

2016-2021

# Alaska's State Plan for Children and Youth with Special Health Care Needs



## EXECUTIVE SUMMARY

State of Alaska | Division of Public Health

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Alaskan families of children and youth with special healthcare needs (CYSHCN) deserve an integrated system of care and access to medical home resources. Only 42.8% of Alaska’s families with CYSHCN report receiving integrated care through a patient centered medical home approach. Families must navigate between separate and distinct health care systems, as well as social service systems and educational resources. Health care providers lack the resources and incentives required 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.

To address these system deficiencies, the Alaska Division of Public Health, Maternal and Child Health Program convened a planning team consisting of parents/foster parents of CYSHCN, health practitioners, non-profit partners, and agency staff to develop a strategic plan to improve the system of care for CYSHCN. The plan helps support the overarching goal of Alaska’s Division of Public Health CYSHCN systems integration efforts. By 2017, increase the proportion of CYSHCN who receive **integrated** care through a patient/family-centered medical/health home approach by 20% over reported 2009/2010 levels of 43%. This goal is being addressed through the following five program goals, and will be supported by this plan:

1. **Assess CYSHCN systems** to integrate families and increase the quality of family-provider partnerships,
2. Develop a “shared resource” for families and providers using the **Help Me Grow** centralized system model,
3. Expand provider access to **medical home concepts and tools** through education and statewide technical assistance,
4. Integrate and adopt **Quality Improvement** measures and associated statewide medical home policy level initiatives, and
5. Ensure ongoing systems integration efforts through **sustainability strategies**.

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### WHAT IS INTEGRATED CARE?

Integrated care is the seamless provision of health care services, from the perspective of the patient and family, across the entire care continuum. It results from coordinating the efforts of all providers, irrespective of institutional, departmental, or community-based organizational boundaries.

*Antonelli, Care Integration for Children with Special Health Needs: Improving Outcomes and Managing Costs. National Governors Association Center for Best Practices, 2012*

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## WHO ARE CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS?

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 of amount beyond that required by children generally”* (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.

- Approximately 10.2 million children in the U.S. – 15 percent of all people under the age of 18 – have special healthcare needs.
- More than a fifth of U.S. households with children have at least one child with special needs.

Source: [Family Voices](#); [Genetic Alliance](#)

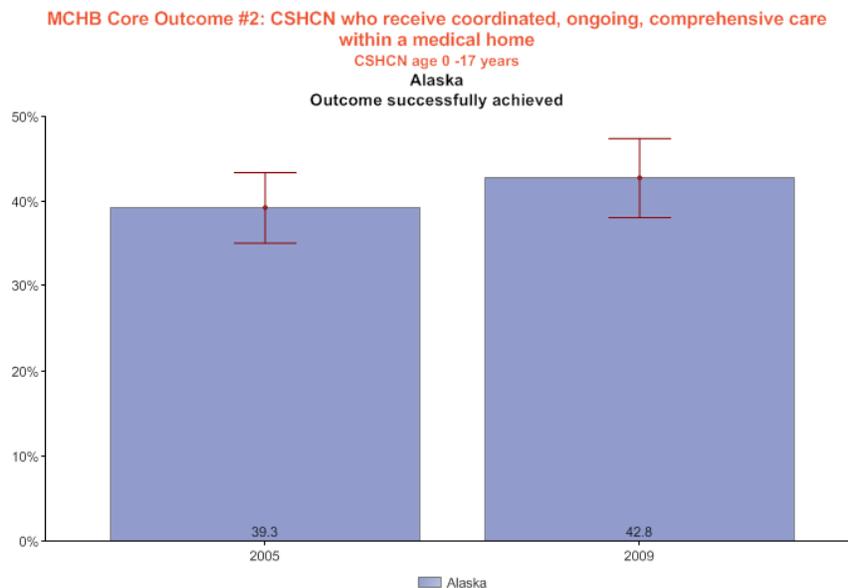
### OVERVIEW OF THE NEEDS OF CYSHCN IN ALASKA

Children age 0-18 years comprise approximately 27% of Alaska’s population, or 198,396. Alaska Natives comprise between 37,315 (one race only) and 53,404 (one or more races) of this age group (Alaska Department of Labor, 2014). Approximately 11% of Alaskan children have special health care needs according to the 2009/2010 National Survey of Children with Special Health Care Needs (NSCSHCN). The NSCSHCN estimates 19,025 children in Alaska meet the criteria of having special health care needs.

Alaskan families of CYSHCN face a host of daunting challenges. Many lack awareness of the medical and specialty care resources that are available, or even if they are aware, they don’t have access to these resources. Navigating between separate and distinct health care systems, social service systems and educational resources can be overwhelming. Unfortunately, many health care providers, especially those in the private sector, lack the resources to implement care coordination services in a way that will benefit children/youth with special health care needs.

The NSCSHCN reports Alaska’s baseline 2009/2010 level of CYSHCN who receive coordinated, ongoing, comprehensive care within a medical home at 42.8%; slightly below the national average of 43.0%. Additionally, the 2007 National Survey of Children’s Health reports Alaskan children as a whole as achieving 52.3% for the same measure; which is significantly lower than the national average of 57.5%. While Figure 1 shows some progress on this outcome between 2005 and 2009 (39.3 to 42.8%), it is clear that further resources and systems improvements are needed to “move the needle” to achieve a 20% increase by 2017.

**Figure 1: Alaska’s Children with Special Health Care Needs who receive coordinated, ongoing, comprehensive care within a medical home**



Source: 2009/2010 National Survey of Children with Special Health Care Needs

See appendix A for a complete summary of Alaska data from the NSCSHCN. While there is room for improvement in the provision of coordinated, ongoing, comprehensive care within a medical home, Alaska does have programs and resources in place to support CYSHCN. In addition, the state is aware of important missing pieces for service delivery and opportunities and challenges. The following summary was gleaned from stakeholders interviewed for this plan.

#### WHAT DO WE HAVE IN PLACE?

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- Solid infant/children programs that “meet families where they are”
- Pockets of service/care coordination but need more and need payment reform to incentivize.
- Developmental Screenings (e.g. Ages and Stages Questionnaire) but need to further standardize across practices
- Caring, concerned communities, families and providers

#### WHAT IS MISSING?

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- Specialized services statewide and information on how to access services.
- System coordination (e.g. medical systems needs to be able to coordinate with: Office of Children’s Services, educational systems, Infant Learning Program, Division of Vocational Rehabilitation, and vice versa)
- Specialized continuing/adult education for transition to adulthood
- Reasonable incentives for physicians to deliver the types of services and care coordination desired

#### WHAT CHALLENGES EXIST?

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- Providing specialized services in all communities of the state; Alaska’s vast geography and limited transportation connectivity makes access to specialized services difficult
- Delivering evidence-based practices, offering “highly qualified” care
- Workforce, appropriate training, credentials, professional development opportunities
- Offering integrated service delivery, currently fragmented and hard to navigate

- Integrating mental health care; Medicaid does not reimburse for mental health delivery in primary care settings

## WHAT OPPORTUNITIES EXIST?

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- Use of technology (smart phones, patient portals, etc.), improved electronic health records and tele-health practices
- Share resources, collaboration; make communities (not agencies) whole
- Increase provider training and workforce development opportunities, offer a living wage
- Medicaid Expansion and 1915i related system improvement
- Enroll children in EI/Infant Learning Programs

## THE ROLE OF TITLE V

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### WHAT IS TITLE V?

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 “crippled children.” (Infectious diseases such as meningitis and polio caused long-term difficulties, so early programs to provide assistance to these children and their families were called Crippled Children’s Programs.) 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 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.

Source: [Genetic Alliance](#)

### WHAT DOES ALASKA’S TITLE V/CYSHCN PROGRAM DO?

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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 CSHCN and other MCH populations, Title V agencies influence the degree to which services will ultimately be coordinated for CSHCN and their families.

Alaska's Title V programs:

- Help increase state systems capacity to identify children with special health care needs.
- Inform policymakers (legislators, Medicaid officials, schools) about our children and their needs.
- Make referrals to services, including health care providers, early childhood programs, Medicaid.
- Educate health and other professionals about our children and family-centered care.
- Provide services such as home visiting/case management programs, pediatric specialty clinics, newborn and diagnostic screenings, and care coordination.
- Support local or state family peer support and information organizations.
- Develop state and local policies that assure quality health care and other programs.

Source: [Family Voices](#)

## KEY PARTNERS

Elements of this plan represent interests and input from a variety of statewide stakeholders dedicated to serving Alaska's children and families, including families of CYSHCN themselves. Stakeholders were engaged through key informant interviews and a series of in-person and webinar style discussions in late 2015.

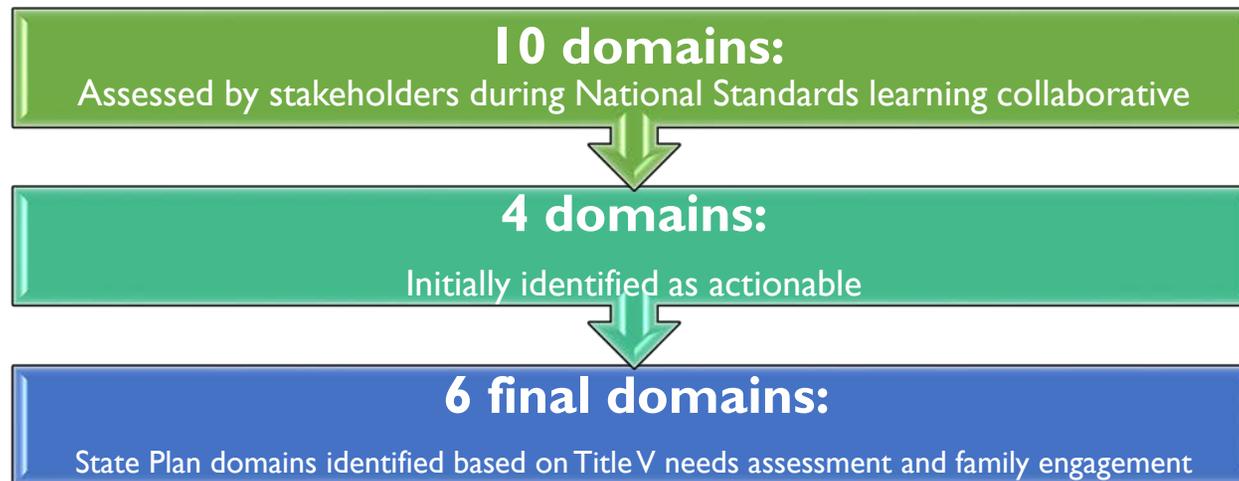
The following entities guided and provided input throughout the planning process and are committed to activities and goals outlined in the following sections:

- Families of Children And Youth with Special Health Care Needs
- Alaska Division of Public Health (Title V and Public Health/School Nursing)
- Alaska Division of Behavioral Health
- Alaska Division of Senior and Disability Services
- Alaska Office of Children's Services, Infant Learning Program (Early Intervention)
- Alaska Division of Health Care Services (Medicaid)
- Governor's Council on Disabilities and Special Education
- All Alaska Pediatric Partnership
- Stone Soup Group
- RurAL CAP
- Alaska Native Medical Center
- Alaska Center for Pediatrics
- SeaView Community Services
- Mat-Su Services for Children and Adults
- Program for Infants and Children
- University of Alaska, Anchorage Center for Human Development (LEND Program)
- Agnew Beck Consulting

## STRATEGIC ACTIONS, GOALS, OBJECTIVES

Alaska's five year CYSHCN State Plan is based on broad stakeholder input using the [National Standards for CYSHCN](#) as a framework. Statewide assessment of the system of care was conducted through a process including systems level input in early 2015 and culminated with a series of stakeholder and individual conversations in late 2015. Additional assessment of the system will be conducted in 2016 using additional data as identified and will be incorporated into the subsequent work plan and CYSHCN State Plan updates. AMCHP technical assistance supported the planning process and continues to offer guidance and resources in planning and implementation using the National Standards.

The plan focuses on six of the ten National Standards for CYSHCN domains. The first four were identified through activities of the AMCHP Action Learning Collaborative on National Standards for CYSHCN. Two additional priority domains were identified through the Title V Needs Assessment, family and stakeholder input. The plan incorporates three "AIM statements;" one from each of the three Systems Integration grant Strategy Teams. Activities will be aligned with the Autism Ad Hoc Committee's five year Autism State Plan which was recently finalized in addition to statewide Early Intervention/Part C strategic planning, Alaska Immunization Program goals, and related Early Childhood Comprehensive Systems (ECCS) efforts, among others.



## ALASKA'S STATE PLAN PRIORITY DOMAINS

This plan focuses on the following six of the National Standards domains in the broad context of services available statewide:

- 1. Screening, Assessment and Referral**
- 2. Access to Care**
- 3. Medical Home**
  - Pediatric preventive and primary care
  - Care coordination
  - Pediatric subspecialty care
- 4. Community-based Services and Supports**
  - Respite care
  - Palliative and hospice care
  - Home-based services
- 5. Family Professional Partnerships**
- 6. Transition to Adulthood**

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## COMMON THEMES AND “META GOALS” IDENTIFIED THROUGH STRATEGIC PLANNING PROCESS

### **Training Theme (potential CYSHCN Training Academy)**

- Training for providers (including family practitioners) who may care for a transition age youth with special healthcare needs
- Training for parent navigators to understand the Medical Home model
- Training for families to understand their roles and the resources available to help them
- Training for caregivers/medical personnel in cultural competence along with referring clients to support services, respite care, and the need for longer appointment times for CYSHCN
- Consistently delivered, high quality parent navigation training
- Basic respite training for family/friends to be eligible for reimbursement
- Training for care coordinators on providing the best services possible

### **Education, Marketing, Promotion Theme**

- Sharing information about medical homes – expectations and available care
- Education and promotion of respite care provider as a part-time job
- Empowering (educating) practices and families about what to do after screening results

### **Foster Care Theme**

- Children in foster care are inherently at-risk and therefore considered CYSHCN
- Caregivers have inconsistent access to necessary health information and need a higher level of support and greater access to information to ensure health and safety of the children they serve

### SCREENING, ASSESSMENT AND REFERRAL

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- Alaska’s screening system generally does well, especially newborn screening. Providers should increase use of evidence based developmental screening tools and knowledge of Bright Futures and Alaska Medicaid guidance on screening and preventative care. Providers and families need greater access to resources and information for follow up to screening, including further assessment and needed referrals.

### ACCESS TO CARE

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- Alaska lacks the full array of specialty providers needed for CYSHCN. The system could better leverage existing specialty resources through improved service linkage. Focused recruitment of specialists needs to continue while exploring alternative delivery systems such as telemedicine. Improved payer travel policies are needed for specialty care not available locally.

### MEDICAL HOME

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- A critical barrier for truly having quality patient centered medical homes in Alaska is the lack of care coordination services. Most health care practices outside the tribal health and community health center models are currently not reimbursement for care coordination. The “shared plan of care” framework should be used to engage the full multidisciplinary team.

### COMMUNITY-BASED SERVICES

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- Help Me Grow Alaska will be a central and valuable resource to inventory and share information about health related and community services available to CYSHCN. A critical issue identified by families is the lack of respite care which needs to be addressed systemically.

### FAMILY & PROFESSIONAL PARTNERSHIPS

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- Parent training on the medical home model should be a focus. A more robust family navigation network is needed to support families at the beginning of their journey. Families should be asked about their experience and offered opportunities to influence policy and decision making by participating in boards and committees.

### TRANSITION TO ADULTHOOD

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- The major challenge is a lack of adult providers who are trained, willing and capable of working with transition age youth and adults with special health care needs. Increased adult provider capacity should be a focus.