



# Autism Issues and Needs

The Governor's Council on Disabilities & Special Education

# Preliminary Report of the Ad Hoc Committee on Autism: Findings and Recommendations

## Governor's Council on Disabilities and Special Education 2006

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## Executive Summary

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Experts agree that early identification and diagnosis of ASD is important.

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**A**lthough incremental changes have occurred on behalf of children and adults with Autistic Spectrum Disorders (ASD) in Alaska, the pace and amount of change has been inadequate to meet needs. Alaska does not have a system to capture the prevalence of ASD, but as in other states, the educational and service delivery systems have experienced an increased demand for ASD-specific intervention in recent years.

Experts agree that early identification and diagnosis of ASD is important. Screening identifies those in need of a comprehensive evaluation and assessment, and a diagnosis leads to appropriate interventions. Research has documented the efficacy of early, intensive intervention (Sheinkopf and Siegel, 1998, Dawson and Osterling, 1997). ASD specific interventions may speed the child's development, ameliorate inappropriate behaviors, and improve functioning over their lifetime. While not all children with ASD experience dramatic improvement with intervention, many do.

The overall cost of caring for a person with autism over his or her lifetime is estimated to be \$3.2 million (Ganz, 2006). Applying national prevalence rates of 1/166 to Alaska's 10,000 births annually results in about 60 babies born each year who will likely develop ASD. The lifetime cost for the 60 Alaskan babies born this year would total \$192 million, as well as for the 60 babies born every subsequent year.

When children do not receive early intervention, the cost of caring for them over their lifetime exerts a substantial economic burden on society. Behavioral

# Executive Summary cont...

therapies represent only 6.5% of the total cost of caring for an individual with ASD. By contrast, adult care represents 21% and lost productivity is nearly 31% of the total annual expense involved in caring for an individual with ASD.

The Governor's Council on Disabilities and Special Education, with the concurrence of the Alaska Mental Health Trust Authority, convened an Ad Hoc Committee on Autism to develop recommendations to present to the Alaska Legislature and Administration. The group organized their 21 recommendations around identification, diagnosis, and treatment. Recommendations were prioritized by the Committee, and submitted to the Council's Executive Committee for final approval.

The following four recommendations were ranked as the Committee's highest priorities. Although each is a separate recommendation, their interdependent nature requires they be considered as a package. One recommendation is to increase screening of children for ASD. Screening is a quick process used to differentiate children who may experience ASD, and identifies those who need a complete developmental and medical assessment. Without enhancing the capacity for comprehensive assessment and diagnosis, screening would be a disservice, leaving families concerned but experiencing a very lengthy wait before confirming or ruling out a diagnosis of ASD. Similarly, because the value of early diagnosis is in the potential for amelioration; diagnosing more children with ASD will make the existing shortage of services even more critical. To provide an adequate level of services, training for families, teachers, and direct service providers is essential to increase the size and quality of the workforce. Finally, the need for family support will intensify as more children are identified with ASDs.

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Research has documented the efficacy of early, intensive intervention (Sheinkopf and Siegel, 1998, Dawson and Osterling, 1997).

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1. **Greatly expand autism resources and referral services** so that the program is well funded, independent, and highly visible with a long-range plan for satellite programs throughout the state.

Several activities are envisioned to expand the functions of an autism resource center. These include:

- An annual comprehensive fair/institute for families to provide up-to-date medical information, guidance in navigating the system, and other topics. Disseminate the institute through a CD or a webcast for people who cannot attend in person.
- The establishment of local resource centers across Alaska that are independent in nature, but collaborative with other providers, and state/local/national experts;

# Executive Summary cont...

- Regional, technical assistance traveling teams with professional oversight; and
- Comprehensive parent training in education, systems and political advocacy, guardianship, medical services, and other topics as needed.

2. **Establish universal screening for autism spectrum disorders**, using a tool such as the parent-completed Modified Checklist for Autism in Toddlers (M-CHAT), and provide systematic referral for comprehensive assessment for children with risk factors for ASD.

Screening is a quick, simple and inexpensive process to identify children who have symptoms that could indicate a disorder. Like hearing or vision problems, early identification and diagnosis of ASD can lead to a better response to treatment and lifelong outcome for children. Universal screening of children at well-child exams is recommended to ensure that children with ASD are identified as early as possible in life. The M-CHAT is a 23-question, parent-completed survey that can be used at well-child check-ups and is valid for children between the ages of 16 and 36 months.

Screening does not take the place of a comprehensive assessment; rather it identifies those children who would benefit from a complete evaluation. The next step for children who show possible signs of an ASD is to refer them to early intervention or the school district where the process of a developmental assessment can begin. A protocol for children with risk factors for ASD should be developed to ensure they are referred for further testing and a comprehensive developmental assessment.

3. **Increase the capacity for comprehensive, timely assessments and diagnosis** of Autism Spectrum Disorders using a multidisciplinary team that is embedded with a system for referral to appropriate services (i.e. Early Intervention/Infant Learning Program, school districts, medical and other clinical providers).

Screening for ASD will identify those children who require a comprehensive assessment across developmental and physical domains. Professionals from multiple disciplines are needed to conduct a complete assessment (i.e. neurodevelopmental pediatrics, psychology, speech, occupational and physical therapy, ophthalmology, audiology). For young children it is especially critical to perform a differential diagnosis to rule out any other possible genetic or medical disorders.

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Early identification and diagnosis of ASD can lead to a better response to treatment and lifelong outcome for children.

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Assessment leads not only to diagnosis, but to a plan of intervention and services for the child and family.

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Currently few clinicians and specialists are skilled and trained in performing ASD assessments. Investing in training and developing specialists in ASD will reduce the time between screening and a comprehensive assessment, as all testing needs to occur before a definitive diagnosis can be made.

The comprehensive assessment leads not only to diagnosis, but to a plan of intervention and services for the child and family. Families need information and active referral to link up with needed health, educational, financial and family support resources.

4. **Change Medicaid to ensure that children with ASD are able to receive time-limited, intensive intervention services.**

The Deficit Reduction Act permits flexibility within state Medicaid plans. It is recommended that the Medicaid State Plan be modified to include time-limited autism intervention services. If modifying the Alaska Medicaid Plan is not feasible, the Committee recommends that the state develop an Autism waiver modeled after Minnesota or Wisconsin. A third alternative would be to change eligibility within the Home and Community Based Waiver to ensure children with ASD receive time-limited intensive services.



## Introduction Autism Spectrum Disorder

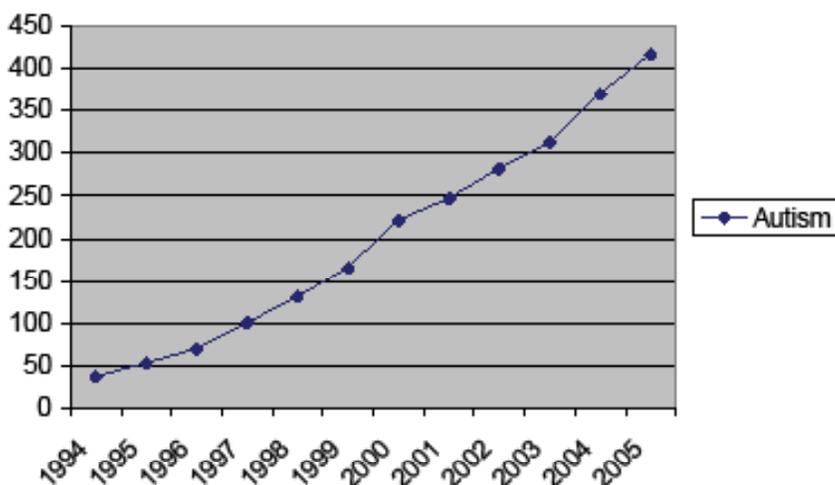
Autism is a complex developmental disability that is the result of a neurological disorder affecting the functioning of the brain (Autism Society of America). Autism Spectrum Disorders (ASD) includes Autistic Disorder, Asperger's Syndrome, Pervasive Developmental Disorder – Not Otherwise Specified, and Childhood Disintegrative Disorder. Studies have produced varying prevalence rates, in part due to method of diagnosis and size of the sample; however, 1 in 166 children are thought to have an Autism Spectrum Disorder (Centers for Disease Control and Prevention, n.d.). Each year about 10,000 babies are born in Alaska, suggesting that 60 of those babies will be identified in their early childhood as having an ASD. Another indicator that Autism is climbing in

Alaska comes from the public school system. The number of children with autism in the Alaskan School system has risen each year for the past 13 years. These trends are similar in other states.

### Growth of the Number of Cases of Autism in Alaskan Schools

ASD covers a wide range of symptoms, from very mild to severe. ASD affects social skills, communication, and cognitive development. ASD affects the individuals' ability to convey or interpret others emotions. Children may engage in restricted and/or repetitive play and have

**Children with Autism in Special Education**



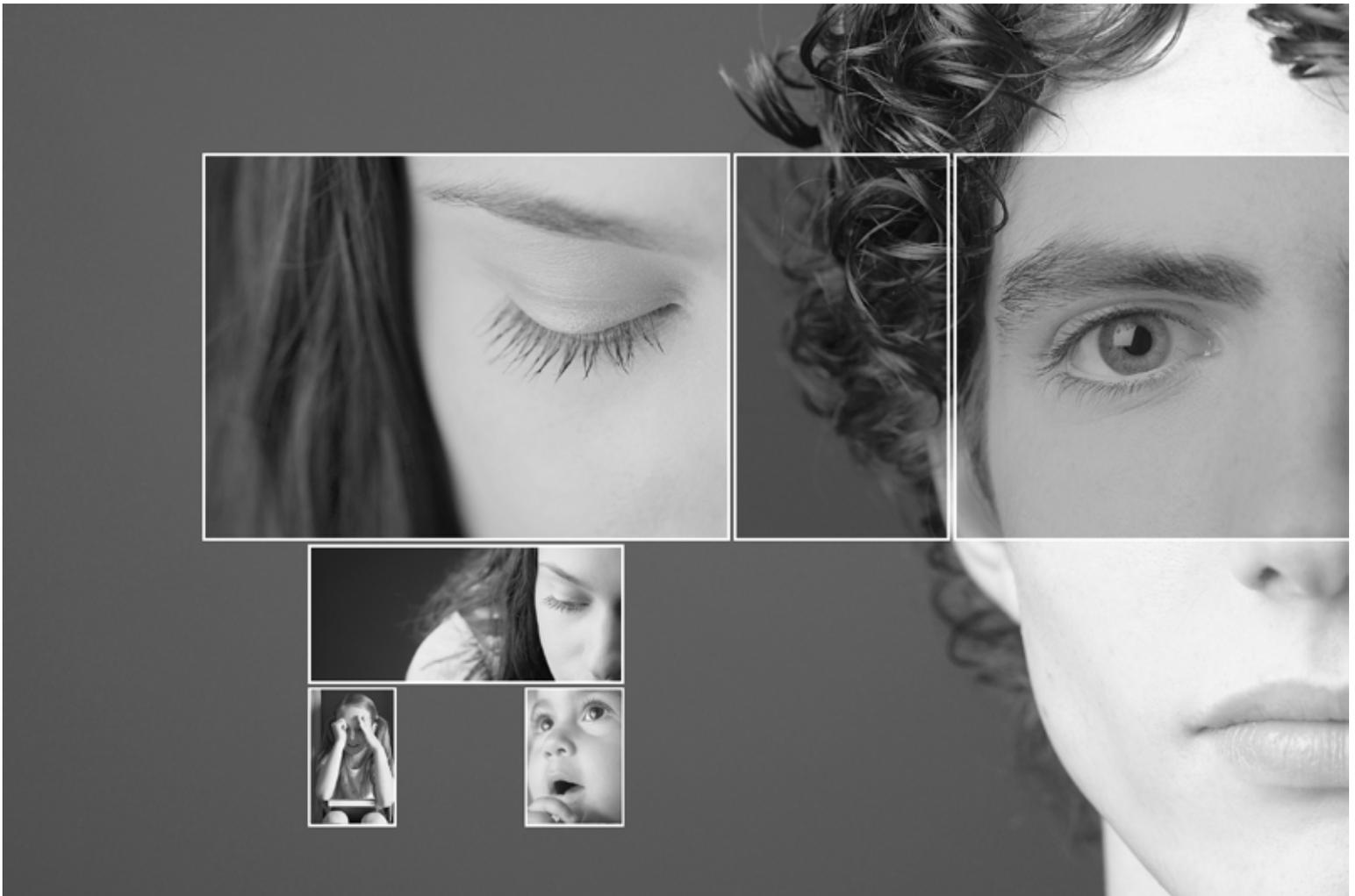
# Introduction cont...

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Some individuals with ASD may be nonverbal, while others may not have any difficulty speaking.

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unusual attachments to objects. People with ASD might not seem interested in other people and prefer to be alone. Some children with ASD do not like to be held or cuddled, and many do not make eye contact with others. Individuals with ASD also show varied degrees of impairment in their verbal and nonverbal communication. Some individuals with ASD may be nonverbal, while others may not have any difficulty speaking. Some repeat something previously heard or use stock phrases or learned scripts to communicate. Cognitively, individuals with ASD develop differently from others. Many people with ASD have difficulty processing sensory stimuli and verbal input, and this affects their understanding of the world around them.





## Ad hoc Committee on Autism

On December 6th 2005, the Governor's Council on Disabilities and Special Education's convened an Ad Hoc Committee on Autism. The purpose of this group was to examine the current status of services needed by people with ASD and their families and make recommendations to the Legislature and state policymakers. The 17 member committee consists of parents of children with ASD, Governor's Council members, and representatives from the Department of Health & Social Services, Division of Senior and Disability Services, Division of Behavioral Health, Department of Education & Early Intervention, Office of Children Services, and the University of Alaska Anchorage. The Committee met monthly over the course of five months. This report contains the recommendations of the Governor's Council and the Ad hoc Committee on Autism.

The report is organized around the following three major areas: Values and Principles, Identification/Screening/Diagnosis, and Services. Topics are prefaced with a summary of the Committee's evaluation of Alaska's current status and followed by recommendations.



# Values and Principles

The following statements articulate the values that guided the Committee's work and recommendations.

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**Early intervention works, is cost-effective and fiscally responsible.**

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## **People with Autistic Spectrum Disorders:**

- Have great promise, gifts and potential;
- Deserve the opportunity to engage actively in the community, with friends and family and in work and volunteer positions;
- Contribute to their families, communities, and Alaska;
- Represent ethnic, socioeconomic, racial, and religious groups, speak many languages and live in urban, rural and remote areas of the state; and
- Are people first – ASD is only a part of who they are.

**Early intervention works, is cost-effective and fiscally responsible.**

## **Services for people with ASD need to be:**

- Individualized, based on family choice and need;
- Family directed, and based on principles of self-determination;
- Evidence-based;
- Provided as soon as possible after identification and diagnosis;
- Culturally appropriate and relevant, available in urban and rural areas;
- Coordinated, comprehensive and collaborative across all disciplines and state service systems;
- Available across the lifespan, and the full spectrum of autistic disorders;
- Delivered in a manner that maximizes independence by providing the supports and services needed; and
- Built on and honoring of individual strengths.



## Identification and Diagnosis

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The importance of early identification and diagnosis of individuals with autism cannot be overstated.

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The importance of early identification and diagnosis of individuals with autism cannot be overstated. Early identification and diagnosis of autism leads to early intervention. Children with autism identified early and enrolled in early intervention programs show significant improvements in their language, cognitive, social, and motor skills, as well as in their future educational placement (National Research Council, 2001). There is also empirical evidence that shows children who enter early intervention at younger ages show greater results than children who enter intervention programs at an older age (Harris & Handleman, 2000; Sheinkopf & Siegal, 1998). There is also a financial incentive for the early identification, diagnosis, and intervention for children with autism. Ninety percent of children with autism who do not receive effective early intervention will require special or custodial care throughout their lives, and this is estimated to cost the United States \$35 billion dollars a year (Ganz, 2006).

### Where we are now

For the past 14 years, the Children's Hospital at Providence has supported the Center for Children with Special Needs, staffed with a neurodevelopmental pediatrician skilled in the diagnosis of children with ASD and other developmental disabilities. In addition, the State of Alaska sponsors neurodevelopmental screening clinics in locations around the state. However, despite Child Find efforts on the part of early intervention and school districts, not all children with significant developmental delays

# Identification and Diagnosis Cont...

are referred for a neurodevelopmental evaluation prior to entering school. Children residing in more remote, rural locations may be identified later than children in communities in more urban settings. Accurate identification of the child's pattern of development/learning style and behavior (i.e. autism diagnosis) leads to an appropriate school certification and program as well as an approach to solving behavior problems. Families living outside of Anchorage with children who are suspected of having autism frequently must wait for an appointment and then travel to Anchorage for a medical work-up and diagnosis.

The current definition used by Alaska's Department of Education & Early Development to determine eligibility is also an obstacle for the provision of special education services for students with ASD. This definition includes Autism, but not the other disorders in the spectrum. This committee proposes a definition that includes Pervasive Development Disorder, Asperger's Syndrome, and Childhood Disintegrative Disorder.

Currently there is not an accurate count of persons with ASD in the state. This adds to the difficulty of planning and securing resources for statewide autism services. This affects people with autism, their families, state and local governments, school districts, and federal agencies. Having hard data on autism in the state will provide a comprehensive information resource that can direct state policies and service decisions that will improve the lives of people with ASD and their families. Autism registries have already been shown to be effective for planning and providing services in the states of Missouri, Virginia, West Virginia, Florida, and Delaware. An autism registry will also facilitate early detection and diagnosis of people with autism.

## Identification and Diagnosis Recommendations

1. **Establish universal screening for autism spectrum disorders, using a tool such as the parent-completed Modified Checklist for Autism in Toddlers (M-CHAT), and provide systematic referral for a comprehensive assessment for children with positive screens.**

Screening is a quick, simple and inexpensive process to identify children who have symptoms that could indicate a disorder. Like hearing or vision problems, early identification and diagnosis of ASD can lead to a better response to treatment and lifelong outcome for children. Universal screening of children at well-child exams is

# Recommendations Cont...

recommended to ensure that children with ASD are identified as early as possible in life. The M-CHAT is a 23-question, parent-completed survey that can be used at well-child check-ups and is valid for children between the ages of 16 and 36 months.

Screening does not take the place of a comprehensive assessment; rather it identifies those children who would benefit from a complete evaluation. The next step for children who show possible signs of an ASD is to refer them to early intervention or the school district where the process of a developmental assessment can begin. A protocol for children with risk factors for ASD should be developed to ensure they are referred for further testing and a comprehensive developmental assessment.

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Children who appear at risk of having an ASD require a comprehensive assessment across developmental and physical domains.

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- 2. Increase the diagnostic capacity throughout the state by developing a system to provide timely, comprehensive diagnosis of Autism Spectrum Disorders using a multidisciplinary team and systematic referral to appropriate services (i.e. Early Intervention/Infant Learning Program, school districts, medical and other clinical providers).**

Children who appear at risk of having an ASD require a comprehensive assessment across developmental and physical domains. Professionals from multiple disciplines are needed to conduct a complete assessment (i.e. neurodevelopmental pediatrics, psychology, speech, occupational and physical therapy, ophthalmology, audiology). For young children it is especially critical to perform a differential diagnosis to rule out any other possible genetic or medical disorders.

Currently few clinicians and specialists are skilled and trained in performing ASD assessments. Investing in training and developing specialists in ASD will reduce the time between screening and a comprehensive assessment, as all testing needs to occur before a definitive diagnosis can be made.

The comprehensive assessment leads not only to diagnosis, but to a plan of intervention and services for the child and family. Families need information and active referral to link up with needed health, educational, financial and family support resources.

- 3. Expand the educational definition of autism to include all disorders in the Autism Spectrum Disorder. See Appendix A for recommended definition language.**

The current definition of autism used by the Alaska  
Department of Education &

# Recommendations Cont...

Early Development to determine the eligibility is restrictive, including Autism Disorder, but not other disorders in the spectrum. The Committee recommends a definition that includes Pervasive Development Disorder, Asperger's Syndrome, and Childhood Disintegrative Disorder.

It is important to define ASD broadly so that students receive an appropriate education. Some children with ASDs are incorrectly categorized as emotionally disturbed resulting in educational programs that disregard the neurological basis for the disorder, and instead treat the child as though they had a behavioral condition. Children receiving proper services are more likely to achieve better outcomes and exit the special education system earlier. A broad definition benefits the State by reducing costs, and providing more accurate data.

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Children receiving proper services are more likely to achieve better outcomes.

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4. **Establish and maintain a statewide autism registry or surveillance program.**

Alaska does not have a reliable way of assessing the number of individuals in the state with ASD. Having valid statistics on the prevalence of ASD in Alaska is critical to understanding trends, planning and developing programs to meet the educational and lifelong needs of individuals with ASD, future budgeting, and ensuring adequate numbers of people trained to provide specialized services. By understanding the prevalence of autism in Alaska, we will be better prepared to garner financial support from many sources to help Alaskan children and adults with ASD. The data collected will also allow our state legislature and school districts to better plan for growing needs for Alaskan's with autism.

5. **Develop capacity to diagnose Asperger Syndrome in older children and adults.**

Unlike other ASDs, Asperger Syndrome is typically not diagnosed in early childhood, but rather when the child is in school or even as an adult. A multidisciplinary team familiar with the features of Asperger Syndrome is needed to do an adequate assessment. Components of this assessment include taking a physical and developmental history, and conducting communication and psychological evaluations. Results of the evaluation need to be translated into a coherent picture and communicated to the child's family or the adult.



## Service

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There is a critical shortage of services for people with ASD in the state.

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There is a critical shortage of services for people with ASD in the state. Reasons for this include an inadequate workforce, lack of evidence-based intervention programs within the state, especially for young children, and a need for more training for all those who work or come into regular contact with individuals with ASD. The lack of services influences the quality of the medical, dental, educational, and treatments offered to people with autism. Without these services, especially in the early childhood years when intervention can dramatically affect long-term outcomes, individuals with ASD and their families will fail to reach their potential, be less self-sufficient and more reliant on state-funded services, and unable to fully contribute as a citizen.

### Where we are now

Providing medical and dental care for individuals with autism can be complicated. The most common medical problems linked with autism are seizures, accidents and injuries, infections, dental problems, and nutritional issues (Volkmar, 2000). Pediatricians are located only in urban areas of the state or on an itinerant basis to hub communities. Smaller communities may be served by family practice physicians, nurse practitioners, or physician assistants while remote areas of the state are most commonly served by community health aides and practitioners. While pediatricians in particular are familiar with autism, many families are unable to access a medical provider who can advise them about the treatment options families may learn about. As many of these treatment options are controversial, having a

medical provider knowledgeable about the current status of autism treatment, would guide families in making informed decisions.

There are a number of evidence-based educational interventions used throughout the country. In Alaska, educational services are provided by the Early Intervention/Early Intervention/Infant Learning Program (EI/ILP) for children birth to three, and by school districts for children from 3 to 18 or 22, depending on the student's Individual Education Plan. The EI/ILP delivers services in the family's home. An early interventionist, early childhood special education teacher, speech therapist, physical therapist, occupational therapist and/or paraprofessional supervised by an early interventionist work with families to teach them ways to enhance their child's development. School districts serve children and youth with ASD through their Individual Education Plan, which outlines the goals and services to be delivered. A statewide assessment of school districts' educational programs for students with ASD has not been conducted. However, nationally-recognized intensive intervention programs designed specifically for individuals with ASD, such as applied behavioral analysis, floor time, and TEACCH (Treatment and Education of Autistic and related Communication Handicapped Children) are largely unavailable to families unless they are able to pay for the services of a consultant outside the state. The Anchorage School District does provide some specialized classrooms for children with ASD.

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Since individuals with ASD have different needs and abilities, providing a range of evidence-based treatments is extremely important.

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This is a critical aspect of autism services because the major treatment for autism is early and ongoing educational intervention. Presently, there are some limited and inconsistent services provided by school districts, private and home programs. Most school districts do not have the capacity to provide intensive interventions for students with autism. Part of the problem is that in both the rural and urban parts of the state, there is difficulty in the recruitment and retention of staff experienced with autism. The intensive, one-on-one nature of many interventions is prohibitively expensive for many school districts. There is also currently a limited amount of time provided for extended school year services. These services may be provided by the school district to some children with developmental disabilities who regress when not in school and are offered during regular school breaks. When extended school year services provided by school districts, some children with autism behaviorally and cognitively regress.

Providing effective autism treatments is found to be deficient in Alaska. Since individuals with ASD have different needs and abilities, providing a range of evidence-based treatments is extremely important. Many parents are forced to go out of state and spend a lot of

money to get the services their children need. There are currently pockets of well-trained professionals providing autism related services in Alaska, but they are mostly clustered in the major urban centers. In Alaska, Medicaid does not reimburse for intensive behavioral treatment as a medical service. Intensive behavioral treatment is an important component of autism treatment.

A contributing factor to the lack of treatment and services for individuals with Autism Spectrum Disorders, is an inadequate level of training, resources and support for professionals and parents. More in-state training is needed, especially due to the high turnover rate in the direct service field and in school districts throughout Alaska.

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More in-state training is needed.

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## Service Recommendations

### Medical Services

#### 1. **Expand specialty clinics at hospitals for individuals with autism.**

Medical services are critical because children with ASD are more likely to develop certain medical conditions such as seizures, accidents and injuries, infections, and dental and nutritional problems. This committee recommends that medical services be expanded to include consultation with the child's or adolescent's primary care provider and other service providers. Families and providers often need advice on such issues as medication, toileting, sleep disturbances, behavior and aggression, self-injurious behaviors, motor tics, social skills, and others.

#### 2. **Amend Medicaid regulations to ensure reimbursement for evidence-based medical interventions and psychological assessments and interventions. Currently only psychologists working in mental health clinics or under the supervision of a psychiatrist are allowed to bill Medicaid.**

School districts perform psychological evaluations every three years. Because children develop rapidly in the early years, a new evaluation is typically needed to complete an assessment. Child psychologists are uniquely qualified to perform cognitive and adaptive behavior skills, and this is an important element of the diagnostic process. Adding psychology services for Medicaid recipients would alleviate this problem.

# Service Recommendations Cont...

### **3. Develop the capacity of medical providers to work successfully with individuals with ASD.**

Increasing the capacity of medical providers to work with individuals with ASD is essential to providing quality health and dental care for the ASD population. Communication and behavior problems as well as unusual and unpredictable response to stimuli complicate medical and dental care. Specialized training and skills will help medical and dental professionals provide quality care for those with ASD in Alaska.

The Committee recommends that training on ASD be provided at medical conferences in Alaska.

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There is strong evidence supporting the validity of intensive early intervention beginning as early as possible after diagnosis.

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## **Educational Services**

### **1. Adopt best practice guidelines and set measures of effectiveness of educational services for children with ASD.**

The National Autism Center is developing national standards for the treatment of ASD. Using evidence-rating criteria the Center will produce a set of national research-based standards for education and behavioral intervention for children with autism. The Committee recommends that Alaska adopt best practice standards, based on national standards, for interventions and educational services provided to individuals with ASD in Alaska.

### **2. Provide adequate funding to establish intensive early intervention services for children with autism through the Early Intervention/Early Intervention/Infant Learning Program, Head Start and school district preschool programs.**

Intensive early intervention has been documented to be an effective intervention for children with ASD (Dawson & Osterling, 1997; Green, 1996). Although the specific intervention models are a source of controversy, there is strong evidence supporting the validity of intensive early intervention beginning as early as possible after diagnosis (Sheinkopf & Siegel, 1998).

Children under three with developmental delays are served by the Early Intervention/Infant Learning Program. Some children receive a diagnosis of ASD before their third birthday and will begin receiving services through this program. Families receive periodic home visits

# Service Recommendations Cont...

from an early intervention specialist, based on the child and family needs. Eligible three to five year old children attend public preschool or Head Start programs.

### **3. Adequately fund and provide appropriate intensive interventions based on best practices to children with ASD in the educational system.**

Currently, schools provide either limited or no ASD-specific intervention programs for children qualified to receive special education. Rather than endorsing a specific model, the Committee recommends that evidence-based models for ASD intervention become available in the educational system. Families need to be provided a choice of models and an opportunity to decide which approach will best meet their child and family's needs. Interventions require a time and lifestyle commitment from the families.

### **4. Enlist Alaska's universities' support and collaboration in developing certification and degree programs for students interested in specializing in autism interventions.**

The University of Alaska system and the small number of private colleges in the state are a resource that can be used to help develop the workforce needed to provide effective services for individual with ASD. Education, Special Education, Social Work, and Psychology degree programs, with a certification in autism interventions can help alleviate the current shortage of qualified personnel. The University of Alaska Anchorage also has the Washington, Wyoming, Alaska, Montana, and Idaho (WWAMI) Biomedical program affiliated with the University of Washington School of Medicine. This program can be used to increase the number of medical doctors in state who specialize in diagnosing and treating children with ASD.

### **5. Build capacity for all early intervention and childcare programs, and school districts, to adopt evidence-based, non-aversive behavioral interventions, such as positive behavioral support and best practice interventions with proven outcomes.**

Challenging behaviors often accompany ASD. When individuals are limited in their communication skills, they may use behaviors as a way to let others know what they want and need. Positive behavior support helps adults decipher the communication intent of behavior, and teaches alternative ways individuals can express themselves. Programs that serve children with

ASD need training and tools for helping the adults better support the communication

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Research has documented the efficacy of early, intensive intervention (Sheinkopf and Siegel, 1998, Dawson and Osterling, 1997).

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# Service Recommendations Cont...

and behavioral needs of students with ASD.

Children with ASD present unique and difficult needs that require specific skills from teachers and education professionals. Currently, no specific certification in ASD interventions for teachers and educational professionals exists in the state.

- 6. Investigate amending Medicaid regulations to allow reimbursements to districts for school-based intensive autism interventions to Medicaid eligible students.**

About half of Alaska's children are Medicaid eligible. Adding intensive intervention for ASD as a Medicaid service would permit the state to collect federal funds to help cover the expense. Shifting some of the cost of intervention would permit school districts to use their funding to reach non-Medicaid students as well.

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Children with ASD present unique and difficult needs that require specific skills from teachers and educational professionals.

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## Home and Community-Based Services

- 1. Change Medicaid to ensure that children with ASD are able to receive time-limited, intensive intervention services.**

The Deficit Reduction Act permits flexibility within state Medicaid plans. It is recommended that Alaska modify their Medicaid Plan to include time-limited autism intervention services. If modifying the Alaska Medicaid Plan is not feasible, the Committee recommends that the state develop an Autism waiver modeled after Minnesota or Wisconsin. A third alternative would be to change eligibility within the Home and Community Based Waiver to ensure children with ASD receive time-limited intensive services.

- 2. Provide supplemental grant funding for providers to offer treatment services for individuals with autism who are not eligible for Medicaid or meet level of care.**

Not all individuals with ASD meet level of care requirements for a Medicaid Home and Community-based waiver or TEFRA, but would benefit from intervention. The DD grant program supports individuals with developmental disabilities who are not eligible for a waiver. Additional funding in the DD grant program would help meet the needs of children and adults with ASD.

# Service Recommendations Cont...

## **3. Bring training on diagnosis and interventions to Alaska.**

Alaska faces a shortage of clinically trained personnel experienced in performing diagnostic assessments and follow-up treatment. The Committee recommends improvement in the availability and expertise of these specialists to assess and treat ASD. Very few psychologists in Alaska are experienced in administering assessment tools for autism and evaluating the results, especially for young children.

Several University-based Autism centers provide training that, if brought to Alaska, would expand statewide capacity for timely and accurate diagnosis and appropriate intervention.

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Bring training  
on diagnosis and  
interventions to Alaska.

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## **4. Change Medicaid regulations to provide reimbursement for autism treatments as a medical service.**

Although research has shown promising results stemming from autism interventions for some individuals with ASD, there are significant differences in the costs, degree of family involvement required, availability, and content and structure of these programs. The Committee believes a continuum of intervention options should be available and billable through Medicaid. Such interventions may significantly reduce the lifetime cost of care for individuals with ASD.

## **5. Remove licensing barriers that prevent out-of-state autism specialists from practicing in Alaska.**

Out-of-state autism specialists would help provide quality treatment for those with ASD in Alaska. Current state licensure and billing regulations that prohibit out-of-state health providers from practicing in the state need to be reviewed and revised so they may provide services for individuals with ASD in Alaska.

## **Parent Training**

- 1. Greatly expand services offered through an autism resource center, so that it is well funded, independent, and highly visible with a long-range plan for satellite programs throughout the state.**

# Service Recommendations Cont...

Several activities are envisioned to expand the functions of an autism resource center. These include:

- An annual comprehensive fair/institute for families to provide up-to-date medical information, guidance in navigating the system, and other topics. Disseminate the institute through a CD or a webcast for people who cannot attend in person;
- The establishment of local resource centers across Alaska that are independent in nature, but collaborative with other providers, and state/local/national experts;
- Training for parents in systems advocacy/political advocacy;
- Regional, technical assistance traveling teams with professional oversight; and
- Comprehensive parent training in education, systems advocacy, guardianship, medical services, and other topics as needed.

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There is a critical shortage of staff to work directly with individuals with developmental disabilities.

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## Service Provider Development

- 1. Fund and deliver training to develop qualified staff who will provide evidence-based autism treatment services in home, child care and community-based settings.**

There is a critical shortage of staff to work directly with individuals with developmental disabilities. The failure to provide evidence-based services to children and adults with Autism Spectrum Disorders impedes their development and limits their potential over their entire lifetime. Training is inadequate for those who provide care to individuals with Autism Spectrum Disorders.

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# APPENDIX A

## PROPOSED DEFINITION OF AUTISM FOR THE DEPARTMENT OF EDUCATION AND EARLY DEVELOPMENT

### 1. Autism Spectrum Disorders (ASD)

*To be eligible for special education and related services as a child with ASD, a child must:*

- a. exhibit a developmental disability significantly affecting verbal and non-verbal communication and social interaction, generally evident before age three, that adversely affects educational performance; and
- b. require special facilities, equipment, or methods to make the child's educational program effective; and
- c. be diagnosed as having an autism spectrum disorder by a psychiatrist, physician, or psychologist; and
- d. be certified by a group consisting of qualified professionals and a parent of the child as qualifying for and needing special education services.

#### **Characteristics of ASD include:**

- Irregularities and impairments in communication
- Engagement in repetitive activities and stereotyped movements
- Resistance to environmental change or change in daily routines
- Unusual responses to sensory experiences

A child who manifests the above characteristics after age 3 may also be diagnosed as having autism spectrum disorder.

A child who is diagnosed as having Asperger's Syndrome or Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS) and who manifests the above characteristics may be found eligible for special education under the category of ASD.