Focus: Children and Youth With Special Health Care Needs (CYSHCN)
Children & Youth With Developmental Delays

"The early years of a child's life are crucial for cognitive, social and emotional development. Children who grow up in environments where their developmental needs are not met are at an increased risk for compromised health and safety, and learning and developmental delays … with long term effects on the foster care, health care, and education systems."[1] *--- Centers for Disease Control and Prevention*

Social and emotional, cognitive and language developmental milestones for children 3 months to 5 years of age have been developed to track the progress of children's growth. The 2007 National Survey of Children's Health has several questions relating to child development.[2]

National Survey of Children's Health (2007): Alaska's Profile

Indicator	%	Est. #
• Children age 4 mos to 5 yrs whose parents have 1 or more concerns about child's development	39.3%	23,172
• Children age 4 mos to 5 yrs who are at high risk for developmental, behavioral or social delay	10.1	5,936
• Children age 6-17 who consistently exhibit problematic social behaviors	7.0	8,429
• Children age 2-17 who currently take medication because of difficulties with emotions, concentration or behavior	5.0	7,969
• Children age 10 mos to 5 yrs who had a health care visit during the previous 12 mos that included developmental screening	20.7	10,172
• Children age 6-17 who have ever repeated a grade in school	6.7	8,020

The **Individuals with Disabilities Education Act (IDEA)** governs how states and public agencies provide early intervention, special education and related services to eligible infants, toddlers, children and youth with disabilities. Infants and toddlers with disabilities from birth - 3 years receive early intervention services under IDEA Part C while children and youth ages 3-21 receive special education under IDEA Part B. In Alaska, the Early Intervention/Infant Learning Program partners with grantees throughout the state to provide services for families of children age birth to 3 with special needs within the family's home area by using direct service staff in the community or itinerant staff from hub services. Among mothers who were surveyed by CUBS, 10.3% reported their 3-year old receiving Early Intervention or Infant Learning Program (ILP) services.[3] In 2008, ILP served 3,097 children.[4]

What Types of Services Are Used by Alaska Families for their 3-year Olds?[3]

Hearing Specialist	12.1%
Speech or Language Therapist	7.2%
Eye Specialist	6.9%
Physical Therapist	4.5%
Behavioral or Mental Health Specialist	1.1%

- In 2000, the percentage of children receiving at least one initial or periodic **well-child screening** was 82% for infants; 48% for children 1-5 years; and 18% for children 6-9 years. There are no indicators regarding type and depth of developmental screening.[5]

- The **Early Childhood Comprehensive Systems (ECCS)** is a framework for delivering services to families with young children ages birth through 8. The Dept of Health & Social Services, Office of Children's Services, developed an ECCS Plan that focuses on four areas: medical homes; social, emotional and mental health; early care and learning; and family support. The plan contains many process objectives to promote comprehensiveness and integration of programs that are delivered by many different organizations and funded by many different sources.[6]
- **Bright Futures** is a national initiative launched by the US Health Resources and Services Administration to promote and improve the health and well-being of infants, children and adolescents. Its centerpiece are guidelines that provide child health promotion information and guidance to health professionals.[7] Bright Futures information is offered through the Alaska WIC Office.

The federal Maternal and Child Health Bureau defines children and youth with special health care needs (CYSHCN) as

> *"those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally".*[8]

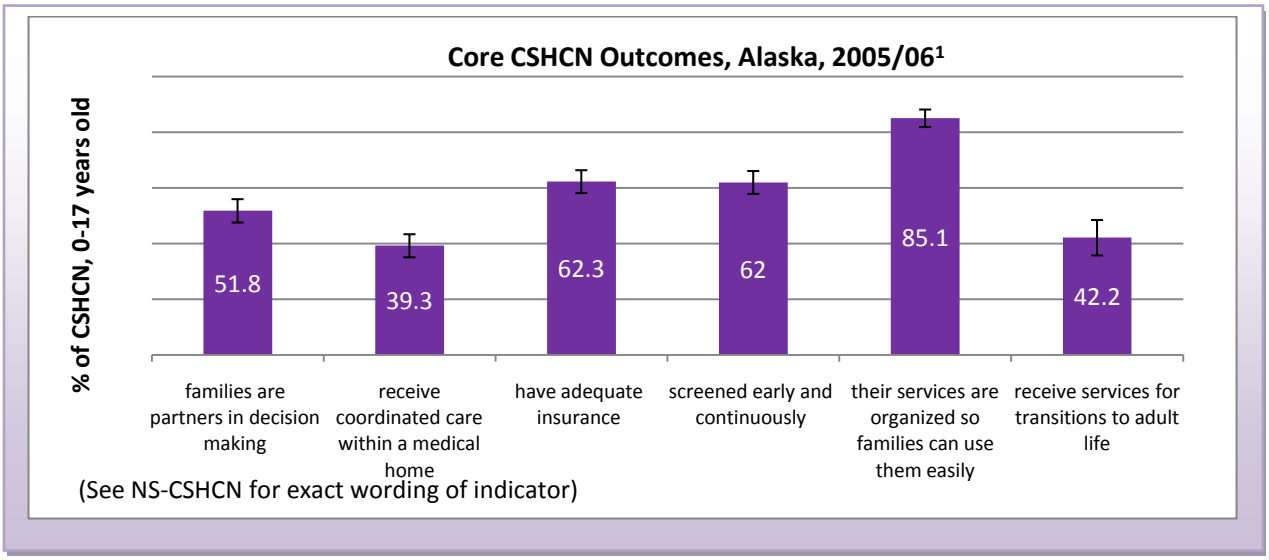
The National Survey of CSHCN estimates that CYSHCN are about 14% of the child population, CYSHCN account for 40% or more of medical expenditures for children overall.[8] In Alaska, approximately 12% of children 0-17 years are estimated to have special health care needs. The highest prevalence is among the 12 - 17 age group (14.6%).[8]

The health of the families of CYSHCN are significantly challenged with the near overwhelming daily time demands of children with these chronic conditions, accessing therapies and interventions for care, the large expense, and emotional toll that affects the quality of family life.

- The State of Alaska includes parents of children with chronic conditions such as asthma, cancers, cystic fibrosis, epilepsy, allergies, and diabetes in all planning and discussion of infrastructure development. Managing and supervising the care of chronic conditions in school children represents a significant work load for school nurses, where one is available.

How does Alaska compare to the US on core outcomes?

According to the 2005/06 National Survey of CSHCN (NS-CSHCN), Alaska is lower than the national average on two of the six core CSHCN outcomes - CSHCN whose families are partners in decision-making at all levels and who are statisfied with the services received, and CSHCN who receive coordinated care within a medical home.



How Does Alaska Track and Serve CYSHCNs ?

A mix of legislation, improved technology and federal and state funding enables several state agencies track and serve children with special health care needs with screening and surveillance programs.

The **pediatric neurodevelopmental clinics** are currently held in Fairbanks, Juneau, Barrow, Nome, Kotzebue, Bethel, Dillingham, Kodiak, Soldotna/Homer, and Ketchikan. The trainings and information sharing during site visits have greatly expanded autism outreach efforts. Some families, especially those from Southeast Alaska, prefer to go to Seattle Children's Hospital for screenings and diagnosis. Most families prefer to stay in their home community for intervention and therapeutic services. The clinic is primarily focused on autism, screens for all pediatric neurodevelopment needs. Providers recommend treatments, interventions, or additional testing.

The **autism and parent services program** is considering an improved tracking system for autism spectrum diagnosis in Alaska. The state has contracting with the University of Alaska, Anchorage, Center for Human Development , to conduct workforce development for service delivery to CYSHCN. The Section of Women's Children's and Family Health is considering an autism surveillance system

The **cleft lip and palate clinic** is held several times a year. During the clinic, a multi-disciplinary team conducts the child examination and family consultation at a central location. The team approach results in better coordination among the providers and less confusion for the family to following up on treatment recommendations.

The **metabolic and genetic clinics** are held throughout the state. Families receive medical and genetic evaluations, children are seen for diagnosis and on-going treatment recommendations, and a genetic counselor is available to help the family understand long-term outcomes and potential for similar outcomes in other children.

The **Early Hearing Detection and Intervention** (EHDI) program has achieved nearly 100% screening of in-hospital births and significantly improved the rate of out-of-hospital birth screening. Faithful and accurate use of the

electronic tracking system by providers and program staff is key to achieving a smooth tracking, follow-up and referral process. The **Newborn Metabolic Screening Program** (NBMS) achieved a 100% screening rate in 2008 and a 100% rate of screen positive newborns who receive timely follow-up.[9] The prevalence of CPT-1 metabolic disorder is high among the Alaska Native population. Although the outcomes are serious, the condition responds very well to treatment, so early detection and parent education is essential.

What We Achieved With Data Integration:
- Improves follow-up rate
- Allows multiple providers access to the same comprehensive set of information on the baby
- Creates a foundation for a medical home
- Helps in coordinating follow-up and care

- The EHDI and NBMS programs have an integrated electronic database to improve coordination of services.
- The state sponsors Cleft Lip and Palate Clinics and Neurodevelopment Clinics to make up for the lack of private sector services. These clinics are held in the larger communities around the state. Some families prefer to go Outside for services.
- The majority of recently confirmed cases of CPT-1 are found in the Alaska Native population. The MCH-Epidemiology Unit received a grant to collaborate with geneticists, AK physicians and the AK Native Tribal Health Consortium to determine the significance of these findings.
- Special challenges in delivering services reflect the geographic nature and the diversity of the population of the state.
- Strengths common to the EHDI and NBMS programs are the excellent collaboration/communication among professionals, and the assistance of parent navigators through the Stone Soup Group. The pediatric neurodevelopmental clinic is following the model of EHDI and NBMS by building a reputation of collaboration and communications among agencies in order to decrease the siloing effect and make service delivery more transparent for the families.
- Continuing education to providers, staff and parents is always needed.

Challenges in delivering services:
- lack of specialists in the state
- difficulty in serving rural families with direct care and medical supplies
- difficulty in follow-up with sub-populations who do not support or want services
- ability to address issues beyond the immediate medical need, such as long term education, financial and legal issues
- this is not a complete list!

- A new state demonstration grant is focusing on earlier diagnosis of autism and other neurodevelopmental needs. An earlier intervention by the skilled EI/ILP, PHN, private therapies, and school-based Part B services is making a significant impact on the long-term outcome of CYSHCN. Earlier diagnosis is increasing referrals to the Infant Learning Program which was successful in acquiring additional resources for training, education, and direct service delivery.
- A major concern is transition of CYSHCN between service providers (Part B and C) and into the workforce.

Most birth defects are not preventable, but early diagnosis and treatment can be successful. **Fetal alcohol spectrum disorders** (FASD) are the second most common type of birth defect reported to the Alaska Birth Defects Registry.[10] As of April 2009, the prevalence of FASD for the 2000 - 2002 birth cohort was 16.9 per 1,000 live births, affecting 505 children. In 2007, 80% of women who recently had a live birth reported having been advised to

avoid alochol by their health care provider.[11] This rate has remained steady since 2004. Recent preliminary analysis of birth defects surveillance data indicate an increase in **neural tube defects** two years in a row, after many years of decline.[12]

- A comprehensive analysis of Alaska's birth defects surveillance data was published in 2006.
- Education on birth defects, including FASD prevention, occurs through the newsletter Alaska Birth Defects Monitor published by the MCH-Epidemiology Unit.
- The Arctic Fetal Alcohol Spectrum Disorders Regional Training Center is located at the University of AK-Anchorage campus and there are diagnostic teams in 13 communities. A diagnosis of FASD does not automatically qualify an individual for intervention services.
- The WCFH Perinatal Nurse Consultant includes these topics in her education messages to public and private health care providers and administrators, as well as to the Perinatal Advisory Committee.
- An affordable and effective home visitation program continues to be of interest.

In October 2009 new national prevalence estimates of autism spectrum disorders (ASD) were published. It is estimated that **ASD** occurs in 1 in 90 U.S. children ages 3 - 17 were given an ASD diagnosis in 2007[13] - that's about 1,814 Alaskan children.

- The Section of WCFH received a federal Combating Autism grant and hired an Autism and Parent Support Services Manager. The funds will be used to collaborate with partners to determine workforce development needs for early screening and training for intervention services, and raise awareness.

It is estimated that during 2002 - 2005, the prevalence of **attention deficit hyperactivity disorder** (ADHD) among Medicaid enrolled children 4 through 19 years old ranged from 3.5% to 4.1%, slightly lower than the 2003 national average. [14] Rural Alaska Native children and to a lesser extent rural children in general had a low ADHD prevalence. Other chronic conditions in children are not being tracked on a regular basis at this time.

Related Title V State Priorities, 2005 - 2010[15]

- Increase public awareness and access to health care services for children and CSHCN.

Related Title V State Performance Measures, 2005-2010[15]

#8. Prevalence at birth of Fetal Alcohol Spectrum Disorders (FASD), per 1,000 live births.*

Reporting Year	Birth Years	Rate	Number
2006	1997-1999	20.9	623
2007	1998-2000	21.9	654
2008	1999-2001	19.2	574
2009	2000 - 2002	16.9	505

* average age of diagnosis for FAS is 5-6 years.

Related Title V National Performance Measures, 2005-2010[15]

#1. The % of screen positive newborns who received timely follow up to definitive diagnosis and clinical management for condition(s) mandated by their State-sponsored newborn screening programs.

Year	Percent	Number
2005	92.6	25
2006	100.0	36
2007	100.0	44
2008	100.0	195

#12. % of newborns who have been screened for hearing before hospital discharge.

Year	Percent	Number
2002	65.4	6430
2003	80.8	8081
2004	87.3	8968
2005	90.5	9351
2006	90.4	9837
2007	95.3	9899
2008	97.7	10426

#17. Percent of very low birth weight infants delivered at facilities for high-risk deliveries.

Year	Rate	Number
2003	75.3	67
2004	74.8	89
2005	76.8	73
2006	78.1	96
2007	76.8	76

References:

[1] Centers for Disease Control and Prevention. [website] Child Development and Public Health. Accessed 9/28/09 from http://www.cdc.gov/ncbddd/child/development.htm.
[2] Child and Adolescent Health Measurement Initiative. National Survey of Children's Health, 2007. Data Resource Center on Child and Adolescent Health website. Retrieved 9/28/2009 from http://www.nschdata.org/.
[3] 2008 AK Childhood Understanding Behaviors Survey (CUBS)
[4] AK FY 2010 Title V Block Grant.
[5] Alaska Dept of Health & Social Services. Early Childhood Comprehensive Systems Plan.
[6] Office of Children's Services. [website] Early Childhood Comprehensive Systems. http://hss.state.ak.us/ocs/ECCS/default.htm
[7] Bright Futures. [website] http://brightfutures.aap.org/index.html
[8] Child and Adolescent Health Measurement Initiative. National Survey of Children with Special Health Care Needs, 2005-2006. Data Resource Center for Child and Adolescent Health website. Retrieved 9/23/2009 from www.nschdata.org.
[9] AK Newborn Metabolic Screening Program.
[10] Schoellhorn KJ, Beery AL. AK MCH Data Book 2005: Birth Defects Surveillance Edition. MCH-Epi Unit, Division of Public Health, AK Dept of Health & Social Services, May 2006.

[11] AK Pregnancy Risk Assessment Monitoring System.
[12] personal correspondence, Janine Schoellhorn.
[13] National Institute of Metnal Health. e-article: NIMH's Response to New Autism Prevalence Estimate. NIMH Update. Retrieved Dec.31, 2009 at http://www.nimh.nih.gov/about/updates/2009/nimhs-response-to-new-autism-prevalence-estimate.shtml.
[14] Alaska Dept. of Health & Social Services, Division of Public Health. Prevalence of Attention Deficity Hyperactivity Disorder Among Medicaid Recipients Less than 20 Years of Age. Epi Bulletin No. 33, November 5, 2007.
[15] State of Alaska, section of Women's Children's and Family Health. FY 2010 Title V Block Grant application.