects to cultural responsiveness as discussed below (#5.).

### 3. Staff are Highly Trained and Qualified

A broad array of therapies and treatments were identified by members as important, including sensory integration, speech therapy, occupational therapy, physical therapy, social skills training, medication management, pediatric behavioral feeding services, dietary services, oxygen therapy, and case management. Smart home technology and personal devices were identified as approaches that might be beneficial for some. These services require trained personnel with broad and focused knowledge, thus resources need to be made available to ensure proper training and workforce development. Council recommendations included using best workforce practices with well-designed training, credentialing, licensing, and supervising of interventionists and implementing program models. It was also mentioned by several members that focused attention needs to be made to train professionals from diverse communities to have expertise in intervention and treatments for children with ASD.

### 4. Programs are Data Driven with Frequent, Ongoing Assessment

Council members indicated that effective ASD assessment was critical in order to receive appropriate early intervention services. These assessments should occur in a timely manner and assessments and programs should be accessible and available to the entire state. Assessments and programs need to be culturally and linguistically appropriate. It was recommended that services be allowed to overlap rather than require parents to choose one service over another.

Preventing provider conflicts of interest and ensuring accountability was also an emerging theme. Members stated that it was important to manage conflicts that might occur when a practitioner is also providing assessment services. This could be managed by requiring that assessments be conducted by a multidisciplinary team that focuses on intervening in response to individual needs rather than intervening in response to diagnosis. Accountability of providers and assessors requires identification and development of ongoing quality measures that assess individual, family, and programmatic outcomes. Finally, it was suggested that state agencies identify a single agency to be solely responsible for identifying children with ASD as mechanism to ensure screening consistency.

### 5. Culturally Responsive and Inclusive Programs

Several council members described situations and provided examples of how families from minority communities are less likely to access programs in a timely manner and that they are more likely to receive less intensive early interventions. Some described situations where a provider systematically refused to serve specific populations. Council members agreed that providers must be equipped to serve all families. There is currently no requirement for providers to report the different racial and ethnic groups they are serving, which makes it difficult to hold providers accountable to serving the most diverse groups.

The council saw a need for more service providers from minority communities and more professional interpreters for families who do not speak English. Some members indicated that providers should know how to access interpreters and must access them when needed. Members reported that greater outreach for minorities in rural communities is needed. Suggestions were made that training and hiring of more minority providers should be funded by state or local programs.

Council members also described cultural differences when it comes to common therapies and behavioral and developmental interventions that have a Western perspective and are not readily embraced by some families. Funding issues can be very difficult for minority families to sort out and families who are frustrated by the "system" may give up and leave needed services.

### 6. Programs Promote Skill Generalization

Most council member comments in this area focused on flexibility on the part of practitioners—that is, that there would be an expectation that therapists, educators, parents, and behavior specialists are on the same page and that what is taught in the home would have connections with schools and the greater community. There were also perceptions that developmental growth does not end at ages 5 or 8 and that individual clinical and educational supports should match what a child needs and not what policy or regulation requires. Lack of coordination of services between private therapy and school systems was identified as a weakness.

### 7. Programs are Funded, Accessible, and Coordinated

Council members recommended that state agencies and policymakers take a leadership role in making sure services are accessible on an equitable basis. This includes identifying what can be paid so counties can feel confident about authorizing services and better integrating early intervention services between state agencies and private insurance systems. The overwhelming majority of members felt it would be beneficial to pass mandated private insurance funding and/or cover benefits similar to Medical Assistance fee-for-service for Medical Assistance managed care and for those who do not qualify due to income caps.

Members indicated that the state should not limit the funding for early intervention services arbitrarily. Many indicated that people who can pay for services should pay for them. Most members reported that these services should have no limitations on weekly service intensity; however, at least one member felt that there should be a weekly cap. More than one member recommended the state retain the Minnesota Comprehensive Health Association (MCHA) funding.

Many members indicated that the current system seems to put the task of service coordination onto the parents. For some, this is a huge burden that the state could aid in alleviating. To ensure that programs respond to individual needs there is a need for planful, flexible, consistent, braided funding that takes advantage of private insurance and the existing public funding systems as much as possible.

Council members reported that to be accessible, programs need to be consumer-directed, timely, competent, available in varied settings, and available irrespective of where a person lives. It was recommended that there be multiple community-based access points for early intervention programs for children with ASD. There was also a need expressed for a simplified information and referral process to aid in navigating the service system; comparing services by funding; and understanding program staff qualifications, practices, intensity, family integration, level of evidence, and outcomes. They also noted a need for service oversight and accountability across all service systems (human services, education, etc.).

### 8. Programs Address Transition, Employment, Education and Other Service Needs Across the Lifespan

Council members indicated the need to link early intervention services to later life stages when appropriate, including ensuring connections between elementary and secondary schools and raising expectations regarding employment. Some parents commented that they were often told not to worry about the "transition to adulthood" but then found out that after public school supports end, it is difficult to connect with adult systems. This also leads to the need to ensure high expectations for all young people—one member said that many people had given up on his son over the years but he is now working and doing well.

## Advisory Council Members on the Direction of Future Research

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.

Specific research questions provided by advisors around effectiveness of early intervention included:

- What therapy models have proven effective through peer-reviewed research?
- What medications have proven effective through peer-reviewed research?
- What communication technology resources have proven effective for children with ASD?
- By developmental age span, which services does the research suggest are most effective?
- What correlation, if any, exists between level of parent participation in weekly therapy and child progress in intensive early intervention services?
- What is the utilization of services and treatment duration across providers of intensive early intervention services?
- What are the common characteristics of those agencies where treatment duration is shorter? What components to their model are contributing to faster progress and better outcomes?

Several council members indicated a need for longitudinal research that looks at the quality of life of individuals with ASD and whether early intervention positively affects children with ASD through the lifespan. Some council members indicated a need to broaden the definition of early intervention to include lifelong intervention. Specific research questions from council members include:

- What interventions are most effective for achieving future independence?
- What services and interventions do individuals who receive ABA as a child require as adults?
- Does intensive early intervention save money across an individual's lifespan?
- Can adults with ASD benefit from staff trained in intensive intervention?

Several Council members indicated more research was needed around education and employment outcomes for children with ASD including access to post-secondary training. Specific research questions were:

- Do children in school based early childhood special education programs make the same, less, or more gains that children in intensive early intervention programs in language, cognitive functioning, and skills of daily living?
- What are effective program elements for secondary students with ASD?
- What are the most promising transition practices for young adults with ASD that lead to gainful employment or post-secondary education success?

### ASD Key Stakeholder Interviews Summary

*Methodology* In-depth, structured telephone interviews were conducted with 24 key stakeholders to examine effective early intervention services for children with ASD. 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. A copy of this protocol is found in Appendix D. Interviewees were sent an email explaining the purpose of the interview and providing a copy of the questions to be asked prior to the interview.

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. A summary of the stakeholder perspectives is provided below (the names of the individuals are not provided in order to protect their privacy).

When asked to identify their roles related to people with ASD:

- Thirteen stakeholders identified their role as a parent,
- Nine as a service provider,

- Five as an employee or volunteer at an advocacy/parent organization, and
- Two as "other."

Several stakeholders indicated that they had more than one role. Of the 13 stakeholders who identified their role as parents, their children with ASD ranged in age from 0-8 (two children), 9-17 (eight children) and 18 and older (six children). Three stakeholders identified themselves as Somali parents and one stakeholder identified as an African American parent. One service provider self-identified as Somali.

### Highlights Emerging From Stakeholder Interviews

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. Some parents commented on the impact having a child with ASD can have on the family including isolation, sleep deprivation, damage to the family home, aggression toward family members, depression, thoughts of suicide, marital problems, divorce, and exhaustion from the constant monitoring of the child.

Several parent stakeholders shared similar experiences in having received a diagnosis between the ages of two and five and having received services from multiple providers that offered different approaches to early intervention for children with ASD. Service providers also reported that they had worked with children who had received more than one type of early intervention service.

Stakeholders commented on the availability of services with several stakeholders indicating that the current wait for assessment can be several months due to a limited number of qualified professionals. One stakeholder noted that ABA is nonexistent in Greater Minnesota. All stakeholders identified intensive early intervention as the key to achieving better long-term outcomes for children with ASD and reported positive experiences with early intervention services. Stakeholders also identified funding as critical to effective early intervention for children with ASD. Stakeholders commented on having had issues with how early intervention services are funded and what services insurance providers will cover. Several stakeholders indicated that mandated coverage would increase access to early intervention services for children with ASD.

### Key Characteristics of Effective Early Intervention Services

This section is a summary highlighting stakeholder responses organized in terms of effective practices in early intervention services. In the interviews, stakeholders were asked to identify characteristics of effective early intervention services. Comments were coded into 11 categories of effective practice in early intervention:

### 1. Early Means Early

Stakeholders identified early screening and diagnosis as the key to effective intervention, with many saying "the earlier the better". Several stakeholders commented on the need for a more accessible and systematic process for conducting screenings and diagnostic assessments by qualified professionals with training in ASD.

Stakeholders described desired program features including a centralized location with 4-5 satellite locations, a multidisciplinary approach, availability of interpreters, and liaisons for families from different cultures.

Stakeholders with older children reported that their children are where they are at today because they got an early diagnosis and accessed intensive early intervention programs before and during their preschool years. Stakeholders with children currently receiving intensive early interventions reported that their children were making progress in their programs.

While all stakeholders emphasized the need for early screening, they also acknowledged that the same kinds of interventions need to be available to older children who may not have been identified during their preschool years; this delay in diagnosis often occurs because of socioeconomic status, culture, or other barriers. Several stakeholders reported that this was a specific need in the Somali community.

Stakeholders noted the need for coordination and collaboration with schools and pediatricians to educate parents about the signs and provide specific information resources for screening and diagnosis. One stakeholder also suggested engaging public health professionals with the background and expertise to connect families to diagnostic clinics on a timely basis.

### 2. Targeted Key Skill Areas

Stakeholders reported that effective early intervention and model programs should include direct instruction that is multidisciplinary, including the domains of behavior, socialization, speech, and communication. Some stakeholders noted the need for a focus on behavior in the context of communication, stating that providers need to figure out what the child is trying to communicate with their behavior. Several stakeholders indicated the need to focus intervention on socialization in a school environment.

### 3. Individualized to Unique Needs

Stakeholders reported a need for staff to show respect for the unique needs, values, and perspectives of the individual with ASD and his/her family. They expect that programs will be designed around the specific needs of the individual with modifications that match his/her spectrum profile, age, and developmental stage, and that they will use individualized motivational strategies and behavioral and developmental support systems.

Stakeholders commented that early intervention services should include age-appropriate services specific to the child's needs; services provided in the home or in a center, depending on the child's needs; family involvement; dietary and nutritional interventions; and ongoing training for staff specific to the child's needs.

### 4. Specific, Structured Approach

Overall, stakeholders agreed that an effective early intervention program requires a structured approach; however, they varied in their responses regarding a specific intervention approach. Several stakeholders indicated that programs using Applied Behavior Analysis (ABA) are effective, although most acknowledged that ABA might not work for every child. Other early intervention approaches or modalities mentioned by stakeholders included occupational therapy, speech therapy, physical therapy, RDI, TEACCH, Floor Time, music therapy, positive behavior supports, water play, the Holland Center Biomedical approach, and Fraser services.

Stakeholders reported that, in addition to having a structured approach, early intervention services should also be available in the home, at school, and/or in a center, depending on the needs of the child and the capacity of the family. Several stakeholders commented that effective early intervention services cannot be a one-size-fits-all model. One stakeholder commented, "the program should fit the child, not fit the child into a program."

### 5. Time Intensive

Stakeholders commented that funding for time-intensive interventions seems to be provided arbitrarily for some families and not for others (currently payments may cover 15 hours a week of services, 25 hours a week, or 40 hours a week depending on the funder). Some stakeholders felt that there is room within the state system to provide the number of hours needed for each child specifically rather than a prescribed set of hours; others indicated that the time intensity should be at least 25 and up to 40 hours of direct intervention individualized to the child that includes a parent training component. One stakeholder commented that while ABA is the standard of care in the community, a child should not receive more than 30-35 hours per week because he/she will become overstimulated.

Some stakeholders indicated that ABA services should be provided in both a center and in the family home to achieve the best outcomes, while other stakeholders indicated that it may not be realistic for parents to accommodate 40 hours of intensive ABA at home.

### 6. Include Staff who are Highly Trained and who Specialize in ASD

Stakeholders were in agreement in their comments about the need for qualified staff who have training specific to working with children with ASD. Stakeholder comments included the need for intensive clinical supervision from a board certified behavior analyst (BCBA) with true ASD experience; a fusion of psychology and behavioral experience/training; several tiers of supervision that include a board certified behavior analyst and a licensed psychologist to oversee the program; licensure of mental health professionals with background in child psychology, ASD services, clinical background, therapeutic staff that meet previous criteria from DHS requirements; and/or supervision by individuals with advanced degrees. Additionally, most stakeholders commented on staff and provider shortages.

### 7. Data Driven with Frequent, Ongoing Assessment

Several stakeholders noted the need for early intervention services that are evidence-based and include specific intervention plans for each child that track progress toward outcomes. One stakeholder commented on the need for some way to monitor outcomes and develop outcome standards to make sure that funders are getting what they are paying for and is effective based on objective criteria.

While several stakeholders commented on the need for an individualized treatment plan, service providers were more likely to comment on the need for ongoing and frequent assessment of the child's progress toward measurable outcomes. A couple of stakeholders commented that families sometimes can have more difficulty seeing their child's progress than providers do. Several stakeholders commented on the need to include parents in the development and review of individual service plans.

### 8. Promote Skill Generalization

Several stakeholders specifically identified skill generalization as a key outcome of effective early intervention services. Stakeholder recommendations included ensuring that center-based interventions are carried over into the family home, providing early intervention in the school setting, and educating regular education teachers on positive behavior supports.

### 9. Include Active Family Involvement

Stakeholders who are service providers were more likely to note the need for family involvement, although several parents indicated that family involvement was important. Stakeholder comments about the need for family involvement included starting at the earliest age possible. Parents need to be aware of the goals their child is working on and how they can reinforce learning throughout child's day. The process should start by establishing ways for children to have strong bonding experiences with parents and other key caregivers using the developmental models proposed by Piaget and Erikson. Other suggestions included parent-to-parent mentoring or families helping other families who have/had children with ASD; collaboration between home and professionals; positive behavior training for all involved staff and parents; creative parental supports; and including parents in home-based services a limited number of times per week.

### 10. Provided Across the Lifespan

Several stakeholders commented on the need for full-day, year-round intervention programs for younger children. Others indicated a need for intensive intervention as children grow into adolescence and adulthood. A couple of parent stakeholders indicated that lack of effective interventions as their child aged resulted in their child moving out of the family home to receive services. One stakeholder commented that since the average age of diagnosis of child in minority community is up to two years older than a white child, early intervention services should be provided and paid for beyond age eight.

### 11. Culturally Responsive and Inclusive

The majority of stakeholders agreed that early intervention services need to be culturally responsive in order to be effective in different cultural or ethnic communities. Stakeholder comments included the need to assess behavior through a cultural lens; for example, in social reciprocity and eye contact there are a whole array of cultural differences that could be seen as characteristics of ASD. Others talked about a funding stream to support translators and to hire staff with certification, competency, and knowledge of cultural considerations. Some stakeholders discussed the lack of insurance coverage for families of lower socioeconomic status. Other mentioned that Somali families don't have the materials needed for ABA in their home and don't understand the importance of these materials in implementing an ABA program.

Stakeholders commented on ways to improve cultural responsiveness of early intervention services including offering materials in different languages and providing staff who can speak the language; educating families about ASD; adapting early intervention training (e.g., in some cultures it is acceptable to eat with one's fingers, whereas western culture focuses teaching on using utensils); increasing the number of providers from a particular culture; and providing more outreach using community liaisons with cultural roots.

## IV. Early Intervention Services in Other States

This section provides information about early intervention needs and actions identified in state ASD plans.

A state ASD plan is a document that has been created in a given state and generally includes a needs assessment, recommendations, and action plans related to ASD. The comparable report in Minnesota is the recently developed strategic plan report completed by the legislatively authorized ASD Task Force (available on the Task Force's Web page). The information provided in this section summarizes the approaches identified in ASD state plans across states. This information is not an evaluative look at what states are actually doing—rather, this section is a compilation of available data contained in state ASD plans related to meeting the needs of young children with ASD. The gulf between the plan and actual services being offered can be wide. Some state plans do provide background information about how services are currently delivered or offered in their states as a component of an environmental scan process or descriptive overview.

As the prevalence of individuals diagnosed with an ASD continues to rise, states are developing a variety of activities and 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. State plans were located via internet search using two approaches. The first involved reading the 2012 updates to the Easter Seals state autism profiles (that are found on the Easter Seals Website) and linking to the websites, reports, and plans of state task forces, councils, and working groups therein. The second involved entering the terms "autism state plan" and "autism state policy" into an Internet search engine.

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. Overall, statewide plans were prepared for or by the governor/legislature, the Department of Education, the Department on Aging/Disability, the Department of Mental Health/Children's Mental Health, or the Department of Health. Table 12 provides information about the statewide ASD plans, the year the plan was written, the lead agency on the report, and a link to the report itself.

**Table 12.  Statewide Plans for Autism Spectrum Disorder (ASD)**

| State | Year | Prepared for/by | Link to report |
|---|---|---|---|
| Alabama | 2009 | Governor/legislature | PDF |
| Alaska | 2007 | Governor/legislature | PDF |
| Arizona | -- | -- | -- |
| Arkansas | -- | -- | -- |
| California | 2007 | Governor/legislature | PDF |
| Colorado | 2009 | Governor/legislature | PDF |
| Connecticut | 2005 | Department of Education | PDF |
| Delaware | -- | -- | -- |
| Florida | -- | -- | -- |
| Georgia | -- | -- | -- |
| Hawaii (a) | 2009 | Mental Health/Children's Mental Health | PDF |
| Hawaii (b) | 2009 | Health | PDF |
| Hawaii (c) | 2009 | Mental Health | PDF |
| Idaho | 2011 | Governor/legislature | PDF |
| Illinois | 2009 | Governor/legislature | PDF |
| Indiana | -- | -- | -- |
| Iowa | 2010 | Governor/legislature | PDF |
| Kansas | 2009 | Governor/legislature | PDF |
| Kentucky | 2006 | Governor/legislature | PDF |
| Louisiana | -- | -- | --- |
| Maine | 2007 | Health Services | PDF |
| Maryland | 2012 | Governor/legislature | PDF |
| Massachusetts | -- | -- | -- |
| Michigan | 2007 | Health Services | PDF |
| Minnesota | 2012 | Governor/legislature | PDF |

**Table 12. Statewide Plans for Autism Spectrum Disorder (ASD)**

| State | Year | Prepared for/by | Link to report |
|---|---|---|---|
| Mississippi | 2011 | Governor/legislature | PDF |
| Missouri (a) | 2012 | Mental Health | PDF |
| Missouri (b) | 2011 | Mental Health | PDF |
| Missouri (c) | 2007 | Governor/legislature | PDF |
| Montana | -- | -- | -- |
| Nebraska | 2001 | Department of Education | PDF |
| Nevada | 2008 | Governor/legislature | PDF |
| New Hampshire | 2008 | Governor/legislature | PDF |
| New Jersey | 2011 | Governor/legislature | PDF |
| New Mexico | 2012 | Governor/legislature | PDF |
| New York | -- | -- | -- |
| North Carolina | 2011 | Department of Education | PDF |
| North Dakota | 2011 | Governor/legislature | PDF |
| Ohio | 2012 | Department of Education | PDF |
| Oklahoma | 2001 | Health Services | PDF |
| Oregon | 2010 | Department of Education | PDF |
| Pennsylvania | -- | -- | -- |
| Rhode Island | 2011 | Health Services | PDF |
| South Carolina | -- | -- | -- |
| South Dakota | -- | -- | -- |
| Tennessee | -- | -- | -- |
| Texas | 2010 | Aging/Disability | PDF |
| Utah | -- | -- | -- |
| Vermont | 2011 | Aging/Disability | PDF |
| Virginia | 2009 | Governor/legislature | PDF |
| Washington | 2007 | Governor/legislature | PDF |
| West Virginia | 2012 | Department of Education | PDF |
| Wisconsin | 2004 | Governor/legislature | PDF |
| Wyoming | -- | -- | -- |

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. It should also be noted that the presence of state plans does not imply that the recommendations identified within the plans are being implemented by the wide range of stakeholders impacted—public, private and non-profit; medical, public health and educational. That said, the information presented below is separated by topic area to assist readers in understanding the complexity of the many plans reviewed for this report.

To provide a context for the topics covered in the state plans the sections below give a short overview of the varied issues and differences and points of agreement with regard to these issues.

### What Do State ASD Plans Say About ASD Screening and Diagnosis?

A national review of statewide autism plans (ASD plans) that identify and set priorities for ASD services reveals a consistent theme 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. As seen in Table 13 (below), all states with statewide plans list early screening and identification as a significant state priority (states without plans are marked NP). Several statewide plans recommended universal screening. However, there are no current state mandates on specific rules or regulations for ASD screening and diagnosis.

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 (e.g., Modified Checklist for Autism in Toddlers, Ages & Stages Questionnaire: Social Emotional, Autism Diagnostic Observation Schedule, Autism Diagnostic Interview, Childhood Autism Rating Scales, etc.).

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 (e.g., developmental behavioral pediatricians, psychologists, etc.) 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. Telemedicine for screening, diagnosis and assessment is currently being considered in a several states. A handful of states (Delaware, Missouri, New Hampshire, New Jersey, Utah, West Virginia, Wisconsin) have a state registry of children identified with ASD; and several states recommended a state ASD registry in their statewide plans (Kansas, Kentucky, Maryland, Mississippi, New Mexico, Vermont, Washington).

**Table 13. Statewide Trends in Early Identification of ASD**

| State | Early Identification Priority | Recommend Universal Screening | ASD Public Awareness Campaign | Current ASD Registry | Recommend ASD Registry |
|---|---|---|---|---|---|
| Alabama | X | | X | | |

| Table 13. Statewide Trends in Early Identification of ASD | | | | | |
|---|---|---|---|---|---|
| **State** | **Early Identification Priority** | **Recommend Universal Screening** | **ASD Public Awareness Campaign** | **Current ASD Registry** | **Recommend ASD Registry** |
| Alaska | X | X | | | |
| Arizona | NP | | | | |
| Arkansas | NP | | | | |
| California | X | X | X | | |
| Colorado | X | | X | | |
| Connecticut | X | | | | |
| Delaware | X | | | X | |
| Florida | NP | | | | |
| Georgia | NP | | | | |
| Hawaii | X | X | | | |
| Idaho | X | X | | | |
| Illinois | X | | | | |
| Indiana | NP | | | | |
| Iowa | X | X | | | |
| Kansas | X | X | | | X |
| Kentucky | X | | | | X |
| Louisiana | NP | | | | |
| Maine | X | X | | | |
| Maryland | X | | X | | X |
| Massachusetts | NP | | | | |
| Michigan | X | | | | |
| Minnesota | X | | | | |
| Mississippi | X | | X | | X |
| Missouri | X | | | X | |
| Montana | NP | | | | |
| Nebraska | X | | | | |
| Nevada | X | X | | | |
| New Hampshire | X | | | X | |
| New Jersey | X | | | X | |
| New Mexico | X | | | | X |
| New York | NP | | | | |
| North Carolina | X | | | | |
| North Dakota | X | X | X | | |
| Ohio | X | X | X | | |
| Oklahoma | X | X | | | |
| Oregon | X | X | | | |

**Table 13. Statewide Trends in Early Identification of ASD**

| State | Early Identification Priority | Recommend Universal Screening | ASD Public Awareness Campaign | Current ASD Registry | Recommend ASD Registry |
|---|---|---|---|---|---|
| Pennsylvania | NP | | | | |
| Rhode Island | X | | | | |
| South Carolina | NP | | | | |
| South Dakota | NP | | | | |
| Tennessee | NP | | | | |
| Texas | X | | | | |
| Utah | NP | | | X | |
| Vermont | X | X | | | X |
| Virginia | X | | X | | |
| Washington | X | X | | | X |
| West Virginia | X | | | X | |
| Wisconsin | X | X | | X | |
| Wyoming | NP | | | | |

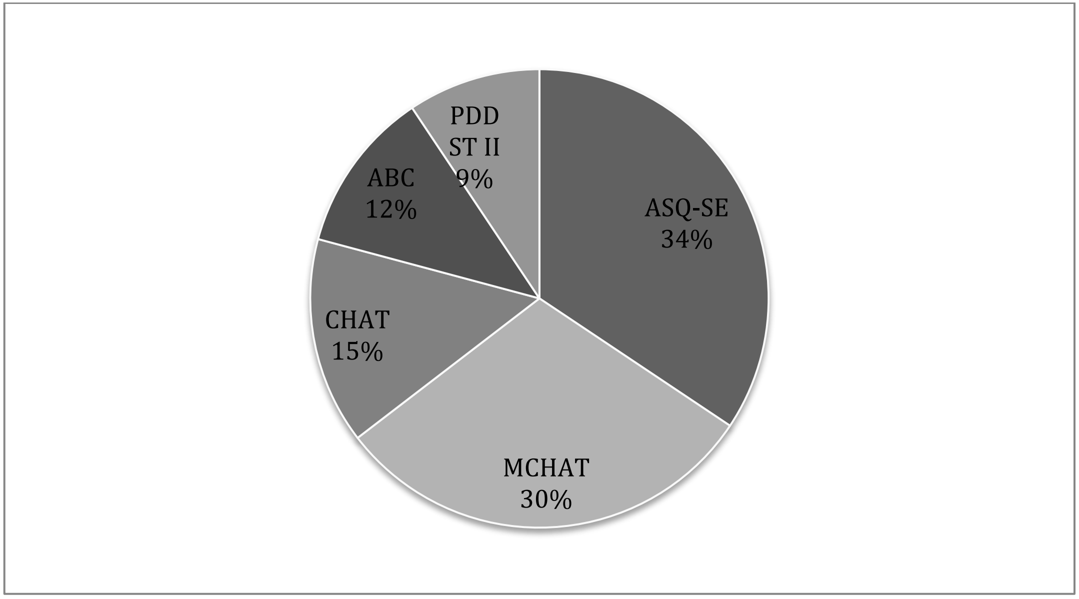
While many states' primary efforts focused on improved screening and early intervention efforts in toddlers and young preschoolers ( Part C services, ages 18-36 months), in some states, Part B agencies developed initiatives to improve identification of older preschool children on the autism spectrum. In many states, health care professionals play a primary role in early identification of ASD among very young children, and the health care community is often a key player in state initiatives to improve screening and diagnosis in very young children. 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.

A recent study, conducted by National Professional Development Center on Autism Spectrum Disorders, examined state policy around screening of children with ASD. Figure 1 shows the five most common screening tools used across states (it should be noted that nearly 20 instruments were identified):

- Ages & Stages Questionnaire: Social Emotional (ASQ-SE)
- Modified Checklist for Autism in Toddlers (M-CHAT)
- Checklist for Autism in Toddlers (CHAT)
- Autism Behavior Checklist (ABC)
- Pervasive Developmental Disabilities Screening Test II (PDD SD II)

The majority of states revealed that more than one tool was often used in the screening process.

**Figure 1. Commonly Used Screening Tools across States**



Note: Data from study conducted by National Professional Development Center on Autism Spectrum Disorders (NPDC-ASD), *Screening and Early Identification of Autism Spectrum Disorders* (2009)

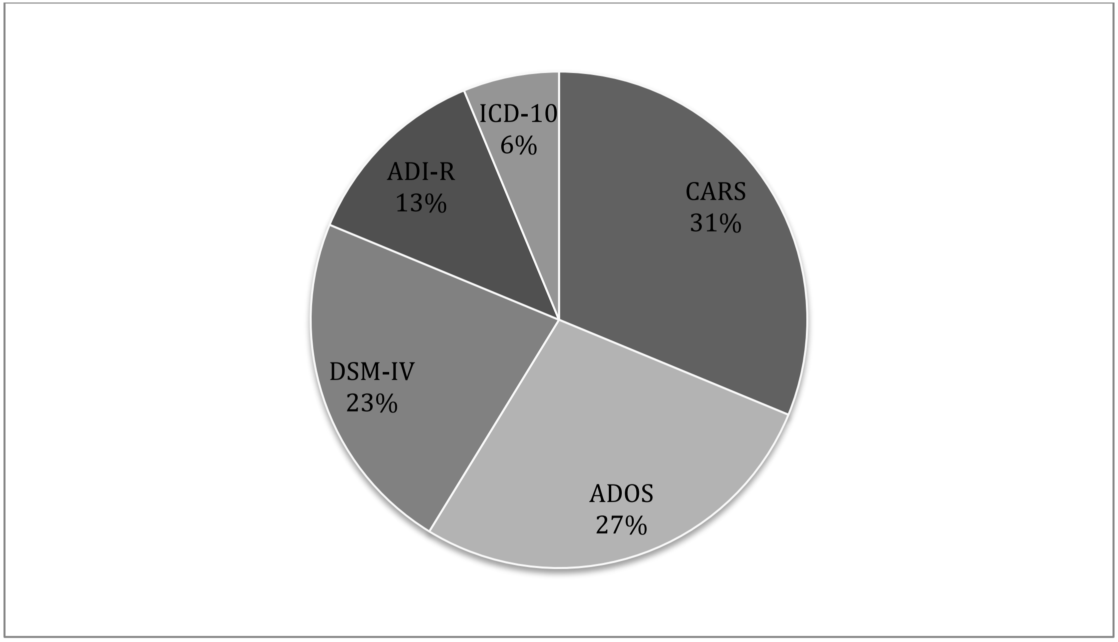
*State Diagnosis and Eligibility Standards* Statewide ASD plans revealed that the majority of states require an ASD diagnosis from a specified list of qualified professionals (e.g., psychologist, pediatrician, psychiatrist, etc.). Best practices in diagnosis involve a comprehensive assessment including standardized tools such as the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview, Revised (ADI-R). These tools are typically administered by a licensed psychologist or another specially trained medical provider. 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. The recommended diagnostic tools across states were highly consistent. The majority of states revealed that multiple assessment methods (surveys, checklists, structured interviews, observations, and direct clinical assessments) were used to diagnosis ASD.

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). Diagnoses should be based on current Diagnostic and Statistical Manual criteria, together with assessments of functional status from direct observations by the multi-disciplinary team and parental/caregiver reports.

The National Professional Development Center on Autism Spectrum Disorders (2009) also determined the most commonly used diagnostic tools for ASD in the U.S. Figure 2 shows the percentage of states that primarily utilized:

- The Childhood Autism Rating Scale (CARS)
- The Autism Diagnostic Observation Schedule (ADOS)
- The Diagnostic and Statistical Manual of Mental Disorders IV (DSM IV)
- The Autism Diagnostic Interview, Revised (ADI-R)
- The International Statistical Classification of Diseases and Related Health Problems (ICD-10)

**Figure 2. Commonly Used Diagnostic Tools across States**



Note: Data from study conducted by National Professional Development Center on Autism Spectrum Disorders (NPDC-ASD), *Screening and Early Identification of Autism Spectrum Disorders* (2009)

A universal trend across states was an increased focus on diagnosis at an earlier age—large national population-based research studies reveal that the average diagnosis of ASD comes well after three years of age (Shattuck et al., 2009).

**Summary of Findings Related to State Trends in Screening, Diagnosis, Identification**
While the approaches to early screening and identification revealed common themes across many states, some states that were evaluated were engaging in creative approaches to screening and diagnosis. Arizona and New Mexico have addressed access issues in rural and underserved communities through mobile or traveling screening assessment clinics. California, Connecticut, and Missouri have published "best practices" in screening, diagnosis, and eligibility guidelines. Maine piloted a program to explore universal screening for ASD in 2008. The

content analysis of statewide ASD plans revealed several common themes as well universal recommendations across states. These include:

- *Increased screening a clear priority*: All states listed the implementation of routine ASD screening as a top priority in statewide plans.
- *Earlier identification a priority and a trend:* The majority of states recommended a push for earlier age of screening. Some states recommend mandated screening for ASD. The most common age for mandated screening was by age 2.
- *AAP Guidelines:* All states cite American Academy of Pediatrics (AAP) guidelines for screening and diagnosis of ASD.
- *Public awareness campaigns*: All states emphasized the importance of public awareness campaigns to increase knowledge and awareness of signs of ASD. A small group of states had current ASD public awareness campaigns.
- *State ASD registry*: Several states recommended a centralized registry to help track children diagnosed with ASD. Certain states, including Missouri, Utah, West Virginia and Delaware, have created a statewide registry to track screening and identification of children with ASD.
- *Increased training and education of professionals*: Health care professionals play a vital role in early identification of ASD. A number of other professions need training in identification of red flags for possible ASD and where to refer when concerned such as child care providers, early childhood educators, early childhood family education teachers, regular education teachers, medical professionals and direct support staff.
- *Increase professional capacity in ASD*: All state plans mentioned the need for more qualified providers to assess and diagnose ASD. Diagnosis must be made by a licensed physician, pediatrician, or licensed psychologist. Best practices in diagnosis involve a comprehensive assessment including standardized tools such as the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview, Revised (ADI-R). These tools are typically administered by a licensed psychologist; therefore the need to expand autism specific capacity was identified.
- *Consistent use of screening and diagnostic tools*: The most utilized screening tools in state ASD plans were the Modified Checklist for Autism in Toddlers Ages (M-CHAT) & Ages Stages Questionnaire: Social Emotional (ASQ-SE). The most recommended diagnostic tools in state ASD plans were the Autism Diagnostic Observation Schedule (ADOS), Childhood Autism Rating Scale (CARS), Autism Diagnostic Interview - Revised (ADI-R).
- *Need for increased coordination*: All state plans recommended a coordinated approach to screening that brings together multiple governmental agencies, private organizations, non-profit organizations, and individuals with ASD and their families/support systems.
- *Decreased time between failed screen, diagnosis, and early intervention:* All statewide plans listed concerns around the process of a timely link between a failed screen, diagnosis, and subsequent connection to early intervention. Many states have quantified this in timelines between failed screen and assessment (e.g., 60 days, 90 days, 6 months).
- *Access Issues*: All states cite challenges in screening, identification, diagnosis of children across geographical areas (e.g. rural), socioeconomic, and cultural groups. All states

mentioned a need for more providers in rural/out state areas.

**What do State ASD Plans Say about Early Intervention?**

Many state plans recommend the provision of early interventions for children with ASD. Early intervention services for children with ASD are designed to remediate at least one of the three core symptom areas of ASD: communication deficits, socialization deficits, and stereotyped behavior/restricted interests. Challenging behaviors such as tantrums, disruption, aggression, self-injury, and sensory issues routinely co-occur for children with ASD and are often targeted for early intervention as well.

State plans vary considerably in their early intervention recommendations, therapeutic modalities, intensity levels, and potential funding sources (see Table 14). 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. In Minnesota, schools are responsible from birth to provide various pre-school services through the early childhood special education system (IDEA Part C). Children with ASD often receive at least a portion of their services prior to age 3 through the early childhood special education system (IDEA Part C). In many other states, the educational sector's responsibilities do not begin until later in a child's life.

As Table 14 illustrates, the various therapeutic modalities recommended or recognized in state plans include behavioral, developmental, medical, and social/communication interventions such as (alphabetically) Applied Behavior Analysis or early intensive behavioral and developmental intervention, computer assisted instruction, the Denver model, Hanen/More than Words, independent work systems, intensive communication, LEAP (Learning Experiences: an Alternative Program for Preschoolers and Parents), naturalistic interventions, occupational therapy, parent training, peer-mediated instruction, positive behavior support, PECS (Picture Exchange Communication System), pharmacology, physical therapy, pivotal response training, psychiatry, psychology, social skills groups, social stories, speech/language therapy, structured programming, TEACCH (Treatment and Education of Autistic and related Communication-handicapped Children), and voice output communication aids.

**Table 14. State plans/reports on & funding for early intervention**

| **State** | **Approaches recognized or recommended** | **Intensity recommended** | **Professional groups recognized or recommended** | **Funding for Implementation** *Private Insurance (PI), Waiver (W), Medicaid (M) |
|---|---|---|---|---|
| Alabama | BI, OT, PH, SL | 25 hours/week minimum | Board certification (all therapists) | PI |
| Alaska | -- | -- | -- | PI, W |
| Arizona | -- | -- | -- | PI, W |
| Arkansas | -- | -- | -- | PI, W |

| Table 14. State plans/reports on & funding for early intervention | | | | |
|---|---|---|---|---|
| **State** | **Approaches recognized or recommended** | **Intensity recommended** | **Professional groups recognized or recommended** | **Funding for Implementation** *Private Insurance (PI), Waiver (W), Medicaid (M) |
| California | -- | -- | -- | PI, W |
| Colorado | BI | 25 hours/week | -- | PI, W |
| Connecticut | Eclectic | -- | -- | PI |
| Delaware | -- | -- | -- | PI, W |
| Florida | -- | -- | -- | PI, M, W |
| Georgia | -- | -- | -- | W |
| Hawaii | BI, IC | -- | -- | -- |
| Hawaii | ABA, OT, PT, SL, PS, PY | -- | LP, MD, BCBA | -- |
| Idaho | -- | -- | -- | W |
| Illinois | -- | -- | BCBA alongside other therapies | PI, W |
| Indiana | -- | -- | -- | PI, W |
| Iowa | ABA, SL, OT | -- | -- | PI |
| Kansas | ABA | 25 hours/week minimum | -- | PI, W |
| Kentucky | ABA, EBP | 25 hours/week minimum | -- | PI |
| Louisiana | -- | -- | -- | PI, W |
| Maine | -- | -- | -- | PI, W |
| Maryland | -- | -- | -- | W |
| Massachusetts | -- | -- | -- | PI, M, W |
| Michigan | BI (well-supported, efficacious)<br>LEAP, PBS, PECS, PRT (supported, probably efficacious)<br>HM, TEACCH, DM (supported, acceptable) | 25 hours/week minimum | -- | PI |
| Minnesota | -- | -- | -- | M |
| Mississippi | -- | -- | -- | W |
| Missouri | -- | -- | -- | PI, W |
| Montana | -- | -- | -- | PI, W |
| Nebraska | -- | -- | -- | W |

| **Table 14. State plans/reports on & funding for early intervention** | | | | |
|---|---|---|---|---|
| **State** | **Approaches recognized or recommended** | **Intensity recommended** | **Professional groups recognized or recommended** | **Funding for Implementation** *Private Insurance (PI), Waiver (W), Medicaid (M) |
| Nevada | ABA, EBP | 25 hours/week minimum | -- | PI, W |
| New Hampshire | SP | 25 hours/week minimum | OT, SL, PS, SE | PI, W |
| New Jersey | -- | -- | -- | PI, W |
| New Mexico | -- | -- | -- | PI, W |
| New York | -- | -- | -- | PI, W |
| North Carolina | NPDC | -- | -- | W |
| North Dakota | -- | -- | -- | W |
| Ohio | -- | -- | -- | W |
| Oklahoma | -- | -- | -- | -- |
| Oregon | -- | -- | BCBA, GE, SE, SL | W |
| Pennsylvania | -- | -- | -- | PI, W |
| Rhode Island | NPDC | -- | -- | PI, W |
| South Carolina | -- | -- | -- | PI, W |
| South Dakota | -- | -- | -- | -- |
| Tennessee | -- | -- | -- | -- |
| Texas | NAC | -- | -- | PI |
| Utah | -- | -- | -- | W |
| Vermont | -- | 25 hours/week minimum | -- | PI, M, W |
| Virginia | NPDC | -- | -- | PI, M, W |
| Washington | -- | 25 hours/week minimum | Behavioral intervention teams to include BCBA, LP, OT, PT, SL | M, W |
| West Virginia | Eclectic | -- | -- | PI, W |
| Wisconsin | ABA | -- | BCBA | PI, W |
| Wyoming | -- | -- | -- | W |

**Codes for Table 14**

- ABA-Applied Behavior Analysis
- BI-Behavioral Intervention/Early Intensive Behavioral Intervention
- CAI-Computer Assisted Instruction
- DM-Denver Model
- HM-Hanen/More than Words
- IWS-Independent Work Systems
- IC-Intensive Communication
- LEAP-Learning Experiences: an Alternative Program for Preschoolers and Parents

- NI-Naturalistic Interventions
- OT-Occupational Therapy
- PI-Peer-mediated Instruction
- PBS-Positive Behavior Support
- PECS-Picture Exchange Communication System
- PH-Pharmacology
- PT-Physical Therapy
- PRT-Pivotal Response Training
- PS-Psychiatry
- PY-Psychology
- SG-Social Skills Group
- SS-Social Stories
- SL-Speech/Language Therapy
- SP-Structured Programming
- TEACCH-Treatment and Education of Autistic and related Communication-handicapped Children
- VO-Voice Output Communication Aids
- *NAC is used when a report/plan recommends established practices as set forth by the National Autism Center.*
- *NDPC is used when a report/plan recommends evidence-based practices as set forth by the National Professional Development Center.*
- *Eclectic is used if a list of available options in lieu of a recommendation.*
- *EBP is used to denote a non-specific recommendation for the inclusion of therapies shown to have a robust evidence base*

Professional/provider emphases:

- BCBA-Board Certified Behavior Analysts
- GE-General Educator
- LP-Licensed Psychologist
- MD-Medical Doctor
- OT-Occupational Therapist
- PT-Physical Therapist
- SE-Special Educator
- SL-Speech/Language Therapist

## V. 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 (National Conference of State Legislatures, 2012). 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. In Minnesota approximately 40% of the state is covered by self-funded plans (National Association of Insurance Commissioners, 2012). It should also be noted that state insurance mandates that cover private, non-self-insured, provider coverage do not include Medicaid funded services.

Indiana became the first state to mandate insurance coverage for ASD behavioral services in 2001, followed by other states in the years following. 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. Three states have lifetime dollar caps, which range from $144,000-$200,000. Two states mandate coverage for early intervention only (cap at age 6). Four states have age floors between 1 and 3 years of age. With respect to early intervention years (0-6), 17 states cap annual dollar amounts between $30,000 and $40,000, 9 states cap annual dollar amounts between $45,00-$50,000 (WI caps at this amount through age 4, $25k thereafter), and 6 states have no dollar cap. Table 13, available from Autism Speaks (2012), provides a summary of the state-by-state requirements, as well as whether they apply to state employees and small businesses policies.

**Table 15. 32 States that Have Dollar Caps and/or Age Caps on Private Insurer Coverage for Intensive Behavioral Services**

| State | Year | State Population | Annual Dollar Cap | Age Cap | State Employees? | Small Group? |
|---|---|---|---|---|---|---|
| Indiana | 2001 | 6,484,000 | None | None | Yes | Yes |
| South Carolina | 2007 | 4,625,000 | $50K | 16 | Yes | No |
| Texas | 2007 | 25,146,000 | None | <10 | No | No |
| Arizona | 2008 | 6,392,000 | $50K: 0-8, $25K: 9-16 | 16/17 | Yes | No |
| Louisiana | 2008 | 4,533,000 | $36K ($144K lifetime) | <17 | Yes | No |
| Florida | 2008 | 18,801,000 | $36K ($200K lifetime) | <18 | Yes | No |
| Pennsylvania | 2008 | 12,702,000 | $36K | <21 | Yes | No |
| Illinois | 2008 | 12,831,000 | $36K | <21 | Yes | Yes |
| New Mexico | 2009 | 2,059,000 | $36K ($200K lifetime) | 19/22 | No | Yes |
| Montana | 2009 | 989,000 | $50K: 0-8, $20K: 9-18 | 18 | Yes | Yes |
| Nevada | 2009 | 2,701,000 | $36K | 18/22 | Yes | Yes |
| Colorado | 2009 | 5,029,000 | $34K: 0-8, $12K: 9-19 | <20 | Yes | Yes |
| Connecticut | 2009 | 3,574,000 | $50K: 0-8, $35K: 9-12; $25K: 13-14 | <15 | Yes | No |
| Wisconsin | 2009 | 5,687,000 | $50K for 4 yrs, $25K after | None | Yes | Yes |
| New Jersey | 2009 | 8,792,000 | $36K | 21 | Yes | Yes |
| Maine | 2010 | 1,328,000 | $36K | <6 | Yes | Yes |
| Kentucky | 2010 | 4,339,000 | $50K: 0-7, $1000/mo: 7-21 | 21-Jan | Yes | Yes |
| Kansas | 2010 | 2,853,000 | $36K: 0-7, $27K: 8-19 | <19 | Yes only | No |
| Iowa | 2010 | 3,046,000 | $36K | <21 | Yes only | No |
| Vermont | 2010 | 626,000 | None | 1 ½ - 6 | Yes | Yes |
| Missouri | 2010 | 5,989,000 | $40K | 19 | Yes | Yes |
| New Hampshire | 2010 | 1,316,000 | $36K: 0-12, $27K: 13-21 | 21 | Yes | Yes |
| Massachusetts | 2010 | 6,548,000 | None | None | Yes | Yes |
| Arkansas | 2011 | 2,916,000 | $50K | <18 | Yes | No |
| West Virginia | 2011 | 1,853,000 | $30K for 3 yrs; $24K up to 18 | 18-Mar | Yes | Yes |
| Virginia | 2011 | 8,001,000 | $35K | 6-Feb | Yes | No |
| Rhode Island | 2011 | 1,053,000 | $32K | 15 | Yes | No |
| New York | 2011 | 19,378,000 | $45K | None | Yes | No |
| California | 2011 | 37,254,000 | None | None | No | No |
| Michigan | 2012 | 8,836,640 | $50K if <7, $40K if 7-12, $30K if 13-18 | Yes | Maybe | Yes |
| Alaska | 2012 | 722,718 | None | 21 | Yes | >20 |

| Table 15. 32 States that Have Dollar Caps and/or Age Caps on Private Insurer Coverage for Intensive Behavioral Services | | | | | | |
|---|---|---|---|---|---|---|
| **State** | **Year** | **State Population** | **Annual Dollar Cap** | **Age Cap** | **State Employees?** | **Small Group?** |
| Delaware | 2012 | 907,135 | $36,000 | 21 | Yes | Yes |

Figure 3 (age caps) and Figure 4 (annual dollar caps for early intervention) provide a summary of this information.

**Figure 3. State age caps on insurance coverage for services for people with autism spectrum disorders**

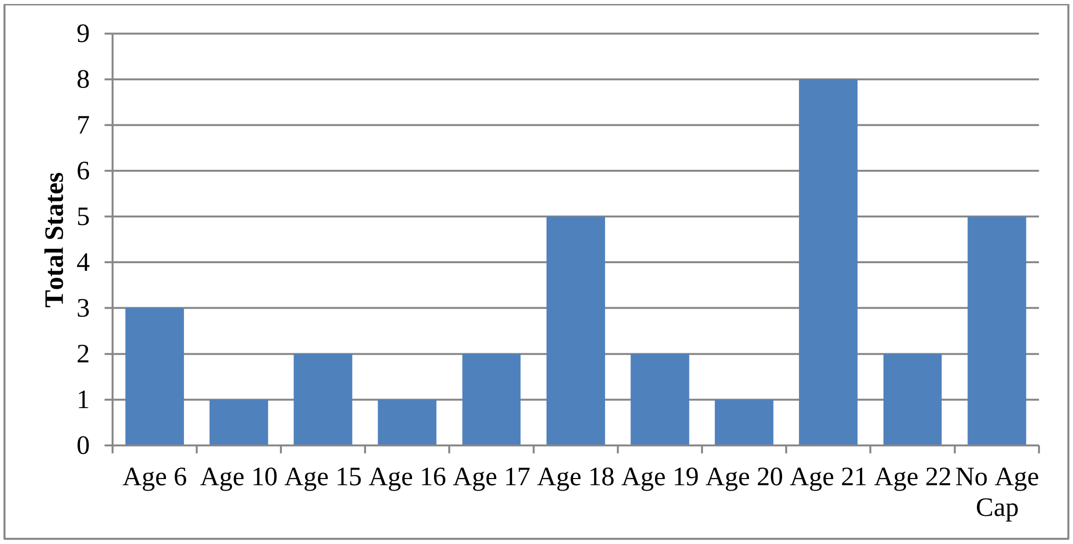
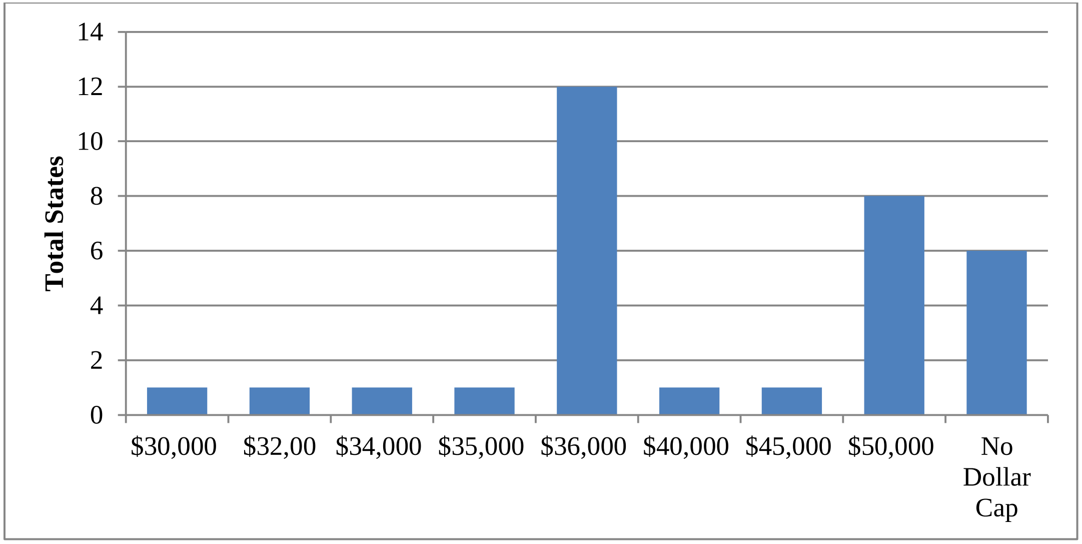


**Figure 4. Annual dollar caps on insurance coverage for early behavioral intervention for children with autism spectrum disorders**



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 source of health insurance funding; in some cases waiver funding covers what private insurance does not cover. The current Medicaid Home and Community Based Services (waiver) system is summarized in more detail later in this report as it applies to coverage for ASD services. It is also important to recognize the contribution of the educational system and families' through their personal finances when evaluating the cost of providing services to people with ASD.

In 2005, the United States General Accounting Office estimated the average cost for educating a child with ASD to be $18,000. This report was based on figures from the 1999-2000 school year and has not been updated, and it is unlikely these costs have decreased in the last decade. Deductibles, co-insurance, premium payments, and other direct costs of care paid for by families related to ASD services (medical, behavioral, and otherwise) are not readily available, but in general, direct medical costs for people with ASD may be twice that of people without ASD over the life course (Alemayehu & Warner, 2004).

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) (Ganz, 2007). Additionally, in coming years the relationship between ASD insurance legislation, mental health parity statutes that charge insurers with covering mental health care with similar parameters as physical health care, and essential benefit sets that be established by each state under the Patient Protection and Affordable Care Act will be evolving and should be closely followed to learn how states interpret the relative funding priorities.

## VI. Medicaid Funded Services

### Medicaid State Plan Services

Early intensive behavioral and developmental intervention (EIBDI) services are generally not included in state Medicaid plans. Exceptions include Florida (via 2012 court order), Washington State (via 2012 settlement agreement), Massachusetts (via the state health reform plan act of 2006), Vermont (as an extension of the 2010 insurance mandate), and Virginia (as part of a 2012 update to the state Behavior Therapy Manual). In these states, EIBDI or ABA is included as a benefit in Early Periodic Screening Diagnosis and Treatment (EPSDT). 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.

*Home and Community Based Services Waivers across States* As the prevalence of ASD diagnoses 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. The 1915(c) waiver program functions as a "capped entitlement." 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. The mounting population of youth and young adults with ASD who are leaving school with substantial support needs increase the demands on an already-stressed service system. Those demands are expected to increase in the coming years as the growing numbers of individuals with ASD are identified and progress through school and into the adult services system.

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. Historically, people who have an ASD have been expensive to support due to the nature of their needs and states have been challenged to develop comprehensive, well-coordinated systems to support individuals with ASD.

Data for this section of the report was provided from the *Policy Research Brief: A National Review of Home and Community Based Services (HCBS) for Individuals with Autism Spectrum Disorders* (Hall-Lande, Hewitt, and Moseley, 2011). The data on children's waivers was updated in December 2012 using the Easter Seals state autism profiles resource guide and linking to the websites, reports, and plans of state task forces, councils, and working groups therein. The review of state policy around waiver services revealed that all 50 states and the District of Columbia (D.C.) reported serving people with intellectual disabilities under one or more of their section 1915(c) or section 1115 Medicaid Waiver programs. The waivers in most states used broad categories when describing who was targeted for services in their comprehensive HCBS waiver, such as, "serves individuals with Developmental Disabilities, Intellectual Disabilities, Mental Retardation, etc." Although many states serve people with ASD under an HCBS waiver, not all states explicitly included ASD as a specific diagnosis. At the time of this review, 40 states and the District of Columbia explicitly included ASD in the definition of people served under the state's HCBS waiver for people with intellectual disabilities.

A growing number of states reported having ASD-specific waivers for children. For the purposes of the current study, Autism Waivers for Children were defined as ASD specific waivers serving the approximate age span of 0-21. Although many states serve children with ASD under the broad DD waiver, those states were not included under Autism Waivers for Children category in Table 16. At the time this data was collected, 11 states offered ASD-specific waivers for children. As shown in Table 16, Arkansas, Colorado, Kansas, Maryland, Massachusetts, Missouri, Montana, Nebraska, North Dakota, South Carolina (PDD waiver), and Utah had ASD waivers specific to children. It should be noted that although Nebraska has an autism waiver for children (Nebraska Autism Waiver #40660.R00.01), the state is currently waiting on a private donation match and has not been able to fully implement the waiver as of this time. Additionally, Connecticut has submitted a plan for ASD waivers. Two states, Indiana and Pennsylvania, had ASD waivers that specifically served adults in 2010. However, Indiana's Autism Waivers have been recently combined into a new Community Integration and Habilitation Waiver.

**Table 16. Status of HCBS Waiver across States (2012)**

| State | Autism Related Clause | Autism Waiver for Children | Autism Waiver for Adults |
|---|---|---|---|
| Alabama | | | |
| Alaska | X | | |
| Arizona | X | | |
| Arkansas | X | X | |
| California | X | | |
| Colorado | X | X | |
| Connecticut* | | | |
| Delaware | X | | |
| DC | X | | |
| Florida | X | | |
| Georgia | X | | |
| Hawaii | | | |
| Idaho | X | | |
| Illinois | X | | |
| Indiana* | X | | |
| Iowa | | | |
| Kansas | X | X | |
| Kentucky | | | |
| Louisiana | X | | |
| Maine | X | | |
| Maryland | X | X | |
| Massachusetts | X | X | |
| Michigan | | | |
| Minnesota | | | |
| Mississippi | X | | |
| Missouri | X | X | |
| Montana | X | X | |
| Nebraska* | X | X | |
| Nevada | X | | |
| New Hampshire | X | | |

| Table 16. Status of HCBS Waiver across States (2012) | | | |
|---|---|---|---|
| **State** | **Autism Related Clause** | **Autism Waiver for Children** | **Autism Waiver for Adults** |
| New Jersey | X | | |
| New Mexico | X | | |
| New York | X | | |
| North Carolina | X | | |
| North Dakota | | X | |
| Ohio | X | | |
| Oklahoma | | | |
| Oregon | X | | |
| Pennsylvania | X | | X |
| Rhode Island | X | | |
| South Carolina* | X | X | |
| South Dakota | | | |
| Tennessee | | | |
| Texas | X | | |
| Utah | X | X | |
| Vermont | X | | |
| Virginia | X | | |
| Washington | X | | |
| West Virginia | X | | |
| Wisconsin | X | | |
| Wyoming | X | | |

**Connecticut:* submitted a plan for ASD waivers
**Indiana:* autism waivers recently combined into new Community Integration and Habilitation Waiver
**Nebraska:* developing a private donation match to augment current autism waiver
**South Carolina:* waiver serves children with Pervasive Developmental Disorders (PDD)

Initial data from Policy Research Brief: A National Review of Home and Community Based Services (HCBS) for Individuals with Autism Spectrum Disorders (2011). Data on children's waivers was updated in December, 2012 using the Easter Seals state autism profiles resource guide.

As seen in Table 17, most states indicated that individuals with ASD were included in one or more of their HCBS programs for persons with intellectual and/or developmental disabilities (the latter sometimes referred to as "related conditions").

| Table 17. Available Funding Options and Specified Evidence-Based Practices | | | | | |
|---|---|---|---|---|---|
| **State** | **Insurance Mandate** | **Medicaid Coverage** | **Autism Waiver for Children** | **HCBS Waiver w/ Autism Clause** | **Recommended or Recognized Evidence Based Interventions in State Plan** |
| Alabama | X | | | | |

**Table 17. Available Funding Options and Specified Evidence-Based Practices**

| State | Insurance Mandate | Medicaid Coverage | Autism Waiver for Children | HCBS Waiver w/ Autism Clause | Recommended or Recognized Evidence Based Interventions in State Plan |
|---|---|---|---|---|---|
| Alaska | X | | | X | |
| Arizona | X | | | X | |
| Arkansas | X | | X | X | |
| California | X | | | X | |
| Colorado | X | | X | X | X |
| Connecticut | X | | | | |
| Delaware | X | | | X | |
| Florida | X | X | | X | |
| Georgia | | | | X | |
| Hawaii | | | | | X |
| Idaho | | | | X | |
| Illinois | X | | | X | |
| Indiana | X | | | X | |
| Iowa | X | | | | X |
| Kansas | X | | X | X | X |
| Kentucky | X | | | | X |
| Louisiana | X | | | X | |
| Maine | X | | | X | |
| Maryland | | | X | X | |
| Massachusetts | X | X | X | X | |
| Michigan | X | | | | X |
| Minnesota | | X | | | |
| Mississippi | | | | X | |
| Missouri | X | | X | X | |
| Montana | X | | X | X | |
| Nebraska | | | X | X | |
| Nevada | X | | | X | X |
| New Hampshire | X | | | X | X |
| New Jersey | X | | | X | |
| New Mexico | X | | | X | |
| New York | X | | | X | |
| North Carolina | | | | X | X |
| North Dakota | | | X | | |
| Ohio | | | | X | |
| Oklahoma | | | | | |
| Oregon | | | | X | |
| Pennsylvania | X | | | X | |

**Table 17. Available Funding Options and Specified Evidence-Based Practices**

| State | Insurance Mandate | Medicaid Coverage | Autism Waiver for Children | HCBS Waiver w/ Autism Clause | Recommended or Recognized Evidence Based Interventions in State Plan |
|---|---|---|---|---|---|
| Rhode Island | X | | | X | X |
| South Carolina | X | | X | X | |
| South Dakota | | | | | |
| Tennessee | | | | | |
| Texas | X | | | | X |
| Utah | | | X | X | |
| Vermont | X | X | | X | |
| Virginia | X | X | | X | X |
| Washington | | X | | X | |
| West Virginia | X | | | X | |
| Wisconsin | X | | | X | X |
| Wyoming | | | | X | |

Initial data from Policy Research Brief: A National Review of Home and Community Based Services (HCBS) for Individuals with Autism Spectrum Disorders (2011). Data on children's waivers was updated in December, 2012 using the Easter Seals state autism profiles resource guide.

## Eligibility under HCBS Waivers

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, 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.

Intelligence quotient (IQ) was a more complicated construct as it related to state eligibility criteria. For the majority of states that explicitly included IQ level as a component of eligibility criteria, the stated allowable IQ score had to be a standard score of 70 or below. A few states offered tiered IQ eligibility criteria with a different IQ cutoff point for related disabilities such as ASD. For example, a few states, such as Florida, have one IQ requirement for people with intellectual disabilities (59 or less) and another threshold (69 or below) for people with secondary conditions such as ASD. Some states, such as Georgia, indicated that persons with listed conditions other than intellectual disabilities qualify if they need similar types of services as persons with intellectual disabilities. Most states included more general terminology related to eligibility criteria, such as "[has a] diagnosis from a qualified professional" or "meets DSM-IVR criteria for MR or ASD." A few states used internal assessments or eligibility screeners for inclusion in the HCBS waiver.

*ASD Specific Waivers* 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). For children's ASD Waivers, some states included financial eligibility statements, such as parents' income (e.g., Colorado), while other states excluded parental income (e.g., Maryland). All children's waivers included eligibility for the diagnosis of ASD, but some states explicitly stated in policy that they extended services to children with Asperger's syndrome, Pervasive Developmental Disorder-Not Otherwise Specified, and/or developmental disability. Diagnosis by a qualified professional such as a psychologist or pediatrician was required on all ASD children's waivers.

*Services Provided Through ASD Specific Waivers* Analysis of 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. When comparing adult ASD waivers to non-specific developmental disability waivers, there appears to be some overlap in the services and supports provided. For example, common services listed under the specific adult ASD waivers included adult day services, respite services, behavioral support, family training, environmental modification, and employment supports. Pennsylvania providers of support under the adult ASD waiver are required to complete ASD-specific training and meet specific standards related to ASD. Clinical and behavioral supports (as well as technical assistance) were made available to enrolled providers under the waiver program. Additionally, the services provided had to be established as effective for people with ASD.

### ASD Waivers for Children are a Growing Trend

A trend across states has been the development of specific waivers for children with ASD. Several states have ASD specific waivers predominantly for children, and others indicated plans to develop one. The impetus to develop these seemed to be in response to multiple factors, including growing demand, extensive waiting lists, and research suggesting a critical window of intervention effectiveness during the early childhood years. Since most children with ASD do not receive a diagnosis until after 3 years of age, access to service is needed quickly. The development of ASD specific children's waivers may help to address this issue by providing more direct and expedient access to services for children with an ASD diagnosis; however, caps in waiver enrollment may result in waiting lists for access.

A review of children's ASD waivers across states revealed both similarities and differences in state policy. A common component of state children's waivers included a diagnosis of ASD and some states extended eligibility to other or broader disability categories such as Pervasive Developmental Disorders (PDD). Family support, Applied Behavior Analysis, and intensive behavioral and developmental interventions were commonly identified services and supports in these programs across states. However, there were relatively wide variations in the ages covered under the children's waivers. Some states exclusively targeted the early childhood window (birth to age 5). Other states extended the age range from birth to age 21. Although specific age ranges for eligibility varied across states, all children's ASD waivers targeted children from birth to age 3.

Not only were the states with ASD waivers for children part of a growing policy trend, states without ASD-specific children's waivers indicated both the growing need and/or strong desire to develop specialized programs for children with ASD. A few states indicated that they were in the preliminary planning stages of a children's ASD waiver, and many other states indicated that they hoped to develop a children's program in the future. Current funding limitations were consistently cited as an obstacle to developing these waivers (Hall-Lande, Mosely, & Hewitt, 2011).

### State Early Intervention ASD Practice Profiles: South Carolina, Missouri, and Wisconsin

Nearly every state has something they do well. Some states try and implement services and practices that are unique or have creative features. In this section, three state profiles are included. While these are here to provide illustrations of interesting services or practices, it is important to recognize that these states likely face challenges as well (e.g. budget constraints, waiting lists).

#### South Carolina

South Carolina leans heavily on a well-established interdisciplinary and interagency Act Early team. This team, as with other Act Early teams across the county, was formed to carry out the Learn the Signs Act Early (LTSAE) initiative of promoting early screening, identification, and intervention for children with developmental disorder, including autism (for more information on LTSAE, see the Centers for Disease Control's Website). The South Carolina Act Early team is composed of the director of the state's University Center for Excellence in Developmental Disabilities (UCEDD), the state representative of the American Academy of Pediatrics, developmental/behavioral pediatricians in key hospital systems, policy representatives from the state Department of Disabilities & Special Needs, the director of the state Developmental Disabilities Council, the coordinator of the Part C system, representative from the state Autism and Developmental Disabilities Monitoring (ADDM) network, director of the state autism society, representative from the state Department of Education, parent advocates, special education faculty from the University of South Carolina, and a UCEDD trainee.

The team developed a Road Map to guide families and professionals through the screening, referral, diagnosis, and intervention system, and the transition from home-based to school-based services. Designed for navigation of the birth-3 system as parents have questions about obtaining screenings and referrals for appropriate services, the road map lays out information in flow-chart format in terms of what happens, when it should happen, who/what professionals are involved, what happens next, what service steps are involved, and decision trees based on assessment and intervention results/outcomes.

In addition to the flow chart, the road map defines key terms, defines and describes key agencies and resources parents will encounter as they navigate the system (e.g., Babynet Part C system, Head Start, Applied Behavior Analysis, Early Intensive Behavioral Intervention), clarifies which professionals are qualified to conduct assessments and provide intervention (e.g., Board Certified Behavior Analysts), and explains school-based planning processes (e.g., Individualized Family Service Plans and Individualized Education Plans) and the outcomes families should expect from them.

The Act Early team also promotes the use of a screening instrument called the STAT (Screening Tool for Autism in Toddlers and Young Children), trains professionals to use the instrument, and maintains a record of trained professionals. The results of the STAT for children 0-3yrs are linked to eligibility for Part C and for behavioral and developmental intervention services.

By leveraging key stakeholders, policymakers, experts across the state, and related national resources (e.g., the Association of University Centers on Disabilities), the South Carolina Act Early team has developed into a strong and productive group with a diversity of perspectives and expertise that has made meaningful progress in driving state policy, best practices, and capacity-building.

### Missouri

Missouri has implemented several promising practices to improve early intervention for children with ASD and their families. To date, it has convened several panels and commissions involving a broad range of interdisciplinary stakeholders within the ASD community (e.g. individuals with ASD, families, health care professionals, educators, clinicians, state departments, and the university/research community and other professionals). These panels have promoted legislation that eventually established the Missouri State Office of Autism Spectrum Disorders and established comprehensive state policy for improved services for individuals with ASD and their families.

Specifically, Missouri has implemented early intervention initiatives to improve screening, diagnosis, and assessment. The first involves the development and dissemination of ASD best practice guidelines. The second involves the establishment of state Autism Centers of

Excellence to decrease delays in ASD assessment and diagnosis and to increase outreach and accessibility to underserved communities throughout the state. Based on Missouri's approach to data based decision-making, they report significantly improved early intervention services within the state.

Missouri has also developed a comprehensive manual promoting best practices in screening, diagnosis, and assessment of individuals with Autism Spectrum Disorders (ASD). Called *Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment*, the manual has been widely disseminated across the state and is accessible to the public online.

The manual has been used for training of pediatricians and health care professionals for guidelines to screening. Universal best practice guidelines were made available for families, clinicians, educators, and direct support professionals. To promote consistency and best practice in ASD diagnosis, the manual presents a tiered approach to diagnosis of ASD. This approach provides an efficient use of the very limited number of ASD assessment specialists within the state.

The manual also provides clear follow up steps for an ASD diagnostic evaluation, and standardized tools recommended for use including the M-CHAT, CARS, ADOS, and ADI-R. Further, the Missouri guidelines advocate for a person and family-centered approach to ASD screening, diagnosis and assessment. Additionally, Missouri is the recipient of a Learn the Signs, Act Early (LTSAE) systems grant to promote increased screening, awareness, and early intervention around neurodevelopmental disorders.

Although the screening initiatives are relatively new, Missouri has collected data on several of these projects. Before dissemination of the *Missouri Best Practice Guidelines* the median age of ASD diagnosis in the state was between 5-8 years old. Using the baseline data, the state has set a comprehensive goal to screen children earlier along with a subsequent goal of earlier assessment (ages 3-6) for ASD. Further, another state training project to increase developmental screening rates with physicians and pediatricians has provided promising research outcomes. Before the screening training project, only 30 % of physicians reported conducting regular developmental screening and fewer than 10% were screening for ASD. After the training project, these screening estimates among physicians increased by 90% and 80% respectively. Further, a formal screening to assessment timeline was established in which a child is referred for diagnostic assessment within three weeks of referral from a physician.

*Autism Centers of Excellence in Missouri* To address the needs of ASD assessment, funds were allocated to develop Autism Centers of Excellence across the state. To date, four regional Autism Centers of Excellence were established across different geographical regions of the state. The goals of these regional centers was to: 1) decrease the time between the first sign of ASD characteristics and a comprehensive ASD diagnostic assessment; 2) build increased capacity and increased access to ASD assessment and intervention services to underserved and hard to reach groups; 3) connect families to effective referral and intervention services; 4) develop ongoing training of ASD for clinicians, professionals, families, and community service providers.

*Data-Based Decision Making* The Missouri Autism Centers of Excellence Centers provide data to the Missouri Division of Developmental Disabilities Office of Autism Services in the form of a state ASD registry. The data provide information of first age of diagnosis in the state. Data on outreach and educational presentations and outreach on Autism Spectrum Disorders are also collected. These data track statewide assessment and intervention information so that gaps and needs in the system can be addressed. Finally, the Missouri Autism Research and Response Agenda, has set the primary goal of organizing ASD research and professional development as well as coordinated ASD services across the state. The six primary research universities in the Missouri have developed a unified research agenda in order to procure ASD grant funds and necessary to develop longitudinal studies focusing on ASD early interventions and individual outcomes.

## Wisconsin

Wisconsin has implemented several promising practices to improve early intervention for children with ASD and their families. In terms of best practices in early intervention, Wisconsin can serve as a model for collaboration of interagency and interdisciplinary collaboration. Through a common goal of improved early intervention services for children with neurodevelopmental disabilities, a variety of key stakeholder groups have committed both time and funds to improving the early intervention system. Wisconsin is the recipient of both a Learn the Signs, Act Early (LTSAE) systems grant and an Act Early Ambassadorship both of which actively promote increased screening, awareness, and early intervention around neurodevelopmental disabilities such as Autism Spectrum Disorders (ASD).

The Wisconsin Act Early Team along with several state agencies/departments, and the University of Wisconsin (Waisman Center, LEND, ADDM network etc.) have developed a comprehensive early intervention system with a focus on comprehensive screening and assessment. Additionally, Wisconsin has received Combating Autism Act Initiative (CAAI) Statewide Implementation Grant further supporting organization and coordination of ASD services and supports throughout the state. Through the work of these key stakeholder groups, a comprehensive set of goals and subsequent activities have been developed across the state to improve early intervention services for individuals with ASD and their families across the state.

Wisconsin identified a common statewide need around universal developmental screening for neurodevelopmental disabilities such as ASD. In 2012, the *Wisconsin Blueprint for a Comprehensive and Aligned System for Screening and Assessment of Young Children* was developed and submitted to the Governor's Early Childhood Advisory Council by the Wisconsin Early Childhood Collaborating Partners Healthy Children Committee. The interdisciplinary team (comprised of a broad range of interdisciplinary stakeholders within the ASD community including individuals with ASD, families, health care professionals, educators, clinicians, state departments, and the university/research community and other professionals) was able to share both a common set of goals across disciplines. The interdisciplinary team created a common goal of developing a comprehensive screening and assessment system throughout the state. Activities included creating a universal early intervention manual including definitions, schedules, timelines, screening and assessment tools, and community models.

The team worked to align cross sector, community screening processes and with assessment timelines and schedules. Through collaboration with state departments, community groups, and private partners, cross-sector approaches were developed to promote the implementation of the screening and assessment schedule for all children in the state of Wisconsin. A plan was proposed to report screening and assessment efforts within the statewide data system. Further, a community toolkit, tip sheets, and webinar series have also been developed to promote early screening initiatives across the state.

*Learn the Signs Act Early (LTSAE) Campaign* Wisconsin is the recipient of a Learn the Signs, Act Early (LTSAE) systems grant to promote increased screening, awareness, and early intervention around neurodevelopmental disabilities such as ASD. The goal of this campaign is to disseminate the CDC materials on early screening. The Wisconsin Act Early team customized the CDC materials to meet the local needs of the communities in which the materials were used. The Act Early team has worked closely with pediatricians and other health care professionals to increase screening rates and reduce the time between screening and diagnosis. Additionally, the Wisconsin Act Early team has developed a website serving as an early intervention resource for families and professionals.

Further, the Wisconsin Healthy Children Committee along with partners from public health and early childhood education (birth to three) integrated the "Act Early Wisconsin" campaign into early identification and screening website and resources. The Wisconsin Act Early team collaborated with the Wisconsin Surveillance of Autism and Other Developmental Disabilities (ADDM Network) project and Wisconsin LEND training program to provide LTSAE technical assistance to help Wisconsin Regional Centers for Children and Youth with Special Health Care Needs conduct LTSAE outreach to child care centers and through public service announcements to the community around ASD screening, diagnosis, and intervention.

*Early Intervention Services and Supports* Screening for ASD are covered under a state insurance mandate, and Medicaid currently reimburses providers for screening. Wisconsin currently offers funds for in home autism treatment through a Children's Developmental Disability Waiver. Children eight years old with a diagnosis of an Autism Spectrum Disorder who demonstrate a medical need can be eligible to receive up to three years of funds for intensive autism treatment services and supports. The Wisconsin Department of Public Instruction conducted a large scale statewide survey of autism services across the state. The department has used the survey results to develop effective educational programs and interventions in schools throughout the state.

## VII. Summary of Findings and Their Implications

This final section of the report summarizes the findings of this project across the various methodologies used to obtain information. This 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. It serves as a cumulative summary of all findings as integrated and summarized by the project staff.

### What are helpful first steps into early intervention services?

When parents begin to sense that a child has developmental problems, they often feel alone and isolated. The combination of emotions including confusion, guilt, sadness, isolation and fear can be profound. Even before a diagnosis is made, parents may fear the worst. As their lives evolve through the diagnostic process, the need for support and understanding becomes essential. Meeting these myriad needs while navigating support and intervention systems can be the most difficult and stressful part of a family's existence. The old adage about it taking a village to raise a child is never truer than when a child has significant developmental needs.

The challenge for the service system is to organize services to meet the needs of children and families through timely and effective diagnostic and treatment services, to fund them, and to make them accessible when and where they are needed. From the data gathered for this project, it is apparent that for many, supports and services are not organized, are not adequately funded, and are not accessible in a timely manner statewide. For other families, early intervention services are available and timely and result in significant changes for the children who benefit from them. Findings from stakeholders indicate that many children are moving through the ASD service maze and meeting resistance from the "system" at several places along the way.

From the ASD Advisory Council and Key Stakeholder interviews, we collected hours of "testimony" describing a system that provides powerful, valuable services and supports to some and scattered, less valuable services and supports to others. We heard about waiting lists and delay of services but also about responsive providers that went out of their way to solve problems or caring county workers who stayed late to help a family in crisis. The testimony focused on meeting family needs but understanding the complexity of serving such a diverse population of children. Profound stories were shared of tremendous success achieved by children through determination and the village approach; tragic tales of pain and frustration that could not be alleviated despite the efforts of the community were also shared.

### What are effective practices for determining that a child is in need of early intervention services?

Earlier identification and diagnosis of ASD is an emerging trend. Routine developmental and social/emotional/mental health screening should be an important focus of child visits. Providing guidelines for routine screening appears to increase screening rates and reduce the overall age of ASD diagnosis. The majority of state plans recommended a significant push for earlier ASD screening and diagnosis. Recommending timelines (e.g., 60 days, 90 days, six months) between a physician/healthcare professional referral and ASD diagnostic assessment may reduce assessment wait times and prevent delays in ASD diagnosis.

Once an assessment shows a child has a developmental delay (not meeting expected developmental milestones), stakeholders state that it is important to refer for a diagnostic medical/educational assessment, but also important to refer immediately to early intervention services through the school or other systems so the child can begin treatment as soon as possible. Stakeholders reported waiting lists as long as 6-18 months for some children for comprehensive assessments in Minnesota.

A multi-method, multi-rater approach represents best practice in assessment and diagnosis. Currently these comprehensive assessments are not available in all areas of Minnesota and there is a lack of specialists trained in autism assessment and diagnosis. The use of empirically-validated diagnostic tools for ASD (e.g., Autism Diagnostic Observation Schedule (ADOS), Autism Diagnostic Interview (ADI-R), Childhood Autism Rating Scales (CARS)) as well as observations and a comprehensive developmental history are important components of an ASD assessment, as are medical examinations and testing in order to rule out other conditions. A person- and family-centered approach to ASD diagnosis and assessment is also important. Children need comprehensive assessment to ensure proper diagnosis and related interventions, yet waiting for assessment and diagnosis should not delay their access to early intensive behavioral and developmental intervention.

### What are effective early intervention approaches?

Many stakeholders reported tremendous outcomes for their children using intensive behavioral or developmental approaches. Some reported that their children needed more hours of service than they were getting. Stakeholders clearly reported that not all families want or can follow through with intensive behavioral or developmental approaches for their children. Instead, some preferred a more holistic approach that included sensory integration, social skills groups, and play therapy. Considering these differences in stakeholder opinions regarding approaches to early intervention services, most agreed that the following characteristics are important:

- Therapeutic approaches or combination of approaches must be tailored to the specific needs and deficits of the child, and include environmental arrangements that support learning as well as specific instructional/intervention strategies.
- The credentials and training of practitioners are critical and impact the quality of services.
- Minnesota has a shortage of trained and licensed practitioners with expertise in treating ASD.
- Specific goals for treatment must be identified that target the three core characteristic symptoms of ASD (communication, socialization, repetitive behavior/restricted interests), and that address challenging behavior when indicated. Progress toward those targets must be objectively and frequently evaluated.

- Intervention must be delivered with appropriate intensity and fidelity to produce significant change in all behaviors and skills targeted for change.
- Generalization of behavioral and developmental improvements across environments (home, community, education) in which they are most important must be planned for, taught, and supported. It is not enough to simply expect generalization of skills across environments.
- Parents/caregivers and families can be critical partners in intervention and ideally should play an active role in the development and implementation of treatment. They are valuable experts on their children and should be supported to learn how to achieve the best results for their children.

### How should early intervention services be funded?

Screening, diagnosis, and medically-necessary services (including but not limited to early intensive behavioral and developmental interventions) should be available and covered for all children. In Minnesota this can be accomplished by a combination of private insurance, Parts B & C early intervention resources through Minnesota Department of Education, and state public health care program dollars (e.g., state plan MA fee-for-service and managed care and/or HCBS waiver). Such resources should be coordinated across state agencies and private and public programs to ensure that all children with ASD have fair access to necessary early intervention supports and services. Combining all existing and possible funding streams may result in more efficient use of these resources, however it is critical to pool these resources in a manner that is easy for parents to access and that reduces abrupt, unwanted changes in service providers and settings.

### Do we have capacity in Minnesota to provide intensive early intervention behavioral and developmental services to all children with autism?

There are early intervention providers with expertise in serving children with autism in Minnesota. This group of providers has expertise in using a variety of interventions for young children with ASD, such as functional assessment, positive behavior support, DIR/Floortime, sensory integration, and Applied Behavior Analysis. However, nearly all of the current providers have waiting lists and the majority of them are located in the metropolitan area. There is more demand for services than there are providers to deliver services. Additionally, stakeholders reported a persistent lack of services within diverse communities using diverse service providers with the same cultural, racial, ethnic, and linguistic background as the children whom they serve.

There is also a lack of service providers who are qualified to conduct comprehensive assessment and diagnosis of children with ASD. Again, those that do exist are primarily concentrated in the metropolitan area. Increased recruitment and placement of these types of providers (e.g., developmental behavioral pediatricians, psychologists, or other certified assessors) is needed to meet the demand for assessment and diagnosis. Additionally, there is a shortage of Board Certified Behavior Analysts (BCBA) and other licensed or appropriately credentialed providers to provide early intensive behavioral and developmental supports. Efforts should be made to increase the number of licensed or appropriately credentialed providers in Minnesota by offering autism specific training and certification programs.

It should be noted that the Minnesota Department of Education and the Autism Society of Minnesota conducted an Autism Spectrum Disorder Needs Survey in 2012. A whole report has not been released at time of this writing but the Executive Summary is available.

### Do we know if early intensive behavioral and developmental intervention services delivered in Minnesota are effective for achieving desired outcomes?

In both the ASD Advisory Council proceedings and in key stakeholder interviews, respondents lamented the lack of longitudinal data on outcomes for children who get intensive early intervention services. Many felt that the development of data sets that monitor outcomes and other indicators of effectiveness alongside the cost and intensity of all interventions should be established and routinely updated. Many also felt that better oversight and monitoring of early intensive behavioral and developmental intervention services needs to occur. A number of stakeholders expressed the view that providers who are not achieving outcomes for children should be deemed ineligible for continued funding.

### Conclusion

Responses from key stakeholders seem to indicate that there are a number of effective early intervention services and providers available in Minnesota and that many families are benefitting from them. There are other families who have been frustrated and unhappy about their own lack of access to these services or about their lack of options when they go about selecting services to match their needs. As expected, many stakeholders are concerned about funding barriers and the complex nature of assessment and eligibility for services that impede access to needed supports. As Minnesota becomes more culturally diverse, connections with families must be approached with sensitivity and culturally specific understanding. Overall, stakeholders are interested in developing better ways to measure outcomes along with more accurate accounting of who is being served and who is not. Ongoing involvement of these stakeholders in policy discussions and funding decisions seems quite prudent and something most stakeholders would be interested in.

## Appendices

A. **References**
B. **Autism Spectrum Disorder Advisory Council Membership Roster**
C. **Protocol for Autism Early Intervention Project, Key Stakeholder Interviews**

## Appendix A-References

Alemayehu, B., & Warner, K. E. (2004). The lifetime distribution of health care costs. *Health Services Research*, 39(3), 627-642.

Autism Speaks (2012). *What is Autism?* Retrieved on December 20, 2012.

Cavagnaro, A. T. (2007). *Autistic Spectrum Disorders: Changes in the California caseload, An update: June 1987-June 2007*. Sacramento, CA: California Health and Human Services Agency.

Centers for Disease Control and Prevention (CDC). (2010). *Autism spectrum disorders: Data and statistics*. Retrieved December 14, 2012.

Centers for Medicare and Medicaid Services (CMS). (2010). *Medicaid waivers and demonstration list.* Retrieved December 12, 2012.

Courchesne, E., & Pierce, K. (2005). Why the frontal cortex in autism might be talking only to itself: Local over-connectivity but long-distance disconnection. *Current Opinion in Neurobiology, 15*(2), 225-230.

Ganz, M. (2006). The costs of autism. In S. O. Moldin & J. L. R. Rubenstein (Eds.), *Understanding Autism* (pp. 475-502). Boca Raton, FL: Taylor & Francis.

Ganz, M. (2007). The lifetime distribution of the incremental societal costs of autism. *Archives of Pediatrics and Adolescent Medicine, 161*, 343-349.

Gerhardt, P. (2009). The current state of services for adults with autism. *Advancing Futures for Adults with Autism: Think Tank*. Arlington, VA: Organization for Autism Research.

Hall-Lande, J., Hewitt, A., Mosely, C. (2011). *Policy Research Brief: A National Review of Home and Community Based Services (HCBS) for Individuals with Autism Spectrum Disorders.* Minneapolis, MN: Research and Training Center on Community Living, Institute on Community Integration. College of Education and Human Development, University of Minnesota.

Horner, R. H., Carr, E. G., Halle, J., McGee, G., Odom, S., & Wolery, M. (2005). The use of single-subject research to identify evidence-based practice in special education. *Exceptional Children*, 71(2), 165-179.

Howlin, P., Magiati, I., & Charman, T. (2009). Systematic review of early intensive behavioralinterventions for children with autism. *American Journal of Intellectual and Developmental Disabilities, 114*(1), 23-41.

Jarbrink, K., & Knapp, M. (2001). The economic impact of autism in Britain. *Autism, 5*, 1, 7-22.

Knapp, M. (2012). Re: Preliminary research suggests that the overall UK cost of autism is about £34 billion each year: there needs to be further evaluation of the economic case for early intervention. Retrieved on December 14, 2012.

Larson, S. A., & Lakin, K. C. (2010). Changes in the primary diagnosis of students with intellectual or developmental disabilities ages 6 to 21 receiving special education services, 1999 to 2008. *Intellectual and Developmental Disabilities, 48*(3), 233-238.

Minnesota Department of Education (2012). Part C and Part B: A.k.a. Early childhood education – The basics. Presentation provided by MDE.

National Association of Insurance Commissioners (2012). *Response to the request for information regarding stop loss insurance*. Retrieved on December 30, 2012.

National Conference of State Legislatures (2012). Insurance coverage for autism. Retrieved from http://www.ncsl.org/issues-research/health/autism-and-insurance-coverage-state-laws.aspx

National Professional Development Center on Autism Spectrum Disorders (2009). *Screening and early identification of autism spectrum disorders*. Retrieved on 12/01/2012.

Newcombe, R. G. (2005). Should the single-subject design be regarded as a valid alternative to the randomized controlled trial? *Postgraduate Medical Journal*, 81, 546-547.

Office of the State Demographer. (2011). *Minnesota population by race and Hispanic origin.* Minnesota Dept. of Admin., Office of Geographic and Demographic Analysis Division.

Ozonoff, S., & Cathcart, K. (1998). Effectiveness of a home program intervention for young children with autism. *Journal of Autism and Developmental Disorders, 28*(1), 25-32.

Rogers, S. J., & Vismara, L. A. (2008). Evidence-based comprehensive treatments for early autism. *Journal of Clinical Child & Adolescent Psychology, 37*(1), 8-38.

Shattuck, P. T., Durkin, M., Maenner, M., Newschaffer, C., Mandell, D.S, Wiggins, L., et al. (2009) Timing of identification among children with an autism spectrum disorder: Findings from a population-based surveillance study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 48(5) 474-83.

U.S. State Education Data, Office of Special Education Programs. (2003). *Twenty-fifth annual report to Congress on the implementation of the Individuals with Disabilities Education Act*. Washington, DC: U.S. Department of Education, Office of Special Education Programs.

Wiggins, L.D, Baio, J., Rice, C. (2006) Examination of the time between first evaluation and first autism spectrum diagnosis in a population-based sample. *Developmental and Behavioral Pediatrics.* 27(2).

## Appendix B-Autism Spectrum Disorder Advisory Council Membership Roster

| Name | Role/Organizational Affiliation |
|---|---|
| Idil Abdull | Parent and Somali American Autism Foundation |
| Delores Alleckson | Rice Institute for Counseling and Education |
| Mike Amon | Alternatives for People with Autism |
| Jean Bender | Parent and The Arc of Minnesota |
| Barb Dalbac | Minnesota Department of Health |
| Amy Dawson | Autism Advocacy and Law Center, LLC |
| Amy Esler | Amplatz Children's Hospital, University of Minnesota |
| Paris Gatlin | Caregiver and The Arc Greater Twin Cities |
| Sheryl Grassie | Parent and End of the Spectrum |
| Kara Hall Tempel | Minnesota Department of Education |
| Diane Halpin | Lionsgate Academy |
| Anne Harrington | Celebrate the Spectrum |
| Anne Henry/Bud Rosenfield | Minnesota Disability Law Center |
| Carey Hodapp | Meeker County |
| Nancy Houlton | UCare |
| Jami Hughes | Alliant Behavioral Pediatrics |
| Kim Kang | Autism Society of Minnesota |
| Ginny Kistler | Parent |
| Peggy Kunkel | REM Minnesota |
| Traci LaLiberte | Center for Advanced Studies in Child Welfare, Univ. of Minn. |
| Istahill Malin | Parent |
| Kathryn Marshall | Minnesota Autism Center |
| Don McNeill | Parent and PACER |
| Bruce Nelson | Association of Residential Resources of Minnesota (ARRM) |
| AJ Paron-Wildes | Parent |
| Pat Pulice | Fraser |
| Teri Sanders | Residential Services, Inc. |
| Nancy Schussler | Behavioral Dimensions |
| Margaret Semrud-Clikeman | Pediatric Neurology, University of Minnesota |
| Phil Sievers | Minnesota Department of Education |
| Denise Steans | Washington County |
| Mike Stern | Parent and Governor's Council on Developmental Disabilities |
| Brad Trahan | Parent and ASD State Task Force |
| Laurie Wabner | Creative Care Resources |
| Abbie Wells-Herzog | Minnesota Dept. of Employment and Economic Development |
| Rich Yudhishthu | Parent |
| Cary Zahrbock | Medica Behavioral Health |
| Andrea Zuber | Ramsey County |
| Timothy Zuel | Hennepin County |

## Appendix C-Protocol for Autism Early Intervention Project, Key Stakeholder Interviews

Name of interviewer(s):
Name of Key Informant(s):
Primary stakeholder perspective(s):
*Parent* *Service Provider* *Advocacy/Parent Organization* *Other*___________
Informant Contact Information:
Date of Interview:
Location of interview:

### <u>Interview Protocol</u>

1. Please describe your role(s) related to supporting children with ASD.
2. What are your experiences in providing or receiving early intervention services (up to age eight) for children with ASD. (Probe for the following: timeline, location(s), description(s), types of programs, services delivered, funding, philosophy toward reducing or treating challenging behavior, impressions (positive and negative), outcomes, barriers and limitations). How were outcomes measured?
3. Please describe the characteristics of effective early interventions for children with ASD? Is this the same for children all across the spectrum?
4. Can you describe what a model early intervention program for children with ASD might look like? (Probe for (settings/physical plant, clinical interventions, funding, staffing, educational components, location(s), philosophy/approach toward challenging behavior, culturally specific considerations/supports, target outcomes.) What credentials would you expect staff to have in such a program?
5. Please describe what you consider effective practices for <u>involving families</u> in early intervention programs for children with ASD. (Probe for: culturally specific considerations/supports, planning, team building, clinical intervention, staff training and family education.)
6. Please describe what you see as culturally responsive residential services and supports?
7. What needs to happen in Minnesota to be able to provide effective early interventions to children with ASD?
8. What are your policy recommendations to improve access to effective early interventions for children with ASD?