

Alaska State Children and Youth with Special Health Care Needs

2022-2027 5-Year State Plan

Executive Summary November 2022

INTRODUCTION TO CHILDREN AND YOUTH WITH SPECIAL HEALTHCARE NEEDS IN ALASKA

The federal Maternal and Child Health Bureau, which houses the Title V Block Grant, 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”* (Department of Health and Human Services, 2012).

Children and youth with special health care needs (CYSHCN) have varying levels of need for medication, equipment, specialists, and rehabilitation and therapeutic services, to manage their care. Regardless of the level of need, all children and youth should have access to coordinated, family-centered care that helps them effectively manage their health care needs and flourish during childhood. Data from the 2018-2019 National Survey of Children’s Health reveal in Figure 1. the following about CYSHCN in Alaska:

Figure 1. "Who are Alaskan Children with Special Health Care Needs?"

Population	<ul style="list-style-type: none"> • 33,465 children (18.3% of Alaskans ages 0-17 years) • 63.2% are male
Race/ Ethnicity	<ul style="list-style-type: none"> • 52.4% White, non-Hispanic • 20.8% Multi-Race, non-Hispanic • 12.6% Hispanic • 7.5% American Indian/ Alaska Native, non-Hispanic • 4.3% Asian, non-Hispanic
Ages	<ul style="list-style-type: none"> • 22.3% or 7,455 or 0-5 years old • 33.3% or 11,160 are 6-11 years old • 44.4% or 14,851 are 12-17 years old
Living Situation	<ul style="list-style-type: none"> • 66.6% live with both parents • 23.5% live with single parent, either mother or father • 2.9% live with grandparents • 7.0% live with other family type

Income	<ul style="list-style-type: none"> • 33.3% live in households with income 0-199% of the Federal Poverty Line • 13.6% in households with income between 200-299% of the Federal Poverty Line.
Medical Home	<ul style="list-style-type: none"> • 39.1% compared to 42.3% nationwide receive care in a medical home. To qualify as care in a medical home one measure listed below must be met: <ul style="list-style-type: none"> • Have a personal doctor or nurse • Seek sick care with personal provider • The provider offers family centered care • Care coordination with the provider is available when needed

Alaskan families of CYSHCN deserve an integrated system of care that offers support in all areas where care is needed and throughout childhood. Currently, when families of CYSHCN need assistance, they must navigate on their own through medical, financial, educational, and social services with little coordination of care. Only 15.1% of families of CYSHCN reported receiving care within a well-functioning system, which includes having adequate health insurance, access to care when needed, receiving preventive care in the previous year, being cared for within a medical home, and the family feeling they are a partner with the provider in the child’s care.¹ Health care providers often are underfunded and lack resources and incentives to implement medical home standards in a way that will benefit CYSHCN and create a comprehensive and coordinated system of care that families can easily access.²

TITLE V MATERNAL AND CHILD HEALTH (MCH) BLOCK GRANT

Through [Title V](#) of the Social Security Act of 1935, the federal government pledged its support to states to extend and improve programs that promote the health of mothers and children. In addition to overall care for women and children, Title V specifically funded services for CYSHCN. This set the stage for decades of Title V-funded programs that support core public health functions, such as resource development, capacity and systems building, information

¹ Data Resource Center for Child & Adolescent Health. [National Outcome Measure 17.2 Systems of Care, children with special health care needs](#). Accessed 29th March 2022.
² Schiff, J., Manning, L., VanLandeghem, K., Langer, C.S., Schutze, M., and Comeau, M. (2022). Financing care for CYSHCN in the next decade: reducing burden, advancing equity and transforming systems. *Pediatrics*, 147 (supplement 7). <https://doi.org/10.1542/peds.2021-056150I>

dissemination and education, knowledge development, outreach and program linkage, technical assistance to communities, and provider training.

Even with the advent of Title V, into the 1970s, children with special healthcare needs were classified by their particular diagnoses. This led to condition-specific services, benefits, and research priorities. However, as public health and healthcare advanced in the 1970s and 80s, people realized that there are common access, service, and coordination challenges across conditions. Rather than narrowly defining the needs of children by their disabilities, it became clear that CYSHCN and their families:

- Often require complex, long-term health services
- Spend more on healthcare than other families
- Are vulnerable to access, cost, quality, and coverage weaknesses in the healthcare system
- Experience disparities in accessing care, especially in minority, non-English speaking populations.³

Title V agencies have a critical function in fostering coordination of services by working at the broader systems level. In their role in helping to plan and develop the larger service systems of family-based, community-based, coordinated care for CYSHCN and other MCH populations, Title V agencies influence the degree to which services will ultimately be coordinated for CYSHCN and their families.

The Alaska CYSHCN program is within the Section Women's Children's and Family Health (WCFH) in the Division of Public Health, Department of Health. At the state level, the program collaborates with families, policy makers, health care providers, agencies, and other public-private leaders to identify and improve health system issues that impact children and families. At the local level, the program supports partners to help families with resources and linkages to community services including family support, care coordination, and health information. The National Standards for CYSHCN is a framework used by the Alaska CYSHCN program to help guide work related to systems of care for this population.

NATIONAL STANDARDS FOR CHILDREN AND YOUTH WITH SPECIAL HEALTHCARE NEEDS

In 2014, the first National Consensus Framework for Improving Quality Systems of Care for Children and Youth with Special Health Care Needs project, funded by the Lucile Packard Foundation for Children's Health, released a core set of structure and process standards for systems of care for CYSHCN.⁴

³ Children and Youth with Special Healthcare Needs in Health People 2020. [A consumer perspective. Chapter 1. Children and Youth with Special Healthcare Needs, Then and Now.](#) Genetics Alliance. February 2013.

⁴ [National Standards for Systems of Care for Children and Youth with Special Health Care Needs.](#) Accessed March 15, 2022.

The National Standards for Children and Youth with Special Healthcare Needs were developed after many decades and much deliberation by those with lived experience and those working with this population. The aim of the standards was to synthesize how best to address all the needs of this population, their families, and those working to identify ways to provide services that are evidence-based. In 2017, the national standards were updated with the hope of making it easier for states and stakeholders to use. There are now eight domains:

1. Identification, Screening, Assessment, and Referral
2. Eligibility and Enrollment in Health Coverage
3. Access to Care
4. Medical Home
5. Community-Based Services and Supports
6. Transition to Adulthood
7. Health Information Technology
8. Quality Assurance and Improvement

STRATEGIC ACTIONS, GOALS, OBJECTIVES

The CYSHCN Advisory Committee has the following vision, mission, and values.

Vision	“All children and youth with special health care needs and their families have access to the information and services they need and are cared for through a wellcoordinated, integrated, family-centered approach.”
Mission	Think, work, and act together to ensure every child, every family is as supported and healthy as possible.
Values	Life-long, whole person care Family-centered Data-informed Equitable Empowered network Innovative

At the heart of the vision, mission, and values of this Committee are the needs of all children and youth with special health needs. This Committee believes all work aimed at improving services and resources for this population, is family-centered, well-coordinated, and encompasses all the needs of the child or youth and their family and support system too. While in seeking to improve equity in access to care and empower those with lived experience to become an essential part of the change process, led to a strategic framework that begins with three broad strategy areas for focus for the next 5 years:

1. Equitable Access to Care
2. System Growth and Improvement
3. Network Building and Partnerships

These strategy areas also reflect the overarching priority identified during the 2020 Title V Needs Assessment for CYSHCN, as stated in the Alaska Title V Maternal Child Health Services Block Grant 2020-2024 State Action Plan:

Increase or promote equitable access to medical and pediatric specialty care and family supports for Children and Youth with Special Healthcare Needs (CYSHCN).⁵

CYSHCN STRATEGIC FRAMEWORK

The Alaska State CYSHCN 5-Year Plan will be guided by the strategic framework below, which outlines the goal statements for each strategic focus area, and the priority strategies and key indicators that will help the CYSHCN Advisory Committee measure progress towards the goal statement. The Plan will be reviewed and updated and adjusted annually, as progress is made or needs change.

PART 1: STRATEGY SUMMARY			
Strategic Focus Areas	1. EQUITABLE ACCESS TO CARE	2. SYSTEM GROWTH and IMPROVEMENT	3. NETWORK BUILDING and PARTNERSHIPS
Goal Statements	<i>All CYSHCN in Alaska, regardless of community, can access the health services they need from well trained, culturally competent providers.</i>	<i>CYSHCN and their families are aided by a robust and extensive system of support services covered by health insurance/Medicaid.</i>	<i>Organizations and individuals who support CYSHCN work effectively together and share information.</i>
Priority Strategies	<ul style="list-style-type: none"> • Extend and Promote Telehealth • Family Navigation • Healthcare Transition 	<ul style="list-style-type: none"> • Patient Centered Medical Home Care Coordination is a covered expense • Expand Child Care and Respite Support 	<ul style="list-style-type: none"> • Collaborate with Foster Parents to build a network of support • Engage People with Lived Experience
Key Indicator(s)	#1: Current legislation will pass allowing for the continuation of payment for telehealth services.	#1: Care coordination is a covered expense #2: Information is available describing how reimbursable care coordination within a	#1: Ensure foster parents know the medical needs of a child/ youth when first coming into care

⁵ p.3 Alaska Department of Health and Social Services. [2020 Title V Needs Assessment Summary. June 2020](#). Children and Youth with Special Healthcare Needs. (CYSHCN).

	<p>#2: Trainings will be available for family leaders to take for skill development and advocacy</p> <p>#3: Healthcare transition materials will be accessible to young adults and families eligible for Medicaid and Denali-KidCare</p>	<p>patient centered medical would benefit the CSYCHN population, their families, and providers</p> <p>#3: Identify high quality child care options in every community</p>	<p>#2 Grow the connections between professionals, families, and individuals with lived experience</p> <p>#3: Communication tools available to share information about organizations and individuals that support CYSHCN</p>
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This document was produced by the Division of Public Health, Women’s, Children’s, and Family Health and Maternal Child Health Epidemiology Unit. If you would like more information about the Children and Youth with Special Health Care Needs Advisory Committee, please contact Joanne Singleton at joanne.singleton@alaska.gov

Information and resources about Children and Youth with Special Health Care Needs can also be found on the State of Alaska website: <https://health.alaska.gov/dph/wcfh/pages/special-needs/default.aspx>