

Alaska Children with Special Health Care Needs

Summary of Available Data

March 2017



Who are children and youth with special health care needs (CYSHCN)?

The federal Maternal and Child Health Bureau defines children with special health care needs 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.”

(U.S. Department of Health and Human Services, 2012)

This definition can include physical conditions, such as sickle cell disease or asthma. It also includes children with disabilities such as cerebral palsy, Down syndrome, autism, or children who are technology dependent.

The broad category of CYSHCN groups together children and youth with a variety of conditions because all of these children face common access, service and coordination challenges. Most CYSHCN require complex and long-term health services, face high costs of care, and experience disparities in access to needed care.

Unfortunately, data on CYSHCN are limited, both nationally and at the state level. This fact sheet was created by the Alaska Division of Public Health, [Section of Women's, Children's, and Family Health](#), to summarize data on Alaska CYSHCN from multiple data sources. Some define CYSHCN very broadly, such as the National Survey of Children with Special Healthcare Needs, while others provide information on children with very specific conditions or diagnoses.

National Survey of Children with Special Healthcare Needs

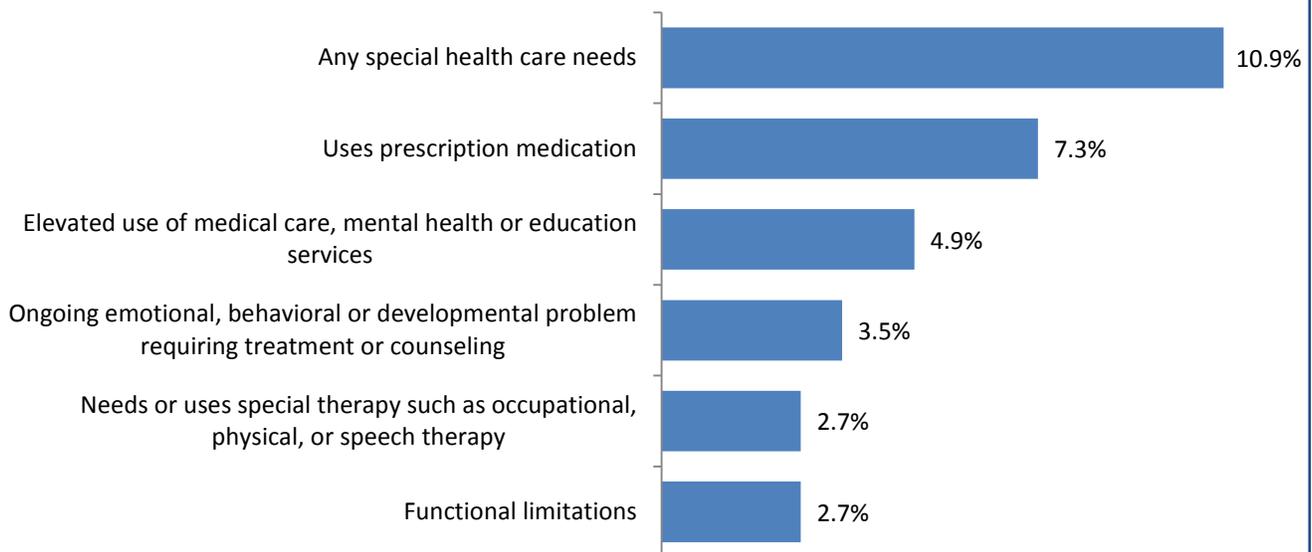
Much of what is known about CYSHCN comes from the [National Survey of Children with Special Health Care Needs](#) (NS-CSHCN), a random digit dial telephone survey that was last conducted in 2009-2010. According to the NS-CSHCN, approximately 10.2 million children in the U.S. – 15 percent of all people under the age of 18 – have special healthcare needs.

During 2009-2010, there were an estimated **19,916** children in Alaska with special health care needs. This was 10.9% of the Alaska population ages 0-17.

CSHCN qualifying conditions

The NS-CSHCN used a series of screening questions to identify children with special health care needs for the purposes of the survey. The following data describe the prevalence of children with each specific qualifying condition. About half (47.0%) of all Alaskan children with special health care needs qualified based on a single screener criteria, while 14.1% qualified on four or five criteria.

Prevalence of special health care needs due to a condition lasting 12 months or longer, among all Alaskan children ages 0-17, 2009-2010

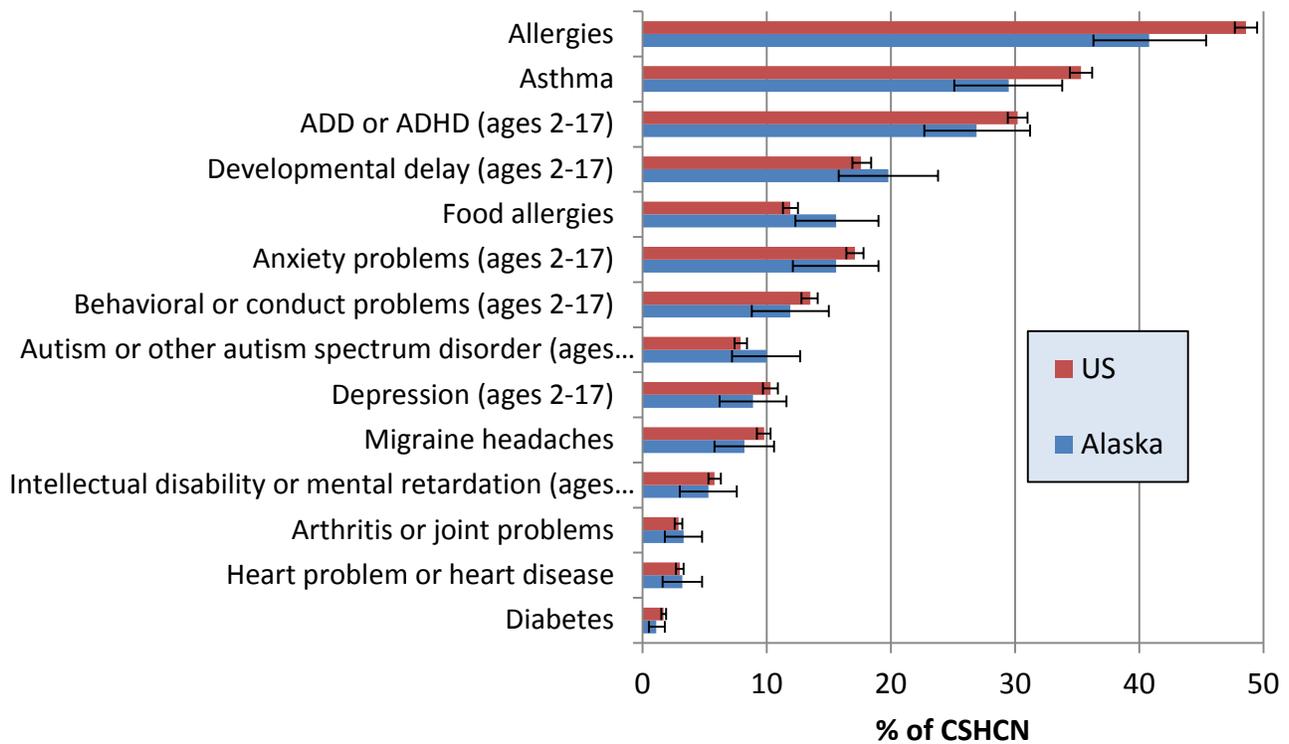


- 7.3% (13,411) of Alaskan children **used prescription medication** due to a health condition lasting 12 months or longer. 4.0% (7,243) qualified as a CSHCN based *only* on use of prescription medication.
- 4.9% (8,987) of Alaskan children had an **elevated use of medical care, mental health or education services** due to a health condition lasting 12 months or longer. 2.2% (3,952) had above-routine service use with no other qualifying needs.
- 3.5% (6,447) of Alaskan children had a special health care need that included an **ongoing emotional, behavioral or developmental problem** which required treatment or counseling.
- 2.7% (4,956) had a need for or used **special therapy** such as occupational, physical, or speech therapy due to a health condition lasting 12 months or more.
- 2.7% (4,936) had **functional limitations** due to a health condition lasting 12 months or longer.

Specific conditions

The survey asked about the presence of 20 individual chronic health conditions among CSHCN. The percent of Alaska CSHCN reporting allergies and asthma was significantly lower than the percent of all US CSHCN reporting these two conditions. For all other conditions asked about, the prevalence among Alaska CSHCN was statistically similar to that of US CSHCN. The estimates for the prevalence among Alaska CSHCN of cystic fibrosis, muscular dystrophy, Down Syndrome, cerebral palsy, brain injury or concussion, blood problems, and epilepsy or seizure disorder, was not reported due to being too small to meet standards for reliability or precision.

Percent of CSHCN ages 0-17 with specific chronic health conditions, U.S. and Alaska, NS-CSHCN 2009/10



Severity

Among Alaskan CSHCN:

- More than 1 in 4 (25.9%) had health conditions that consistently and often greatly **affect their daily activities** and 17.9% had 11 or more days of **missed school** days due to illness.
- More than 2 in 3 (67.5%) had a little or a lot of difficulty with 1 or more of the following **bodily functions**:
 - ✓ breathing or respiration,
 - ✓ swallowing or digestion,
 - ✓ blood circulation,
 - ✓ chronic physical pain including headaches,

- ✓ seeing even when wearing glasses or contacts,
- ✓ hearing even when using a hearing aid.

- Almost 2 in 3 (63.1%) had a little or a lot of difficulty with 1 or more of the following **activities**:
 - ✓ self care,
 - ✓ coordination or moving around,
 - ✓ using hands,
 - ✓ learning,
 - ✓ understanding or paying attention,
 - ✓ speaking,
 - ✓ communicating or being understood.
- Over half (57.4%) of those ages 18 months to 17 years had a little or a lot of difficulty with 1 or more of the following **emotional or behavioral factors**:

- ✓ feeling anxious or depressed,
- ✓ acting-out,
- ✓ fighting,
- ✓ bullying or arguing,
- ✓ making and keeping friends.

Urgency

Health Insurance Coverage

- At the time of the survey, 55.2% of Alaskan CSHCN had private insurance only, 26.3% had public insurance only (Medicaid/Denali KidCare or other public insurance), and 14.5% had a combination of public and private insurance.
- 3.8% of Alaskan CSHCN were **without insurance** at the time of the survey and 10.5% were without insurance at some point during the past year.
- 38.8% of currently insured Alaskan CSHCN **did not have adequate coverage**.

Access to Care

- 28.1% of Alaskan CSHCN had one or more unmet needs for specific health care services during the 12 months before the survey.
- Nearly 1 in 4 (22.7%) CSHCN needed specialty care and had a problem getting a referral, 10.5% did not have a usual source of care when sick (or relied on the emergency room), and 6.8% did not have a personal doctor or nurse.
- 8.0% of families of CSHCN had one or more **unmet needs for family support services** specifically because of their child's medical, behavioral or other health conditions. Family support services asked about on the survey included respite care, family genetic counseling, and family mental health care or counseling.

Impact on Family

- Families of 23.6% of Alaskan CSHCN experienced **financial problems** due to providing for the special needs of the child.
- 27.3% of CSHCN had special needs that caused family members to cut back or stop working.
- Families of 12.0% of CSHCN spent 11 or more hours per week providing or coordinating health care for their child.

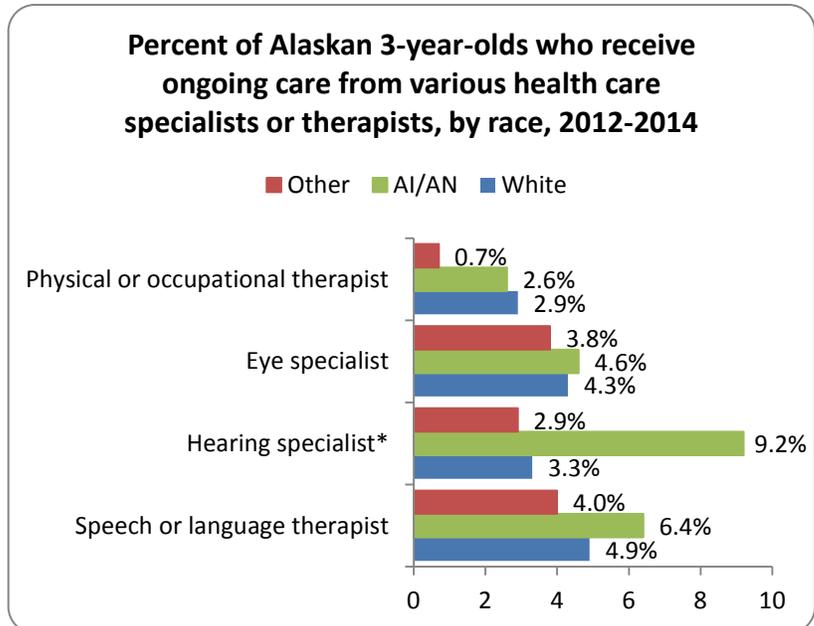
Disparities

- The prevalence of special health care needs among Alaskan children ages 0-17 years was **higher among males than females** – 12.7% and 8.8%, respectively.
- The **poorest families, those below the Federal Poverty Level (FPL), spent the most hours per week providing or coordinating care for their child** – 22.1% spent 11 or more hours per week compared to less than 10% of families with incomes more than twice the FPL (200% FPL or more).
- **White families were more likely to pay more than \$1000 per year** out-of-pocket for their child's medical expenses (29.5%) compared to families of Other race (23.4%) and American Indian/Alaska Native (AI/AN) families (19.2%).
- AI/AN CSHCN families and families of Other race were more likely than White families of CSHCN to report difficulties getting a referral for specialty care when they needed it (31.7% vs. 17.3%).
- AI/AN CSHCN families were less likely to report having family centered care than families of other races (40.9% for AI/AN vs. 68.1% for White and 57.7% for Other race)

Childhood Understanding Behaviors Survey: Alaskan 3-year-olds

The Alaska [Childhood Understanding Behaviors Survey](#) (CUBS), an on-going mail and phone survey, provides some information about special health care needs of 3-year-old children. The following data were gathered during 2012-2014. The children asked about on CUBS during these years will turn six, seven, and eight years old in 2017. CUBS data are self-reported by the child's mother around the time of the child's third birthday, and are weighted to the cohort of all children who were born in Alaska and still live in the state at the time the survey is mailed.

- 5.2% of 3-year-olds received ongoing care from a speech or language therapist, 4.7% received ongoing care from a hearing specialist, 4.4% from an eye specialist, and 2.6% from a physical or occupational therapist.
- The percent receiving ongoing care from a hearing specialist was approximately three times as high among Alaska Native children as among White children and children of Other races. (*Figure*)
- Overall, 8.2% of Alaskan 3-year-olds were ever enrolled in Early Intervention (EI)/Infant Learning Program (ILP). This percent was higher for American Indian/Alaska Native children (11.9%) compared to children with White (7.7%) and Other race (2.9%).



- 12.7% of mothers of 3-year-olds indicated that during the past 12 months they had had concerns about how their child acts, gets along with others, or shows feelings. Among these mothers, 39.8% sought professional help or advice because of their concerns.

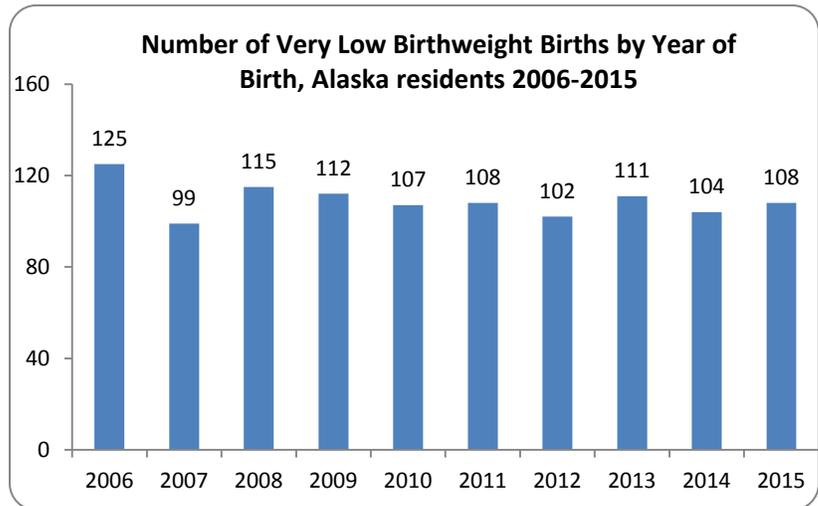
Hot off the Press – 2015 CUBS Data

In 2015, 7.9% of mothers of 3-year-olds said that their child needs or uses more medical care, mental health, or educational services than is usual for most children of the same age. Among these mothers, 66.3% said that this was because of a medical or behavioral condition that has lasted or is expected to last for at least 12 months.

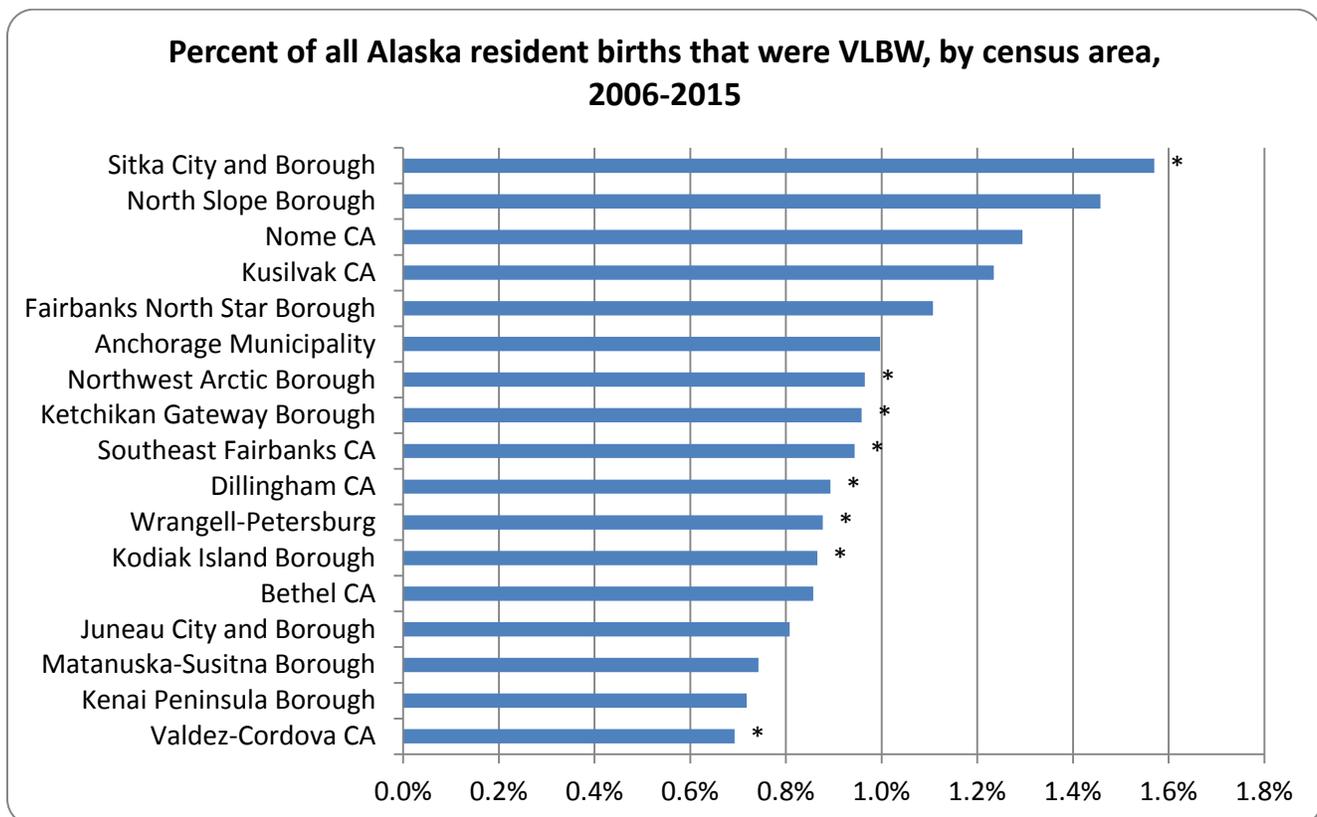
4.0% of mothers said that their child is limited in his or her ability to do things most children of the same age can do.

Birth Certificate Data: Very Low Birth Weight

Infants born at [very low birth weight](#) (VLBW, less than 1500 grams/3 pounds 5 ounces) have a greater likelihood of having special needs requiring Neonatal Intensive Care Unit admission right after birth compared to normal weight infants ($\geq 2,500$ grams).¹ As they get older, VLBW infants are more likely to have lower IQ scores, higher rates of learning disabilities, and a higher incidence of chronic medical conditions, in particular neurosensory impairment.²



During 2006-2015 there were 1,091 Alaskan infants born VLBW. The percent of all births that were VLBW ranged from 0.9% to 1.1% annually during this 10 year time period.



*Interpret with caution. Estimate based on fewer than 20 occurrences and subject to large variation.

Data Source: Alaska [Health Analytics and Vital Records Section](#). Estimates for the following census areas (CA) are not shown due to <6 occurrences: Aleutians East Borough, Aleutians West CA, Bristol Bay Borough, Denali Borough, Haines Borough, Lake And Peninsula Borough, Prince Of Wales-Hyder CA, Skagway Municipality-Hoonah-Angoon CA, Yakutat City and Borough. Yukon-Kovukuk CA.

1. CDC. Neonatal Intensive-Care Unit Admission of Infants with Very Low Birth Weight – 19 States, 2006. MMWR 2010. 59(44);1444-1447.
2. Hack et al. Outcomes in Young Adulthood for Very-Low-Birth-Weight Infants. N Engl J Med 2002; 346:149-157.

American Community Survey Disability Statistics

The ACS definition of disability is based on six questions. A person is coded as having a disability if he or she or a proxy respondent answers affirmatively for one or more of these six categories.

1. Hearing Disability (asked of all ages): Is this person deaf or does he/she have serious difficulty hearing?
2. Visual Disability (asked of all ages): Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?
3. Cognitive Disability (asked of persons ages 5 or older): Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?
4. Ambulatory Disability (asked of persons ages 5 or older): Does this person have serious difficulty walking or climbing stairs?
5. Self-care Disability (asked of persons ages 5 or older): Does this person have difficulty dressing or bathing?
6. Independent Living Disability (asked of persons ages 15 or older): Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?

Ages 4 and under*	Alaska %	90% MOE	US %	90% MOE
Any disability	0.8	±3.29	0.7	±3.29
Visual	0.5	±3.29	0.4	±3.29
Hearing	0.3	±3.29	0.5	±3.29
Ages 5-15				
Any disability	2.3	±1.03	5.4	±0.09
Visual	0.4	±3.29	0.8	±3.29
Hearing	0.1	±3.29	0.6	±3.29
Ambulatory	0.3	±3.29	0.6	±3.29
Cognitive	2.0	±0.96	4.2	±0.08
Self-care	0.2	±3.29	1.0	±3.29

*Children ages 4 and under were only asked the visual and hearing disability questions.

Reference: Erickson, W., Lee, C., von Schrader, S. (2016). Disability Statistics from the 2014 American Community Survey (ACS). Ithaca, NY: Cornell University Yang Tan Institute (YTI). Retrieved Oct 19, 2016 from www.disabilitystatistics.org

Additional Sources of Data on Alaska CYSHCN

The following are additional data sources and examples of the types of data they provide related to Alaska CYSHCN.

[Alaska Birth Defects Registry](#) (ABDR). The ABDR publishes estimates of reportable conditions per 10,000 live births.

- The top five birth defects based on reported prevalence for Alaska births during 2008-2012 were Atrial septal defect (160.2 per 10,000 births), hypospadias (113.6), ventricular septal defect (101.2), clubfoot (36.9), and Trisomy 21/Down Syndrome (17.8).
- Prevalence reports on specific conditions are available [online](#).

[Alaska Pregnancy Risk Assessment Monitoring System](#) (PRAMS). PRAMS is an on-going survey of mothers of newborns that collects population-based data on maternal attitudes and experiences before, during, and after pregnancy.

- In 2014, 10% of women who delivered a live birth indicated their infant went to the ICU.
- In 2014, 3% of women indicated their infant stayed in the hospital for more than 14 days after birth.

[Alaska Maternal Child Death Review](#) (MCDR). The MCDR program conducts systematic and comprehensive reviews of all child deaths in Alaska using a multi-disciplinary consensus decision-making approach.

- Among the 117 Alaska child deaths ages 0-17 which occurred in 2015 and 2016 and have been completely entered into the MCDR Case Reporting System, 47% had some type of disability or chronic illness, including physical disability (n=49), mental/substance abuse (n=8), cognitive disability (n<5), or sensory disability (n<5).

[Office of Children's Services](#) (OCS). According to the [American Academy of Pediatrics](#), children in foster care often have "complicated and serious medical, mental health, developmental, oral health, and psychosocial problems rooted in their history of childhood trauma."

- On average, there are approximately 3,000 children each month in foster care in Alaska.
- In 2015, 56% of foster children in Alaska were Alaska Native children, 29% were White, and 15% were Other races. ([ISER web report](#), March 2016)
- The rate of foster-care placement by region in 2015 varied from 10 children per 1,000 in the Northern and Southeastern regions to 17 per 1,000 in the Western region – marking the first year that rates in all regions were in the double digits. ([ISER web report](#), March 2016)

[Early Intervention/Infant Learning Program](#) (EI/ILP). The Alaska Infant Learning Program is a statewide system of professionals dedicated to serving all Alaskan Families with children who are at risk for or experience developmental delay. The EI/ILP [2014 Annual Report](#) includes data on children referred, screened, evaluated, and enrolled.

- In Fiscal Year 2014, 2,748 children were referred.