# 2016-2021

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



State of Alaska | Division of Public Health
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#### **INTRODUCTION**

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**.

#### 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

#### 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

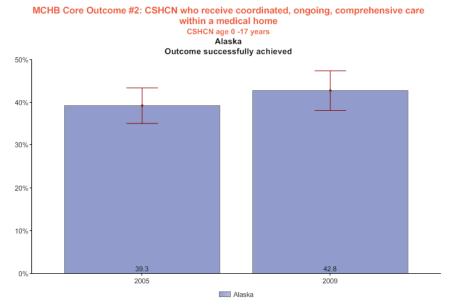
#### OVERVIEW OF THE NEEDS OF CYSHCN IN ALASKA

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?

- 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?

- 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?

- 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?

- 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 El/Infant Learning Programs

#### THE ROLE OF TITLE V

#### WHAT IS TITLE V?

Through <u>Title V</u> 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?

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.

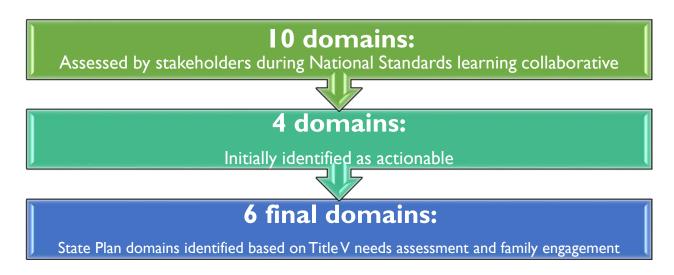
The following entities guided and provided input throughout the planning process and are committed to activities and goals outlined in the following sections:

- 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 <u>National Standards for CYSHCN</u> 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

#### 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

#### STAKEHOLDER PRIORITY DOMAIN ASSESSMENT SUMMARY

#### SCREENING, ASSESSMENT AND REFERRAL

 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**

• 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

• 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**

• 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**

• 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

• 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.

## PRIORITY: SCREENING, ASSESSMENT AND REFERRAL

#### SYSTEM DOMAIN: CHILDREN ARE SCREENED EARLY AND CONTINUOUSLY FOR SPECIAL HEALTH CARE NEEDS

#### Areas of Focus:

- Early identification including newborn screening;
- Needs identified by insurance plans and Medicaid's Early Periodic Screening, Diagnosis and Treatment (EPSDT) program, and Bright Futures;
- Documented, transportable plans of care.

#### ONF - TWO YEAR PRIORITIES:

- A. Develop an agency-level written agreement between two or more state or regional level entities to improve the timely receipt of information following the initial referral of a CYSHCN by a medical home. (Systems Integration Grant Strategy)
  - By October 2017, an agency-level written agreement will be developed between Alaska's Title V and Part C programs to improve the timely receipt of information following the initial referral of a CYSHCN by a medical home.
- B. Develop a comprehensive training for providers to effective and appropriately screen for CYSHCN.
- C. Update billing and reimbursement codes to match EPSDT and Bright Futures guidelines.

#### THREE - FIVE YEAR PRIORITIES:

- 1. All children enrolled in Denali Kid Care, Tribal Health Care, Military Health Care are screened for SHCN when enrolled.
- 2. When screening results indicate SHCN, the children's providers, caregivers, school, etc. are informed.
- 3. Primary care provider is provided screening results and always follows up with CYSHCN to offer support, referrals, and care coordination.
- 4. Increase use of Bright Futures guidelines for screening and well-child care.

## PRIORITY: ACCESS TO CARE

#### Areas of Focus:

- Statewide access to physical, mental health, dental and specialty care with provider choice
- Transportation and interpreter supports

#### ONE - TWO YEAR PRIORITIES:

- A. Develop outreach campaign to enroll providers in network.
- B. Align Medicaid/Xerox processing schedule with travel request schedule.
- C. Remove travel escort limitation for complex medical needs.

#### THREE - FIVE YEAR PRIORITIES:

- 1. Build and foster a network of providers offering a range of services for CYSHCN.
- 2. Increase the number of "in network" specialist providers in Alaska (align with All Alaska Pediatric Partnership efforts.)
- 3. Every CYSHCN receives transportation assistance when needed.

## PRIORITY: MEDICAL HOME

Includes: pediatric preventative and primary care; care coordination; pediatric specialty care

System Domain: CYSHCN will receive family-centered, coordinated, ongoing comprehensive care within a medical home.

#### ONE-TWO YEAR PRIORITIES:

- A. 20% of targeted CYSHCN will achieve a "Shared Plan of Care" as defined by guidance from Lucile Packard Foundation (Systems Integration Grant Strategy)
  - By October 2017, 20% of the targeted CYSHCN within participating Anchorage School District schools will have a Shared Plan of Care.
- B. Align with State of Alaska immunization workgroup to identify opportunities to improve immunization rates for CYSHCN.
- C. Educate families of CYSHCN on medical home and care coordination concepts to increase self-advocacy for quality services.
- D. Reform payment structure to incentivize medical home based care coordination.
- E. Inform Medicaid Reform initiatives to allow reimbursement for used durable medical equipment (align with Governor's Council on Disabilities and Special Education efforts).

#### THREE - FIVE YEAR PRIORITIES:

- 1. Increase the number of patient-centered medical homes prepared and willing to provide care to CYSHCN.
- 2. Increase the proportion of CYSHCN who are fully immunized according to the Advisory Committee on Immunization Practices (ACIP).
- 3. Increase the likelihood that care coordination is part of CYSHCN experience of care.
- 4. Increase Alaska's capacity to provide children's behavioral health services.

## PRIORITY: COMMUNITY-BASED SERVICES

**System Domain:** CYSHCN and their families are provided access to comprehensive and community-based supports, provided by their health plan and/or in partnership with other community agencies including family organizations, public health, education, Early Intervention (Part C), Special Education welfare, mental health, and home health care organizations.

#### Areas of focus:

- Patient and family centered respite services
- Home-based services
- Palliative and hospice care
- Transportation
- Interpreter supports

#### ONE-TWO YEAR PRIORITIES:

- A. Establish Help Me Grow Alaska as a centralized resource for families and providers to connect with community-based services (Systems Integration Grant Strategy).
- B. Increase respite care provider capacity through promotion of respite care as a part-time job for college students.
- C. Simplify and streamline hiring processes to make it easier for family members and friends to provide respite care for CYSHCN.
- D. Educate health care providers on respite care options and train to screen families to identify needed respite services.

#### THREE - FIVE YEAR PRIORITIES:

- 1. Standardize and expand Parent Navigation training to increase statewide access to community-based services.
- 2. Increase the availability of respite care services and providers for CYSHCN.

## PRIORITY: FAMILY PROFESSIONAL PARTNERSHIPS

**System Domain**: Families of CYSHCN will partner in decision making at all levels and will be satisfied with the services they receive. **Areas of focus**:

- Families are active members of the team
- Connection with family organizations, peer support
- Strength-based
- Culturally and linguistically appropriate

#### ONF-TWO YEAR PRIORITIES:

- A. Establish and promote *Help Me Grow Alaska* as point of entry for family medical home identification and partnership (Systems Integration Grant Strategy).
  - October 2017, 50% of families and medical home providers of CYSHCN contacting Help Me Grow Alaska for a needed specialist, support or service will obtain the needed specialist, support, or service.
- B. Create and distribute educational materials for families to better understand medical home concepts and the central family role in family-professional partnership.
- C. Educate families about Consumer Assessment of Healthcare Providers and Systems (CAHPS) patient experience to advocate for increased statewide practice/provider participation.
- D. Inventory health system advisory board structures to identify CYSHCN family advisory and engagement opportunities.

#### THREE - FIVE YEAR PRIORITIES:

- 1. Increase access to Parent Navigation model of family support to encourage family-professional partnership development.
- 2. Increase pediatric practice participation in CAHPS patient experience survey using enhanced survey version including CYSHCN module.

## PRIORITY: TRANSITION TO ADULTHOOD

**System Domain:** Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence

#### **Areas of Focus:**

- Youth engagement
- Transition and transfer of care policies and processes
- Transition assessment and plan in place and current
- Coordination between pediatric and adult providers

#### **ONE-TWO YEAR PRIORITIES:**

A. Identify a cohort of adult care providers who are interested in working with transitioning youth with special health care needs and provide training and support to increase capacity.

#### THREE - FIVE YEAR PRIORITIES:

1. Increase health literacy of transition age youth by working with systems in which they are already engaged (school Individualized Education Plans, school nurses, foster care and Office of Children's Services (OCS)) to provide specific health education.

#### Additional strategies related to this domain:

- Medicaid Reform and reimbursement for care coordination to help transition aged youth, transition.
- Senior and Disabilities Services Medicaid Waiver care coordinator trained/required to connect with medical homes.
- Review respite care regulations to maximize provider access.
- OCS & Foster Care
  - Assess where CYSHCN within OCS system have been receiving care (integrate and leverage data systems to improve coordination and transitions; i.e. VacTrak)

#### SUSTAINABILITY

Partnerships and physician practice champions will ensure sustainability of systems integration and Medical Home program efforts.

This plan will reside within the Title V CYSHCN Program and be regularly reviewed and revised throughout the five-year period. Workgroups will be convened to identify more specific strategies and timelines required to accomplish stated goals and objectives. Funding opportunities will be explored and leveraged to implement and measure success.

## ALASKA CYSHCN PROFILE

## 2009/10 National Survey of Children with Special Health Care Needs Estimated Number of CSHCN: 19,916

Prevalence of CSHCN	State %	Nation %	National Indicators	State %	Nation %
CSHCN Prevalence			Child Health		
Percent of children who have special health care needs	10.9	15.1	CSHCN whose conditions affect their activities usually, always, or a great deal	25.9	27.1
CSHCN Prevalence by Age			CSHCN with 11 or more days of school absences due to illness	17.9	15.5
Age 0-5 years	5.0	9.3	Health Insurance Coverage		
Age 6-11 years	12.9	17.7	CSHCN without insurance at some point in past year	10.5	9.3
Age 12-17 years	14.6	18.4	CSHCN without insurance at time of survey	3.8	3.5
CSHCN Prevalence by Sex			Currently insured CSHCN whose insurance is inadequate	38.8	34.3
Male	12.7	17.4	Access to Care		
Female	8.8	12.7	CSHCN with any unmet need for specific health care services	28.1	23.6
CSHCN Prevalence by Poverty	Level		CSHCN with any unmet need for family support services	8.0	7.2
0-99% FPL	9.3	16.0	CSHCN needing a referral who have difficulty getting it	22.7	23.4
100-199% FPL	10.5	15.4	CSHCN without a usual source of care when sick (or who rely on	10.5	9.5
200-399% FPL	11.7	14.5	the emergency room)  CSHCN without any personal doctor or nurse		C 0
400% FPL or more	11.4	14.7	••	6.8	6.9
CSHCN Prevalence by Hispanic	Origin ar	d Race	Family Centered Care		
Non-Hispanic	11.0	16.2	CSHCN without family-centered care	37.6	35.4
White	11.9	16.3	Impact on Family		
Black	12.0	17.5	CSHCN whose families pay \$1,000 or more out of pocket in medical expenses per year for the child	26.6	22.1
Other	9.4	13.6	CSHCN whose conditions cause financial problems for the family	23.6	21.6
Hispanic	8.9	11.2	CSHCN whose families spend 11 or more hours per week	12.0	13.1
Spanish Language Household	3.5	8.2	providing or coordinating child's health care  CSHCN whose conditions cause family members to cut back or	27.3	
English Language Household	10.4	14.4	stop working		25.0
MCHB Core Outcomes				State %	Nation %
CSHCN whose families are partne	ers in shar	ed decision-n	naking for child's optimal health	66.8	70.3
CSHCN who receive coordinated,	ongoing,	comprehensi	ve care within a medical home	42.8	43.0

MCHB Core Outcomes	State %	Nation %
CSHCN whose families are partners in shared decision-making for child's optimal health	66.8	70.3
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	42.8	43.0
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	56.7	60.6
CSHCN who are screened early and continuously for special health care needs	75.3	78.6
CSHCN who can easily access community based services	55.2	65.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	45.0	40.0

<sup>&</sup>quot;Alaska Report from the 2009/10 National Survey of Children with Special Health Care Needs." NS-CSHCN 2009/10. Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved from www.childhealthdata.org.

#### **Core Values**

- Statewide parity
- Family centered
- Cultural Competency
- Respectful
- Collaborative
- Reduce burden on families
- Sustainable
- Creative/ Innovative
- Compassion

# Long-Term Goal & Vision

All Alaska's 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 well- coordinated, integrated, patient-centered approach

### Long-Term Measure

Proportion of CYSHCN who receive integrated care through a patient/familycentered medical/health home.

- Baseline = 43% (2010 level)
- Target = 52%

#### 3-5 Year Priorities

#### 2016 Priorities

**Priority Area #1: Screening, Assessment and Referral:** Children are screened early and continuously for special health care needs.

- All children enrolled in Denali Kid Care, Tribal Health Care, Military Health Care are screened for SHCN when enrolled
- When screening results indicate SHCN, the children's providers, care givers, school, etc. are informed
- Primary care provider is provided screening results and always follows up with CYSHCN to offer support, referrals, and care coordination
- Increase the use of Bright Futures guidelines for screening and well child care
- Develop an agency-level written agreement between two or more state, or regional-level entities to improve the timely receipt of information following the initial referral of a CYSHCN by a medical home
- Develop comprehensive training for providers for how to effectively and appropriately screen for CYSHCN
- Update billing/reimbursement codes to match Bright Futures guidelines

3-5 Year Targets (Where)	<b>2016 Goals</b> (What)		
% of children in DKC, Tribal Health, Military Health screened		Agreement written	#
% CSHCN who are screened early and continuously for special health care needs	75.3%	Agreement implemented	#
% of CSHCN needing a referral who have difficulty getting it	22.7%	Training curriculum developed & delivered	#

#### Priority Area # 2: Access to Care

- Build and foster a network of providers offering a range of services for CYSHCN
- Increase the number of specialist providers that are "in network" in Alaska.
- Every CYSHCN receives transportation assistance when needed
- Develop outreach campaign to enroll providers in network.
- Align Medicaid/Xerox processing schedule with travel request schedule.
- Remove escort limitation for complex medical needs.

3-5 Year Targets (Where)	<b>2016 Goals</b> (What)	on 10%		
% of CSHCN with any unmet need for specific health care services	28.1%	Increase % of transportation assistance requests granted	over	
% of CSHCN without a usual source of care when sick (or who rely on the emergency room)	10.5%			
% of CSHCN without any personal doctor or nurse	6.8%			
% of currently insured CSHCN whose insurance is inadequate	38.8%			
% of CSHCN whose families have adequate private and/or public insurance to pay for the services they need	56.7%			

#### Priority Area #3: Medical Home: CYSHCN will receive family-centered. coordinated, ongoing comprehensive care within a medical home.

- Increase the number of PCMH prepared and willing to provide care to CYSHCN
- Increase the proportion of CYSHCN who are fully immunized according to
- Increase likelihood that care coordination is part of CYSHCN treatment experience
- Increase Alaska's capacity to provide children's behavioral health services

- 20% of the targeted CYSHCN have a shared plan of care (AIM #I)
- Conduct survey of CYSHCN to determine which providers are well-regarded for medical home provision, disseminate results
- Partner with immunization workgroup
- Educate families to ask for care coordination
- Reform payment structure to incentivize care coordination
- Change Medicaid regulations to allow reimbursement for used medical equipment

3-5 Year Targets (Where)	<b>2016 Goals</b> (What)		
% of CSHCN with family-centered		CAHPS family/patient	5%
care within medical home (National   65%		experience survey reports	over
Survey of Children's Health)		improved experience	2015

#### Priority Area #4: Family Professional Partnerships

- Increase access to Parent Navigation model of family support to encourage family professional partnership development.
- Increase pediatric practice participation in CAHPS patient experience survey using enhanced version including CYSHCN module

- Establish and promote Help Me Grow as point of entry for family medical home identification and partnership
- Create and distribute educational materials for families to better understand medical home concepts and central family role.
- Educate families about CAHPS survey so they can ask their practice to participate.
- Inventory Health System advisory board opportunities for family members of CYSHCN

3-5 Year Targets (Where)	)	2016 Goals (What)		
CSHCN whose families are partners in shared decision-making for child's optimal health		Increase # of CAHPS patient experience survey practice/agency participants	Total 8	

Priority Area #5: Community-Based Supports: CYSHCN and their families are provided access to comprehensive and community-based supports, provided by their health plan and or in partnership with other community agencies.

- Standardize and expand Parent Navigation training to increase statewide access to community-based services
- Increase the availability of respite care services and providers for CYSHCN
- Establish Help me Grow as a centralized resource for families and providers to connect with community-based services
- Promote respite care as a part-time job for college students
- Make is easier for family members/friends to provide respite

3-5 Year Targets (Where)	3-5 Year Targets (Where)			
% of CSHCN who can easily access community based services	55.2%	Increased utilization of respite care services available through SDS Medicaid Waivers	5% over baseline	
Priority Area	Priority Area #6: Transition to Adulthood			
age YSHCN by working with t systems they are a part of (sch	age YSHCN by working with the systems they are a part of (school IEP, school nurses, foster care/OCS) to		are ed in YSHCN,	
3-5 Year Targets (Where)	3-5 Year Targets (Where)			
Youth with special health care needs receive the services necessary to make appropriate transitions to adult health care, work, and independence	45%	Cohort of providers trained in transition aged youth and accepting new patients	5 providers	