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Standards for Systems of Care for Children and Youth with Special Health Care Needs

A Product of the National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs Project

AMCHP
ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

Lucile Packard Foundation for Children's Health

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The work of this project was led and authored by Karen VanLandeghem, senior advisor, AMCHP, and project director of the National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs Project; Phyllis Sloyer, former director of the Florida Children's Medical Services Network and AMCHP President, and consultant to this project; Vivian Gabor, consultant; and Veronica Helms, program manager, AMCHP. Other AMCHP staff who contributed to this project are: Michael Fraser, former chief executive officer of AMCHP;Treeby Brown, associate director, children's and adolescent health; Brent Ewig, director, public policy and government affairs; Caroline Stampfel, senior epidemiologist; and Laura Goodwin, program manager, who designed and edited this document.

About AMCHP

The Association of Maternal & Child Health Programs is a national resource, partner and advocate for state public health leaders and others working to improve the health of women, children, youth and families, including those with special health care needs. AMCHP members come from the highest levels of state government and include directors of maternal and child health programs, directors of programs for children with special health care needs, and other public health leaders who work with and support state maternal and child health programs. Our members directly serve all women and children nationwide, and strive to improve the health of all women, infants, children and adolescents, including those with special health care needs, by administering critical public health education and screening services, and coordinating preventive, primary and specialty care. Our membership also includes academic, advocacy and community based family health professionals, as well as families themselves.

About the Foundation

The Lucile Packard Foundation for Children's Health works in alignment with Lucile Packard Children's Hospital and the child health programs of Stanford University. The mission of the Foundation is to elevate the priority of children's health, and to increase the quality and accessibility of children's health care through leadership and direct investment. Through its Program for Children with Special Health Care Needs, the Foundation supports development of a high-quality health care system that results in better health outcomes for children and enhanced quality of life for families. The Foundation is a public charity, founded in 1997.

National Work Group Members

Terry Adirim
Office of Special Health Affairs, Health Resources and Services Administration

Richard C. Antonelli
Boston Children's Hospital, Harvard Medical School

Bruce Ardis
District of Columbia Health Services for Children with Special Needs

Christina Bethell
The Child and Adolescent Health Measurement Initiative

Christopher M. Born
Texas Children's Health Plan

Meg Comeau
The Catalyst Center, Health and Disability Working Group, Boston University School of Public Health

Robert Dimand
California Department of Health Care Services

Brenda DuHamel
Rhode Island Executive Office of Health and Human Services

Susan Dull
Children's Hospital Association

Barbara Coulter Edwards
Center for Medicaid, CHIP, and Survey & Certification, Centers for Medicare & Medicaid Services

Michelle Esquivel
American Academy of Pediatrics

Sharon Fleischfresser
Wisconsin Department of Health and Family Services

Eileen Forlenza
Colorado Department of Public Health and Environment

Deborah Garneau
Rhode Island Department of Health

Kristine Green
Alaska Department of Health and Social Services

Marilyn Sue Hartzell
Oregon Center for Children and Youth with Special Health Needs, Institute on Development and Disability at Oregon Health & Science University

Catherine Hess
National Academy for State Health Policy

Lynda Honberg
Family Voices

Henry T. Ireys
Mathematica Policy Research

Laura Kavanagh
Maternal and Child Health Bureau, Health Resources and Services Administration

Tom Klitzner
Mattel Children's Hospital at UCLA, David Geffen School of Medicine at UCLA

National Work Group Members *continued*

Colleen Kraft
Virginia Tech Carilion School of Medicine and Research Institute

Christopher A. Kus
New York State Department of Health

Michael C. Lu
Maternal and Child Health Bureau, Health Resources and Services Administration

Marie Y. Mann
Maternal and Child Health Bureau, Health Resources and Services Administration

Jeanne W. McAllister
Indiana University School of Medicine

Margaret A. McManus
The National Alliance to Advance Adolescent Health

Merle McPherson
Retired, Maternal and Child Health Bureau, Health Resources and Services Administration

Kathleen Nolan
National Association of Medicaid Directors

Laurie Norris
Center for Medicaid, CHIP, and Survey & Certification, Centers for Medicare & Medicaid Services

Jaime A. Resnick
Maternal and Child Health Bureau, Health Resources and Services Administration

Gina Robinson
Colorado Department of Healthcare Policy and Financing

Sarah Hudson Scholle
National Committee for Quality Assurance

Edward Schor
Lucile Packard Foundation for Children's Health

Colleen Sonosky
District of Columbia Department of Health Care Finance

Bonnie Strickland
Maternal and Child Health Bureau, Health Resources and Services Administration

Fan Tait
American Academy of Pediatrics

Debra Waldron
University of Iowa Children's Hospital, Child Health Specialty Clinics

Kathleen Watters
Maternal and Child Health Bureau, Health Resources and Services Administration

Nora Wells
Family Voices

Background

Creating a comprehensive, quality system of care for children and youth with special health care needs (CYSHCN) has been one of the most challenging areas for state health leaders and other stakeholders such as state Title V CYSHCN programs, health plans, private insurers, state Medicaid and CHIP agencies, pediatricians and family physicians, and families. The *Patient Protection and Affordable Care Act* (ACA) has further heightened this need as states extend coverage to millions of uninsured children and adults, design essential health benefits, and implement initiatives to improve the quality of care to reduce health care costs and improve overall health outcomes.

For more than three decades, numerous national reports, initiatives, and research have described or called for frameworks, standards and various measures to advance a comprehensive system of care for CYSHCN and their families. These and other efforts have helped to establish important work in states, communities, health plans, provider practices, and other areas to build comprehensive systems of care for CYSHCN. However, they have not resulted in an agreed on national set of standards that could be used and applied within health care and public health systems and other child-serving systems to improve health care quality and health outcomes for this population of children. Furthermore, many of these frameworks and tools were developed prior to the passage of the ACA and other significant health system reforms that are currently underway across the country.

Achieving consensus on the necessary capacity and performance of systems serving CYSHCN is essential to comprehensive, quality systems of care for this population of children. A central purpose of the *National Consensus Framework for Improving Quality Systems of Care for Children and Youth with Special Health Care Needs* project is to develop a core set of structure and process standards for systems of care for CYSHCN, based on the research and national consensus among a diverse group of stakeholders with expertise in their field. The standards that are described in this document are intended for use by a range of national, state and local stakeholder groups including state Title V CYSHCN programs, health plans, state Medicaid and CHIP agencies, pediatric provider organizations, children's hospitals, insurers, health services researchers, families/consumers and others.

Children and Youth with Special Health Care Needs

Children and youth with special health care needs (CYSHCN) are a diverse group of children ranging from children with chronic conditions such as asthma or diabetes, to children with autism, to those with more medically complex health issues such as spina bifida or other congenital disorders, to children with behavioral or emotional conditions. Overall, CYSHCN are defined as children birth to age 21 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.[1] In a recent national survey, children with a chronic condition birth to age 18 represented approximately 15 percent of the entire child population in the United States.[2]

These standards focus on children and youth with special health care needs for several reasons. Federal requirements under Medicaid require state Medicaid agencies and their partners to identify this population of children. Additionally, there are operational considerations in terms of processes and contract requirements that are specific to CYSHCN within health care systems. That said, in order to fully achieve a comprehensive system of care and ultimately improved health outcomes for all children, including CYSHCN, it is critical to recognize that all children have the potential for having a special health care need at some point in their life. As such, some standards in this document have relevance for all children.

About the Development of the System Standards

The standards that are described in the following table address the core components of the structure and process of an effective system of care for CYSHCN. The standards and related core domain areas (see below) were derived from a comprehensive review of the literature, early guidance during the project from more than 30 key informants, case studies of standards currently in use within selected sites, and input and

[1] McPherson M, Arango P, Fox H. A new definition of children with special health care needs. Pediatr. 1998;102:137-140.
[2] United States 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: 2005–2006. Rockville, MD: United States Department of Health and Human Services, 2008.

Background *continued*

guidance from a national work group comprised of national and state leaders representing state Title V CYSHCN programs, health plans, state Medicaid and CHIP agencies, pediatric providers, children's hospitals, insurers, health services researchers, families/consumers, and others. The system standards were fully vetted by the national work group members. They are intended for use or adaptation by a wide range of stakeholders at the national, state and local levels.

The standards are grounded in the six core outcomes for systems of care for CYSHCN that were developed by the federal Maternal and Child Health Bureau, Health Resources and Services Administration. Additionally, they include a seventh outcome – cultural competence in the health care system – that was identified through the work of this project and recommended by national work group members to this project. (Please see below.)

Where there were existing standards in the literature and/or practice, those standards were synthesized and cited to the source. For some core domain areas, there were no specific standards described in the literature or practice of the sites that were interviewed as part of this project. In other cases, the content of a standard was implicit and/or embedded within national frameworks, guidelines and/or program principles. In both of these cases, new standards were developed.

Finally, these standards are designed to supplement, not substitute, federal statute and regulatory requirements under Medicaid, the ACA and other relevant laws. Additional information about the history, need and rationale for a nationally endorsed set of core system standards, methodology, and examples of sites that are using system standards are described in a companion background white paper that was developed as part of this project.

[3] Ibid.

[4] National Committee for Quality Assurance. Standards and Guidelines for NCQA's Patient-Centered Medical Home (PCMH) 2011, Appendix 2: NCQA's Patient-Centered Medical Home (PCMH) 2011 and CMS Stage 1 Meaningful Use Requirements. Available at: http://www.ncqa.org/Portals/0/Public%20Policy/NCQA_PCMH_2011_Meaningful_Use_Crosswalk_11.21.2011.pdf. Updated November 21, 2011. Accessed March 10, 2013.

Overall System Outcomes for CYSHCN:[3,4]

1. **Family Professional Partnerships:** Families of CYSHCN will partner in decision making at all levels and will be satisfied with the services they receive
2. **Medical Home:** CYSHCN will receive family-centered, coordinated, ongoing comprehensive care within a medical home
3. **Insurance and Financing:** Families of CYSHCN have adequate private and/or public insurance and financing to pay for the services they need
4. **Early and Continuous Screening and Referral:** Children are screened early and continuously for special health care needs
5. **Easy to Use Services and Supports:** Services for CYSHCN and their families will be organized in ways that families can use them easily and include access to patient and family-centered care coordination
6. **Transition to Adulthood:** 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
7. **Cultural Competence:** All CYSHCN and their families will receive care that is culturally and linguistically appropriate (attends to racial, ethnic, religious, and language domains)

Core Domains for System Standards

1. Screening, Assessment and Referral
2. Eligibility and Enrollment
3. Access to Care
4. Medical Home, including:
   - Pediatric Preventive and Primary Care
   - Care Coordination
   - Pediatric Specialty Care
5. Community-based Services and Supports, including:
   - Respite Care
   - Palliative and Hospice Care
   - Home-based Services
6. Family Professional Partnerships
7. Transition to Adulthood
8. Health Information Technology
9. Quality Assurance and Improvement
10. Insurance and Financing

System Principles, Standards and Availability of Quality Measures for Systems of Care for CYSHCN

SYSTEM DOMAINS	System Standards (Structure and Process)	Existing National Principles and Frameworks	Federal Requirements or Relevant Federal Law	Overall Availability of Relevant Quality Measures
SCREENING, ASSESSMENT, AND REFERRAL				
Children are screened early and continuously for special health care needs.	**Screening and Assessment:** 1. Upon enrollment and transfer between insurance coverage (e.g., public and private), a consistent and culturally and linguistically appropriate mechanism for identifying CYSHCN, including children with significant health conditions, is in place to ensure that these children are referred to appropriate types and sources of enhanced care.[1] 2. Promptly after enrollment in a health plan, all CYSHCN are provided a documented initial assessment that is conducted in collaboration with the child's family or caregiver.[2] 3. State newborn screening information is delivered to providers and parents in a timely fashion and arrangements made for necessary follow-up services are documented. If indicated, the need for repeat screening and follow-up is communicated to the health plan and providers by the hospital or state program.[3] 4. The child's health plan and medical home have a documented plan and process to demonstrate how they follow-up with a hospital or state health department when newborn screening results are not received.[4] 5. All children, including CYSHCN, receive periodic, developmentally appropriate, and recommended	• Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents, American Academy of Pediatrics[7] • Draft Structure and Process Measures for Integrated Care for People with Dual Eligibility for Medicare and Medicaid, National Committee for Quality Assurance[8]	Early and Periodic Screening, Diagnosis and Treatment (EPSDT) screening requirements for children enrolled in Medicaid:[9] • comprehensive health and developmental history • comprehensive unclothed physical exam • vision and hearing screening and referral to a dental provider[10] • appropriate immunizations • lab tests • anticipatory guidance Federal Medicaid managed care regulations for screening of CYSHCN[11] The *Patient Protection and Affordable Care Act* (ACA) requires that Bright Futures Guidelines be followed as the standard that provides the basis for eligible preventive services[12]	• Healthy People 2020 Measures • National Quality Forum Measures • Children's Health Insurance Program Reauthorization Act (CHIPRA) Core Measures • National Survey of Children's Health

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	comprehensive screenings (to include screening for physical health, oral health, mental health, developmental, and psychosocial needs, and cultural and linguistic needs, preferences or limitations) as part of a well-child visit or other preventive visit and in response to triggering events such as hospitalization, trauma, or sudden onset of new symptoms, in accordance with Bright Futures Guidelines. 6. Screening efforts, results and referrals for further assessment are documented, relayed to the child's medical home and family, and, to the extent feasible, coordinated among all screening entities, including but not limited to clinical care settings, medical homes, child care settings, and schools. **Referral/Follow-up:** 1. Following a screening and assessment, the CYSHCN and their family are referred to needed services including pediatric specialists, therapies, other service systems such as Early Intervention, Special Education, family organizations and community-based agencies, and follow-up is provided to ensure such referrals are completed. In turn, those services and systems should ensure follow-up to the child's medical home and other members of the child's care team after referral visits.[5] 2. Regardless of the entity conducting a screening and referral, protocols and documentation methods are in place for the primary care provider, medical home or other such entity to follow-up with the child and family in areas including: assessment of follow-up			

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	received, barriers to care, and, where feasible, assistance in addressing barriers to obtaining needed follow-up.[6]			
ELIGIBILITY AND ENROLLMENT				
	1. Outreach activities to enroll children into public and private insurance coverage include strategies designed and proven to be effective in reaching CYSHCN and their families, and are coordinated with relevant family organizations at the state and community level. 2. Continuity of care is ensured during periods of enrollment and transition such as changes in or temporary loss of insurance coverage (public and private). 3. Written policies and procedures are in place for transitioning CYSHCN between non-network and network providers and communication with the medical home and family to ensure continuity of care. 4. Written policies and procedures are in place allowing CYSHCN who are newly enrolled or have recently changed health plans to continue seeing out-of-network providers, for up to six months after enrollment.[13] 5. A comprehensive member services program with specialized staff and linkages to relevant family organizations at the state and local level is available to provide information and assistance to CYSHCN and their families in areas including: family resource needs, insurance coverage options, eligibility and enrollment questions, covered and non-covered		The ACA requires that states:[17] • Provide seamless enrollment and transition for eligibility in Medicaid and CHIP[18] • Screen for eligibility for Medicaid, the Children's Health Insurance Program (CHIP) and the Insurance Exchange using MAGI (2014) and without multiple eligibility determinations • Provide a single streamlined eligibility application form for any federal insurance program (Medicaid, CHIP, Insurance Marketplace) • Establish a Medicaid and CHIP enrollment website that is connected to an Exchange or default to the federal marketplace[19] • Conduct outreach to and enroll vulnerable and underserved	**Enrollment**: Experience of Care and Health Outcome Survey (ECHO)

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	services, navigating the medical and community system of care available for CYSHCN,[14] enrollee status, complaints and grievances, and selection of a primary care provider or other such medical home with experience in serving CYSHCN.[15] 6. Written and oral information that is provided for purposes of determining insurance eligibility and enrolling a child into public or private insurance coverage is culturally appropriate and provided in a manner and format appropriate for a child or their caregiver, including for those families who have limited English proficiency or sensory impairments.[16]		populations eligible for medical assistance or for child health assistance, including children, unaccompanied homeless youth, children and youth with special health care needs, racial and ethnic minorities, rural populations, victims of abuse or trauma, individuals with mental health or substance-related disorders, and individuals with HIV/AIDS[20]	
ACCESS TO CARE				
	1. The system has the capacity to ensure CYSHCN geographical and timely access to appropriate primary and specialty services, including in-network providers and timely referrals to out-of-network physical, mental and dental care providers, pediatric primary care and pediatric subspecialists, children's hospitals, pediatric regional centers where available, and ancillary providers.[21] 2. Pediatric specialists who have a demonstrated clinical relationship as the clinical coordinator of care for a CYSHCN, among other responsibilities, are able to serve as a primary care provider (PCP) for CYSHCN.[22] 3. Freedom of choice in selecting a primary care provider and written policies and procedures describing		• CMS Draft Rule Requirement for Medicaid • EPSDT requirement for transportation • MACPAC Reports to Congress • Secretary's Annual Report on Pediatric Health Care Quality	• Healthcare Effectiveness Data and Information Set (HEDIS) • Consumer Assessment of Healthcare Providers and Systems (CAHPS) • Promoting Healthy Development Survey (PHDS) • National Survey of Children with Special Health Care Needs (NSCYSHCN)

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	how enrollees choose and are assigned to a PCP, and how they may change their PCP is in place.[23] 4. Access to pediatric specialists (face-to-face or via telemedicine) specified in a child's plan of care is provided without prior authorization from a child's primary care provider or Contractor (e.g., health plan) whether or not such specialists participate in a Contractor's provider network. 5. Transportation assistance is provided to families with difficulties accessing needed medical services.[24]			
MEDICAL HOME				
CYSHCN will receive family-centered, coordinated, ongoing comprehensive care within a medical home.	**Overall Systems Standard**: The medical home is ready and willing to provide well, acute and chronic care for all children and youth, including those affected by special health care needs or who hold other risks for compromised health and wellness.[25] The medical home, comprised of a primary care provider and/or pediatric subspecialist and as part of an integrated care team, does the following: 1. Provide access to health care services 24 hours, seven days a week. 2. Provide health care services that encourage the family to share in decision making, and provide feedback on services provided.[26] 3. Perform comprehensive health assessments.[27] 4. Promote an integrated, team-based model of care coordination.[28] 5. Develop, maintain, and update a comprehensive, integrated plan of care that has been developed with the	• Joint Principles of the Patient Centered Medical Home[33] (See Appendix A) • Physician Practice Connections (PPC)-Patient Centered Medical Home (PCMH) Goals and Standards, National Committee for Quality Assurance (NCQA)[34] (See Appendix A) • Medical Home Index (Six Domains), Center for Medical Home Improvement[35] (See Appendix A) • Family-Centered Care Assessment for Families (FCCA-F), National Center for Family Professional Partnerships[36] • Standards and Guidelines for NCQA's Patient-Centered Medical Home (PCMH) 2011, NCQA[37]		• NSCYSHCN • Consumer Assessment of Healthcare Providers and Systems (CAHPS) • ECHO • National Initiative for Children's Healthcare Quality (NICHQ)

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	family and other members of a team, addresses family care clinical goals, encompasses strategies and actions needed across all settings, and is shared effectively with families and among and between providers[29] (See standards for care coordination). 6. Conduct activities to support CYSHCN and their families in self-management of the child's health and health care. 7. Promote quality of life, healthy development, and healthy behaviors across all life stages.[30] 8. Integrate care with other providers and ensure that information is shared effectively with families and among and between providers. 9. Perform care tracking, including sending of proactive reminders to families and clinicians of services needed, via a registry or other mechanism.[31] 10. Provide care that is effective and based on evidence, where applicable.[32]			
►**PEDIATRIC PREVENTIVE & PRIMARY CARE *(as part of the medical home)***				
	1. Bright Futures Guidelines for screening and well child care including oral health and mental health services are followed. 2. Care focuses on overall health, wellness and prevention of secondary conditions, especially for CYSHCN whose care tends to center on a particular condition. 3. All children, including CYSHCN, have access to medically necessary	Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents, American Academy of Pediatrics[42]	The ACA requires all private plans to cover preventive services for infants, children and adolescents according to *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents* without cost sharing.	• NSCYSHCN • HEDIS • CAHPS

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	services to promote optimal growth and development, maintain and avert deterioration in functioning, and to prevent, detect, diagnose, treat, ameliorate, or palliate the effects of physical, genetic, congenital, developmental, behavioral, or mental conditions, injuries, or disabilities.[38] 4. All children, including CYSHCN, receive recommended immunizations according to the Advisory Committee on Immunization Practices (ACIP). 5. Reasonable access to routine, episodic, urgent, and emergent physical, oral health and mental health care are provided. 6. Reasonable wait times and same day appointments are available for physical, oral health, and mental health care.[39] 7. Accommodations for special needs such as provision of home visits versus office visits are available. 8. Scheduling systems that recognize the additional time involved in caring for CYSHCN exist.[40] 9. Pre-visit assessments are completed with the family to ensure that the medical home team provides family-centered care and is better able to make necessary referrals.[41]			

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► **CARE COORDINATION** ***(as part of the medical home and integrated with community-based services)***				
	1. All CYSHCN have access to patient and family-centered care coordination. 2. To provide optimal coordination and integration of services needed by the child and family, care coordinators: o serve as a member of the medical home team[43,44] o assist in managing care transitions of CYSHCN across settings and developmental stages[45] o provide appropriate resources to match the health literacy level, primary language, and culture of CYSHCN and their family[46] 3. A plan of care is jointly developed and shared among the primary care provider and/or the specialist serving as the principal coordinating physician, and the CYSHCN and their family, and implemented jointly by the child, their family and the appropriate members of the health care team.[47] The plan of care: o Addresses the physical, oral health and mental health problems identified as a result of the initial and ongoing evaluation and describes the implementation and coordination of all services required by the CYSHCN and their family[48] o Identifies the strengths and needs of the child and family;	• Definition of Care Coordination[52] (See Appendix A) • National Quality Forum Framework for Care Coordination[53] (See Appendix A) • Key Elements of High-Performing Pediatric Care Coordination Framework[54] (See Appendix A) • The Functions of Care Coordination[55] • (See Appendix A) • 2013 Special Needs Plans Structure and Process Measures (See SNP Element 1), National Committee for Quality Assurance (NCQA)[56] • A Standardized Approach to a Shared Plan of Care[57]		• NSCYSHCN • CAHPS

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	incorporates and states their goals with clinical goals; and guides the roles, activities, and functions of the family, and the care team[49] o Is routinely evaluated and updated in partnership with the family as needed but no less frequently than every six (6) months[50] o Clearly identifies and delineates the roles, responsibilities, and accountabilities of all entities that participate in a child's care coordination activities. These entities include but are not limited to physical, oral health and mental health care providers and programs, acute care facilities as needed, and other community organizations providing services and supports to the child and family o Is maintained and updated with evaluative oversight and should be used to make timely referrals and track receipt of services[51]			
►PEDIATRIC SPECIALTY CARE ***(integrated with the medical home and community-based services)***				
	1. Shared management of CYSHCN between pediatric primary care and specialty providers is permitted.[58] 2. Where needed, systems such as satellite programs, electronic communications, and telemedicine are used to enhance access to specialty care, regional pediatric centers of			

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	excellence where available, and other multidisciplinary teams of pediatric specialty providers. 3. Physical health, oral health and mental health are coordinated and integrated. 4. Pediatric centers of care (e.g., cardiac, regional genetics, end stage renal disease, perinatal care, transplants, hematology/oncology, pulmonary, craniofacial, and neuromuscular) are available to CYSHCN and their families when needed. 5. The system serving CYSHCN includes Title V CYSHCN programs, LEND and UCEDD Centers for individuals[1] with developmental disabilities, where available. 6. Durable medical equipment and home health services are customized for CYSHCN. 7. A "full continuum" of services for children's behavioral health needs, including acute services in a 24-hour hour clinical setting, intermediate services, and outpatient services and community support services are provided.[59]			

[1]**L**eadership **E**ducation in **N**eurodevelopmental and Related **D**isabilities Programs (LENDS) are interdisciplinary leadership training programs Federally funded through HRSA's MCHB. LEND programs operate within a university system, usually as part of a University Center for Excellence (UCEDD). UCEDDs collaborate with local university hospitals and/or health care centers.

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COMMUNITY-BASED SERVICES AND SUPPORTS				
	CYSHCN and their families are provided access to comprehensive home 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, child welfare, mental health, and home health care organizations. 1. Agreements are in place between the health systems and various community agencies and programs serving CYSHCN and are structured to: o promote family support through linking families to family organizations and other services and supports o promote shared financing o establish systems for timely communications and appropriate data sharing o ensure access and coordination of services for individual children and their families o promote collaboration between community-based organizations and agencies, providers, health care systems, and families o specify responsibilities across the various providers, and community-based agencies serving children and their families[60]	Ease of Use Framework[61] (See Appendix A)		

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► RESPITE CARE				
	1. Respite services, both planned and emergency, are available to all families and caregivers of CYSHCN. 2. Families are informed about available respite services and helped to access them. 3. When out-of-home respite services are needed, transportation is available to help a child and family access these services. 4. Health providers and plans screen families and caregivers of CYSHCN for respite care needs, make them aware of available respite services in their community, and provide them with appropriate and timely referrals to providers that are qualified to serve CYSHCN. 5. Health providers and plans have a system in place for ensuring timely referrals for families of CYSHCN with emergency respite needs.	• Definition of Respite Care: "Planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult." Respite services may be provided in a variety of settings, on a temporary basis, including the family home, adult day centers, respite centers, or residential care facilities. Respite is a key component of family support and home and community-based long-term services and supports[62] • National Respite Guidelines: Guiding Principles for Respite Models and Services. ARCH National Respite Network and Resource Center[63]	The Lifespan Respite Care Act of 2006 (PL 109-442) amends the Public Health Service Act to authorize the Secretary of Health and Human Services to award matching grants or cooperative agreements to eligible state agencies to: (1) expand and enhance respite care services to family caregivers; (2) improve the statewide dissemination and coordination of respite care; and (3) provide, supplement, or improve access and quality of respite care services to family caregivers, thereby reducing family caregiver strain.[64]	
► PALLIATIVE AND HOSPICE CARE				
	1. Curative and palliative care (also known as concurrent care) is available and offered at the same time. 2. Palliative and hospice care utilizes family-centered models of care that respect individual's preferences, value, and cultural beliefs, and provide family access to psychosocial screening and referrals to needed supports and services. 3. The child and family plays an active role in decision making regarding goals and plans of care.	Guiding Principles for Pediatric Palliative Care, National Hospice and Palliative Care Organization (NHPCO)[65] (See Appendix A)	• Provision of curative and palliative care (also known as concurrent care) to be offered at the same time[66] • Coverage of hospice services for children with a life expectancy of six months or less is required under Medicaid and CHIP[67] • Section 2302 of the ACA requires all state Medicaid programs to	

SYSTEM DOMAINS	System Standards (Structure and Process)	Existing National Principles and Frameworks	Federal Requirements or Relevant Federal Law	Overall Availability of Relevant Quality Measures
			pay for both curative and hospice services for children under 21 who qualify (termed "Concurrent Care for Children" Requirement (CCCR))[68]	
►HOME-BASED SERVICES				
	1. Home health care is a covered benefit for CYSHCN that includes health care for the child and supportive care for the family, and is provided in the family's home by licensed professionals who have experience in pediatric care.[69]		• The EPSDT benefit requires coverage of medically necessary personal care, private duty nursing, and physical, occupational and speech-language therapy in the home or other community-based settings, as appropriate for the individual child	
FAMILY PROFESSIONAL PARTNERSHIPS				
Families of CYSHCN will partner in decision making at all levels and will be satisfied with the services they receive.	1. Families are active, core members of the medical home team. 2. Family priorities and concerns are central to care planning and management. 3. Families are connected to family organizations, peer support and family support programs. 4. Family strengths, including cultural and ethnic identities, are respected in the delivery of care.[70] 5. Care is delivered in culturally appropriate ways, respecting family desires for inclusion of extended family members in decision making.			• NSCYSHCN • PHDS • CAHPS • ECHO • CMHI • Title V Maternal and Child Health Services Block Grant Guidance, Form 13

SYSTEM DOMAINS	System Standards (Structure and Process)	Existing National Principles and Frameworks	Federal Requirements or Relevant Federal Law	Overall Availability of Relevant Quality Measures
	6. Families receive information about the services and supports that they will receive in a method chosen by the family (e.g., written, verbal, language of choice).[71] 7. All written materials provided to CYSHCN and their families are culturally appropriate, provided in the primary language of the CYSHCN and their family, and provided in a manner and format appropriate for children and their parents or caregivers who have limited English proficiency or sensory impairments. 8. Health systems that serve CYSHCN solicit feedback from the family and children on the experience of care that they receive. 9. Health systems that serve CYSHCN have a family advisory board or committee, inclusive of families of CYSHCN that guides their policies, programs and quality improvement activities and offers family members training, mentoring, and reimbursement for their participation as active members of these boards and committees.[72]			
TRANSITION TO ADULTHOOD				
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.	**Pediatric Setting**: 1. A policy and process for transition preparation and planning for youth with special health care needs (YSHCN) and their families as they prepare to move between pediatric and adult care systems is in place within the health plan and medical home.[73] YSHCN are encouraged to learn about and engage in their health care as part of this process.	• AAP/AAFP/ACP Clinical Report on Transition[74] • Six Core Elements of Health Care Transition (Version 2.0)[75] (See Appendix A)		NSCYSHCN

SYSTEM DOMAINS	System Standards (Structure and Process)	Existing National Principles and Frameworks	Federal Requirements or Relevant Federal Law	Overall Availability of Relevant Quality Measures
	2. An individual flow sheet or registry for identifying transitioning YSHCN is maintained by the health plan and medical home to track completion of the transition process. 3. A transition readiness assessment and plan of care, including a medical summary and emergency care plan, are first developed when a YSHCN reaches age 14, and then regularly updated in partnership with the youth and her/his family or caregiver. A family's cultural beliefs are respected in the development of the transition plan. 4. A transfer package including a final transition readiness assessment, plan of care with transition goals, and medical summary and emergency plan is prepared and communicated with the new adult medical home, prior to the transfer of a YSHCN from a pediatric to an adult medical home. 5. The pediatric medical home is available for consultation assistance with the adult medical home, as needed. 6. A process is in place in the pediatric medical home to ensure that follow-up of a YSHCN is provided 3 – 6 months after transfer to an adult medical home to confirm transfer and elicit feedback on their transition experience. 7. Transition quality improvement includes collaboration and, for some YSHCN, co-management between pediatric and adult health care providers.			

SYSTEM DOMAINS	System Standards (Structure and Process)	Existing National Principles and Frameworks	Federal Requirements or Relevant Federal Law	Overall Availability of Relevant Quality Measures
	Adult Setting: 1. A policy describing the adult medical home approach to accepting and partnering with new YSHCN, including legal changes at age 18, is in place. 2. An individual flow sheet or registry for identifying transitioning YSHCN through 26 years of age is maintained by the health plan and medical home to track completion of the transition process. 3. A process for identifying providers who are interested in caring for YSHCN exists at the adult medical home and health plan levels. 4. A process for welcoming and orienting young adults exists within the adult medical home. 5. A process for confirming the transfer between the pediatric and adult medical home is in place to assist the YSHCN with ongoing care management and referral to adult specialists and other community supports and elicit feedback about their experience of care.			
HEALTH INFORMATION TECHNOLOGY				
	1. Electronic health record systems meet meaningful use requirements. 2. Medical homes have the capacity for electronic health information and exchange, including maintenance of clinical information.[76] 3. Families have easy access to their electronic health information and the opportunity to contribute to the record. 4. HIT systems incorporate the five specific health policy priorities of the Centers for Medicare and Medicaid		• Technology for Economic and Clinical Health Act (HITECH) enacted as part of the American Recovery and Investment Act of 2009 (ARRA) outlines Title IV of Division B of ARRA which authorizes infrastructure creation	CMS Stage 1 and Stage 2 “meaningful use” criteria includes clinical quality measures.

SYSTEM DOMAINS	System Standards (Structure and Process)	Existing National Principles and Frameworks	Federal Requirements or Relevant Federal Law	Overall Availability of Relevant Quality Measures
	Services: improving quality, safety, and efficiency; improving patient access to care; improving care coordination; improving public health; and ensuring privacy and security protections for personal health insurance.[77] 5. To promote care coordination across providers and systems serving children, electronic health information should be accessible, retrievable, and available, and use a documented process for exchanging health information across care settings that includes an agreement about exchanging information, the types of information to be exchanged, time frames for exchanging information, and how the health plan facilitates referrals.[78]		to promote nationwide adoption of "meaningful use" of certified electronic health records (EHR) technology. "Meaningful use" is promoted via incentive payments for Medicare and Medicaid providers who become certified "meaningful users"[79,80] • The Health Insurance Portability and Accountability Act outlines requirements regarding confidentiality and sharing of information[81,82]	
QUALITY ASSURANCE AND IMPROVEMENT				
	1. Health plans and insurers have a specific and ongoing quality assurance (QA) and quality improvement (QI) process in place for CYSHCN and their families. This includes: o families of CYSHCN as members of the primary care provider and health plan QI teams o periodic monitoring of network provider capacity to ensure the full continuum of children's physical, oral health and mental health needs are met on a timely basis and promote geographic accessibility to needed services[83] o periodic monitoring of utilization of	2013 Special Needs Plans Structure and Process Measures (SNP Element 2), National Committee for Quality Assurance (NCQA)[87]	• Federal law requires state Medicaid programs using managed care organizations (MCOs) or prepaid inpatient health plans (PIHPs) to develop and update a quality strategy that includes standards for access to care, health plan structure and operations, and quality measurement and improvement • Part 438 of the federal	• CAHPS • Agency for Health Care Research, Center for Outcomes and Evidence

SYSTEM DOMAINS	System Standards (Structure and Process)	Existing National Principles and Frameworks	Federal Requirements or Relevant Federal Law	Overall Availability of Relevant Quality Measures
	care by CYSHCN and their families, appropriateness of care for CYSHCN, and compliance with all system standards for CYSHCN[84] o experience of care surveys of families of CYSHCN and youth (including targeted feedback from relevant racial/ethnic and language groups) to obtain their feedback and assess their experiences with care[85] o assessment of out of pocket expenses and lost work burden on families o assessment of child outcomes including measures of health and functional status 2. Child medical record reviews include a sample of CYSHCN. 3. The utilization review and appeals processes for CYSHCN include members of a child's integrated care team.[86]		Medicaid regulations requires that states using a managed care delivery system must have a written quality strategy for assessing and improving the quality of managed care services offered[2]	
INSURANCE AND FINANCING				
Families of CYSHCN have adequate private and/or public insurance to pay for the services they need.	1. Insurance plans for CYSHCN are affordable and have cost-sharing policies that protect CYSHCN and their families from financial strain and are without risk of loss of benefits.[88] 2. Coverage and payment levels are adequate to facilitate access to	National Association of Insurance Commissioners Definition of habilitative Services: "health care services that help a person keep, learn or improve skills and functioning for daily living."[97]	The Essential Health Benefits provisions of the ACA designate mandatory classes of benefits including "rehabilitative and habilitative services and devices."	

[2]Under Part 438 of the federal Medicaid regulations, states using a managed care delivery system must have a written quality strategy for assessing and improving the quality of managed care services offered. States must solicit recipient and stakeholder participation in the development of the quality strategy. The strategy must include, at a minimum, quality standards and measures, procedures to assess quality of care, regular monitoring of managed care plans for compliance with standards, and an annual, external independent review of quality. The quality standards must include but are not limited to access standards, assurance of adequate capacity and services, and coordination and continuity of care. States must implement a mechanism for identifying children with special health care needs to managed care plans. The managed care plans must then provide assessments and direct access to specialists.

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	pediatric primary care and comprehensive and coordinated medical subspecialty and surgical specialty services; developmental, behavioral, and mental health services; inpatient and emergency department care; home health care; dental care; and other specialized pediatric services within a medical home model of care.[89] 3. All children, including CYSHCN, have access to medically necessary services to promote optimal growth and development, maintain and avert deterioration in functioning, and to prevent, detect, diagnose, treat, ameliorate, or palliate the effects of physical, genetic, congenital, developmental, behavioral, or mental conditions, injuries, or disabilities.[90] 4. Comprehensive habilitative services include therapies, services and devices for a child, based upon their individual needs, to prevent and avert deterioration of functioning or attain or maintain a skill or function never learned or acquired due to a chronic or disabling condition, including those early intervention services specified in a child's Individualized Family Service Plan (IFSP as part of Early Intervention) and the services outlined in a school-age child's Individualized Education Plan (IEP as part of Special Education) are available.[91] 5. Habilitative services are a covered benefit and offered in addition to rehabilitative services, and are of like type and substantially equivalent in scope, amount and duration to rehabilitative services.[92,93,94] 6. Provider payment policies promote			

SYSTEM DOMAINS	System Standards (Structure and Process)	Existing National Principles and Frameworks	Federal Requirements or Relevant Federal Law	Overall Availability of Relevant Quality Measures
	recruitment and retention of primary care providers (e.g., pediatricians, pediatric nurse practitioners) and pediatric medical and surgical specialists and serve to incentivize providers. 7. Authorization processes are flexible to the unique aspects of CYSHCN and simplified to promote access to services.[95] 8. Families of CYSHCN may seek second opinions from qualified health care providers without restrictions to such opinions.[96] 9. Performance or financial incentives are in place to promote medical homes and care coordination and enhance access to services and promote quality.			

Appendix A: Additional Resources for Existing National System Definitions, Principles, and/or Frameworks

SYSTEM DOMAIN	Existing National Principles and/or Frameworks
SCREENING, ASSESSMENT, AND REFERRAL	
	Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents[98]
ACCESS TO CARE	
	Core Set of Children's Health Care Quality Measures for Medicaid and CHIP (Child Core Set)[99]
MEDICAL HOME	
NCQA Goals:[100] 1. Enhance access and continuity 2. Identify and manage patient populations 3. Plan and manage care 4. Provide self-care and community support 5. Track and coordinate care 6. Measure and improve performance **NCQA Medical Home Standards:**[101] 1. Access and Communication 2. Patient Tracking and Registry Functions 3. Care Management 4. Patient Self-Management Support 5. Electronic Prescribing 6. Test Tracking 7. Referral Tracking 8. Performance Reporting and Improvement 9. Advanced Electronic Communications **Medical Home Index Domains:**[102] 1. Organizational Capacity 2. Chronic Condition Management 3. Care Coordination 4. Community Outreach 5. Data Management 6. Quality Improvement/Change	**Joint Principles of the Patient Centered Medical Home**:[103] 1. Personal physician – each patient has an ongoing relationship with a personal physician trained to provide first contact, continuous and comprehensive care 2. Physician directed medical practice – the personal physician leads a team of individuals at the practice level who collectively take responsibility for the ongoing care of patients 3. Whole person orientation – the personal physician is responsible for providing for all the patient's health care needs or taking responsibility for appropriately arranging care with other qualified professionals. This includes care for all stages of life; acute care; chronic care; preventive services; and end of life care 4. Care is coordinated and/or integrated across all elements of the complex health care system (e.g., subspecialty care, hospitals, home health agencies, nursing homes) and the patient's community (e.g., family, public and private community-based services). Care is facilitated by registries, information technology, health information exchange and other means to assure that patients get the indicated care when and where they need and want it in a culturally and linguistically appropriate manner 5. Quality and safety are hallmarks of the medical home: • Practices advocate for their patients to support the attainment of optimal, patient-centered outcomes that are defined by a care planning process driven by a compassionate, robust partnership between physicians, patients, and the patient's family • Evidence-based medicine and clinical decision-support tools guide decision making • Physicians in the practice accept accountability for continuous quality improvement through voluntary engagement in performance measurement and improvement • Patients actively participate in decision-making and feedback is sought to ensure patients' expectations are being met • Information technology is utilized appropriately to support optimal patient care, performance measurement, patient education, and enhanced communication • Practices go through a voluntary recognition process by an appropriate non-governmental entity to demonstrate that they have the capabilities to provide patient centered services consistent with the medical home model • Patients and families participate in quality improvement activities at the practice level • Enhanced access to care is available through systems such as open scheduling, expanded hours and new options for communication between patients, their personal physician, and practice staff 6. Payment appropriately recognizes the added value provided to patients who have a patient-centered medical home. The payment structure should be based on the following framework: • It should reflect the value of physician and non-physician staff patient-centered care management work that falls outside of the face-to-face visit • It should pay for services associated with coordination of care both within a given practice and between consultants,

	ancillary providers, and community resources • It should support adoption and use of health information technology for quality improvement • It should support provision of enhanced communication access such as secure e-mail and telephone consultation • It should recognize the value of physician work associated with remote monitoring of clinical data using technology • It should allow for separate fee-for-service payments for face-to-face visits. (Payments for care management services that fall outside of the face-to-face visit, as described above, should not result in a reduction in the payments for face-to-face visits) • It should recognize case mix differences in the patient population being treated within the practice • It should allow physicians to share in savings from reduced hospitalizations associated with physician-guided care management in the office setting • It should allow for additional payments for achieving measurable and continuous quality improvements
PEDIATRIC AND PREVENTIVE PRIMARY CARE (as part of the medical home)	
	Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents[104]
CARE COORDINATION	
"Pediatric care coordination is a patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families. Care coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs in order to achieve optimal health and wellness outcomes."[105]	**National Quality Forum Framework for Care Coordination:**[106] • A proactive plan of care that includes follow-up monitoring of progress toward patient-specific goals • Communication between and among all members of the health care team and the patient, emphasizing shared decision-making with families • Use of standardized, electronic information systems • Coordinated efforts to optimize safety and accuracy during handoffs, or transfers between health care settings **Key Elements of High-Performing Pediatric Care Coordination Framework:**[107] 2. Needs assessment for care coordination and continuing care coordination engagement 3. Care planning and communication 4. Facilitating care transitions (inpatient, ambulatory) 5. Connecting with community resources and schools 6. Transition to adult care **The Functions of Care Coordination:**[108] 1. Establish relationships with children, youth, and families through introductory visits dedicated to setting expectations for care coordination 2. Promote communication with families and among professional partners, and define minimal intervals between communications 3. Complete a child/youth and family assessment 4. Working with the family, develop a written care plan, including a medical summary, action plan, and, if needed, an emergency plan, that reflects mutual goals 5. Arrange for, set up, and coordinate referrals, and track referrals and test results 6. Provide condition-specific and related medical, financial, educational, and social supportive resource information, while coaching for the transfer of skills supportive of partnerships with families to care for their children and youth 7. Ensure the health care team integrates multiple sources of health care information; communicate this summary, thereby building caregiver skills and fostering relationships between the health care team and families 8. Support and facilitate all care transitions from practice to practice and from the pediatric to adult systems of care 9. Coordinate family-centered team meetings (across organizations as needed)

	10. Use health information technology to effectively deliver and continually monitor care coordination and the effectiveness of service delivery **The Ten Steps for Plan of Care Development:**[109]
COMMUNITY-BASED SERVICES AND SUPPORTS	
	Ease of Use Framework:[110] 1. Universality of System: Engages all eligible families and CYSHCN: a. Identification of families and youth eligible for services b. Effective outreach specifically tailored to families/CYSHCN c. Screening and referral promote utilization and access d. Continuous monitoring and assessment of sub-populations in need 2. Accessibility of Services: Families and CYSHCN get the services they need a. Services are available to families and CYSHCN b. Labor/Workforce Development activities are tied to needs of families/CYSHCN c. Supply of providers/specialists meets population needs d. Competencies of providers/specialists e. Providers/specialists accept FCYSHCN (Families of CYSHCN) into practice f. Services are convenient for FCYSHCN 3. Value of Services: Services are valued by families and CYSHCN and make measurable advances in functioning and development a. Family/CYSHCN experience indicators are included in quality assessments b. Family and child/youth satisfaction ratings are acted upon to improve service delivery c. CYSHCN measures of functioning in school, home, and community are outcomes of services d. Services for CYSHCN are measured for improving growth and development e. Community based services meet the full comprehensive needs of families and CYSHCN 4. Affordability: Services are affordable and enable families to maintain economic security a. Direct costs of services are reasonable b. Direct costs are predictable c. Indirect costs of services are contained (such as but not limited to travel costs, family time off from work, child time out of school, job attachment, and time spent acquiring or waiting for services is minimal)
RESPITE CARE	
Definition: Planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult.[111]	**National Respite Guidelines: Guiding Principles for Respite Models and Services**[112] **Principles of Quality Respite Care:**[113] 1. Respite is available to all families and caregivers. Respite should be available to any caregiver providing ongoing care for individuals of any age with any physical or mental disability, chronic or terminal illness, or other special need, or at risk of abuse or neglect, regardless of family income, race, gender or situation 2. Respite is accessible. Respite should be easily accessible by caregivers when, how, and where it is needed 3. Respite is affordable. Sufficient resources should be available to ensure that all caregivers have access to high quality respite services 4. Planned and emergency respite is available. Respite is also an important component of a continuum of comprehensive family support services available to caregivers not only on a planned basis, but also in emergency situations 5. Families have an array of options and can choose respite services that meet their unique needs. A wide array of respite options, including in-home and out-of-home, and a diverse pool of providers that meet families' needs should be available. Culturally competent providers should be available to all families. Caregivers should be free to choose their respite providers

	6. Respite systems address capacity issues and ensure enough providers are available. The current supply of individuals available to provide respite is inadequate in many communities, especially respite for individuals with mental illness or severe medical conditions, or in some rural and urban areas 7. Respite systems ensure caregivers are aware of respite and know how to access respite. Adequate outreach and support services should be made available to increase caregiver awareness about available respite options and community resources 8. Respite systems empower caregivers to select, hire and train competent providers. A mechanism should be in place to support and assist caregivers in the process of selecting providers to meet their individual needs 9. Respite systems are made up of agencies and individuals committed to addressing gaps and barriers in services 10. Respite systems should include families, stakeholders, agencies and community-based partners 11. Respite is high quality. All available and accessible respite options should be of high quality and ensure the safety of the individual being cared for. Services are evaluated and feedback from families drives program improvements
PALLIATIVE AND HOSPICE CARE	
	NHPCO Guiding Principles for Pediatric Palliative Care and Hospice:[114] 1. **Patient and Family Centered Care**: The palliative care and/or hospice interdisciplinary team provides family centered care that includes the child and family as one unit of care, respecting individual preferences, values, and cultural beliefs, with the child and family active in decision making regarding goals and plan of care 2. **Ethical Behavior and Consumer Rights**: The best interests of the child shall be the primary consideration in decision making 3. **Clinical Excellence and Safety**: Health professionals providing pediatric palliative care and/or hospice have a responsibility to pursue comfort aggressively and minimize the child's physical, psychosocial, and spiritual pain and suffering 4. **Organization Excellence**: Flexibility in pediatric program design and service delivery facilitates access to services for children. A pediatric palliative care and/or hospice model that offers multiple support services over time and across settings ensures enhanced access for this underserved population 5. **Workforce Excellence**: The organization's leadership develops and monitors systems to ensure that pediatric palliative care and/or hospice interdisciplinary team members, including volunteers, are adequately trained, staffed and supported to provide the services offered by the program, and that sufficient support is in place for staff to engage in routine self-care 6. **Standards**: Palliative care and/or hospice programs adopt the NHPCO Standards of Practice for Hospice Programs, and utilize the appendix "Standards of Practice for Pediatric Palliative Care and Hospice" as the foundation for their pediatric care 7. **Performance Measurement**: The program develops, defines and utilizes a systematic approach to improving performance. This approach is authorized and supported by the program's governing body and leaders. The approach assures that information is collected and analyzed, actively uses performance measurement data to foster quality assessment performance improvement, and is specific to pediatric patients being served
TRANSITION TO ADULTHOOD	
Sample tools to implement the Six Core Elements of Health Care Transition (Version 2.0) are available at **www.gottransition.org**.	**Six Core Elements of Health Care Transition (Version 2.0):**[115] 1. Transition Policy 2. Transitioning Tracking and Monitoring 3. Transition Readiness 4. Transition Planning 5. Transfer of Care 6. Transition Completion
HABILITATIVE SERVICES	
	National Association of Insurance Commissioners: Definition of habilitative services: "health care services that help a person keep, learn or improve skills and functioning for daily living."[116]

ENDNOTES:

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