Women's, Children's, & Family Health

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Characteristics and Issues of Children with Special Health Care Needs in Alaska

The National Survey of Children with Special Health Care Needs (CSHCN) found that 12.8% of children in the United States ages 0-17 years have special health care needs.[1] Approximately 23% of these children are usually or always affected in their activities by their conditions, 37% are sometimes affected, and 39% are never affected in their activities. More than 1 in 10 (11.6%) CSHCN were uninsured at some point during the year prior to the survey.

*This fact sheet is a summary of findings from the 2001 National Survey of Children with Special Health Care Needs.[1]

Seriousness

Healthy People 2010 Targets and National Data

Indicator	Alaska 2001	Nation 2001	Healthy People 2010 Goal
The percent of CSHCN (ages 0-17 years) that receive coordinated, ongoing, comprehensive care within a medical home	46.4	52.7	Dev.

The Healthy People 2010 objective is developmental and no target has been set at this time.

- The percent of children with special health care needs in Alaska that have a medical home is slightly lower than the Nation.

Severity

Approximately 20% of parents of Alaskan CSHCN ranked their child's condition as 'severe' or 'most severe', 51.2% ranked their child's condition as 'moderate', and 28.2% ranked their child's condition as 'mild'.

More than 1 in 4 (26.9%) of Alaskan CSHCN have health conditions that consistently and often greatly affect their daily activities and 15.6% had 11 or more days of missed school days due to illness.

More than 1 in 5 (21.3%) parents of Alaskan CSHCN reported that the specific information they needed about their child's health or health care (such as the causes of any health problems, how to care for the child now, and what changes to expect in the future) were never or only sometimes provided by their doctors or health care providers.

Urgency

Health Insurance Coverage

- At the time of the survey, 8.3% of Alaskan CSHCN were currently uninsured and 13.9% were without insurance at some point during the past year.
- One-third of Alaskan CSHCN that were currently insured at the time of the survey did not have adequate coverage.
- Among Alaskan CSHCN that were insured at the time of the survey, 56.4% had private insurance only, 23.6% had public insurance only (Medicaid, SCHIP, Title V, or other public insurance), and 11.6% had a combination of public and private insurance.

Access to Care

- 1 in 5 Alaskan CSHCN have 1 or more unmet needs for specific health care services.
- Among Alaskan CSHCN, of families who needed respite care, genetic counseling and/or mental health services, 1 in 5 families did not get all the care they needed.
- Nearly 1 in 4 (23.3%) of Alaskan CSHCN needed specialty care and had a problem getting a referral, 8.1% did not have a usual source of care (or relied on the emergency room), and 18.1% did not have a personal doctor or nurse.

Impact on Family

- Among families of Alaskan CSHCN, 21.3% experienced financial problems due to their child's health needs.
- Nearly one-third (31.7%) of Alaskan CSHCN had health needs that caused family members to cut back or stop working.
- Among families of Alaskan CSHCN, 15.6% spent 11 or more hours per week providing and/or coordinating health care for their child.

Disparities

- Among Alaskan families of CSHCN, low-income families were more likely to spend more time providing, arranging, or coordinating care for their child each week and were more likely to have stopped

working due to their child's needs compared to higher-income.

- The poorest families, 0-99% of the Federal Poverty Level (FPL), spend the most hours per week providing or coordinating care for their child - 38.7% spend 11 or more hours per week compared to 11.8% for families at 200-399% FPL and 10.6% for those at or above 400% FPL.

- The prevalence of special health care needs among Alaskan children ages 0-17 years was higher among males ages than females – 13.3% and 8.1%, respectively.

Economic Loss

Economic loss was not evaluated.

Interventions & Recommendations

Early and continuous screening efforts begin with newborn metabolic screening and hearing screening; screenings and diagnosis may continue through Early Periodic Screening and Diagnostic Testing (EPSDT) for children from birth through age five. It is a priority to organize access to community-based services so that families can easily find and use them. Another priority is expansion of services to cover children as they transition from youth to adulthood.

Alaska's CSHCN program has been taking part in nationally funded efforts to assure access to a medical home. An effort has been made to identify, access and connect with adequate sources of affordable health insurance. Furthermore, families of CSHCN serve on local, state and national boards to bring light to their challenges and to partner in decision making.

In 2003 an Alaska CSHCN Summit was held to bring together families, health care providers, health care administrators, health care advocates, administrative personnel and community leaders so they could share their strategies for future work with CSHCN.

Alaska Maternal Infant Mortality Review (AMIMR) provides reliable and timely information on fetal, infant and maternal deaths in Alaska. The information is used in evaluating current health initiatives and in making recommendations for future health initiatives to reduce untimely deaths.

The All Alaska Pediatric Partnership (AAPP) is a network of children's health services providers that works to maintain and improve the health of all of Alaska's children. It acts as a catalyst for the developmental and implementation of collaborative programs.

Intervention Effectiveness

Effectiveness of these interventions was not evaluated.

Capacity

Propriety

Improving the health of and assuring health services access for CSHCN is within the overall mission of the Women's, Children's, and Family Health Section. Improving access to health services among the CSHCN population is a national objective (HP2010) and there are several indicators related to access to care and links to services that are required by the Maternal and Child Health Bureau to be followed and assessed on a yearly basis (Title V Block Grant).

Economic Feasibility

Economic feasibility was not evaluated, however, continued monitoring of demographics, characteristics, and health/economic issues of CSHCN is entirely feasible through the National Survey of Children with Special Health Care Needs. Although this survey is not done on a yearly basis, it will be available every 2-3 years.

Acceptability

The overwhelming response to the Alaska CSHCN Summit demonstrated that the community recognizes CSHCN issues need to be addressed. The Summit identified needs and challenges and developed strategies for addressing them. All encompassed elements of hope, understanding and commitment to allow Alaskan children an opportunity to have a healthy and exhilarating childhood.

Resources

Alaska's Genetics and Specialty Clinics Programs; Alaska's Developmental Disabilities Program; Family Resource Project; STAR Projects; PARENTS, Inc.; Governor's Council on Disabilities and Special Education; Denali KidCare; Early Periodic Screening, Diagnosis and Treatment; Supplemental Security Income.

Legality

Alaska Regulation (7 AAC 27.012) established a registry for reporting birth defects.

Alaska Law (18.15.200) requires that all babies born in Alaska receive screening tests for PKU and other metabolic disorders that can result in mental retardation and/or other serious health problems.

Alaska Law (21.42.345) requires that insurance coverage for a newly born child under this section shall consist of coverage of injury or sickness, including the necessary care and treatment of medically diagnosed congenital defects and birth abnormalities.

February 2005 a bill was introduced to mandate hearing screening for all newborns within the state of Alaska.

References

[1] U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. The National Survey of Children with Special Health Care Needs Chartbook 2001. Rockville, Maryland: U.S. Department of Health and Human Services, 2004.