Standards
for Systems of
Care for Children
and Youth with
Special Health Care Needs
Version 2.0

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AMCHP
ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

NASHP
NATIONAL ACADEMY FOR STATE HEALTH POLICY

Lucile Packard Foundation
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Acknowledgements

Dedication to Phyllis Sloyer

We dedicate the National Standards for Children and Youth with Special Health Care Needs, Version 2.0 in fond memory of Phyllis Sloyer, former director of the Florida Children's Medical Services Network, AMCHP president, consultant and advisor to this project, long-standing advocate and champion for children, friend, and mentor. Phyllis' decades of work to develop, advise, and shape health care systems so that they best meet the needs of children with chronic and complex health care conditions and their families is borne out in the content of these National Standards. We are indebted to her legacy.

About AMCHP

The Association of Maternal & Child Health Programs (AMCHP) 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 NASHP

The National Academy for State Health Policy (NASHP) is an independent academy of state health policymakers. We are dedicated to helping states achieve excellence in health policy and practice. A nonprofit and nonpartisan organization, NASHP provides a forum for constructive work across branches and agencies of state government on critical health issues. To accomplish our mission, we: convene state leaders to solve problems and share solutions, conduct policy analyses and research, disseminate information on state policies and programs, and provide technical assistance to states. The responsibility for health care and health care policy does not reside in a single state agency or department. At NASHP, we provide a unique forum for productive interchange across all lines of authority, including executive offices and the legislative branch.

About the Foundation

The mission of the Lucile Packard Foundation for Children's Health 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.

Children and youth with special health care needs (CYSHCN) are a diverse group of children ranging from children with chronic conditions, to children with autism, to those with more medically complex health issues, 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] Approximately 15 percent of all U.S. children ages birth to 18 years (over 11 million children) have a chronic and/or complex health care need.[2] A smaller but growing group of children have complex health care needs (approximately 3 million children), with estimates for children with the highest levels of need ranging from 0.4 – 0.7 percent of all U.S. children (approximately 320,000 – 560,000 children).[3]

Creating a comprehensive, quality system of care for 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. For more than three decades, numerous national reports, initiatives and research studies have described or called for frameworks, standards, and various measures to advance a comprehensive system of care for CYSHCN and

their families. Efforts in the mid-1980s, led by Surgeon General C. Everett Koop, called for a national agenda to "develop strategies for comprehensive services needed by children with special health care needs, address the challenges and burdens of the families of these children, and stimulate community resources."[4] Since that time, the Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) adopted and led federal efforts to focus on the following six system outcome areas tied to national performance measures for CYSHCN: 1) families as partners, 2) medical homes, 3) financing of care for needed services, 4) coordinated services, 5) early and continuous screening, and 6) effective transition to adult health care.[5] The MCHB, HRSA has a longstanding commitment to and investment in improving systems of care for CYSHCN as part of its federal mandate through

the Title V Maternal and Child Health Services Block Grant program. This work includes national guidelines on the core elements of a comprehensive system of care[6], a definition of CYSHCN[7] and related data collection and tracking[8], promotion of a medical home through creation of the National Center for Medical Home Implementation[9], investments in research and workforce development. These and other efforts have helped to establish important efforts 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, nationally endorsed set of standards for a system of care for CYSHCN.

Building upon this work in March 2014, the National Consensus Framework for Improving Quality Systems of Care for Children and Youth with Special Health Care Needs project, funded by the Lucile Packard Foundation for Children's Health, released a core set of structure and process standards for systems of care for CYSHCN along with a white paper on the development of the standards.[10] These National Standards were the result of decades of work to establish an endorsed set of standards that could be used and applied within health care systems to improve quality and outcomes for CYSHCN. The system standards were fully vetted by a national work group comprised of state and national leaders with expertise in CYSHCN, health systems, and quality measurement.

The National Standards address the core components of the structure and process of an effective system of care for CYSHCN. The Standards Version 1.0 were derived from a comprehensive review of the literature, early guidance

The Standards Version 1.0 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 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.

Since their publication in 2014, the National Standards have been used by 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 to improve systems of care for CYSHCN.

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Since their publication in 2014, the National Standards have been used by 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 to improve systems of care for CYSHCN.

About Version 2.0
In version 2.0, the National Standards have been updated to increase the readability and ease of use while also maintaining their integrity and essential content. This revision was done with input from the National Standards work group as well as other key stakeholders and subject matter experts. A list of the national work group members can be found on the inside cover.
Version 2.0 of the National Standards for CYSHCN uses and builds upon the critical domains, elements, and standards from the original National Standards work (Version 1.0), while streamlining content for easier use by states and stakeholders. It is organized by eight core domains, with Family Professional

Partnerships and Insurance and Financing as foundational standards that should exist in any system that serves CYSHCN. Individual standards from these two previous domains in Version 1.0 are retained in either the foundational standards or in one of the eight relevant domains in Version 2.0. Standards that were focused on clinical care have been moved to the appendices or reframed to focus on standards at the systems level. Finally, all standards have been reviewed and updated with recent federal guidance or regulations in mind, such as the Medicaid and CHIP Managed Care Final Rule released in 2016.

The National Standards for Systems of Care for Children and Youth with Special Health Care Needs (Version 2.0) are guided by the following essential principles. These four principles are the foundation for all standards in each domain, and should be in place to ensure a comprehensive, quality system of care for children and youth with special health care needs (CYSHCN).

Foundational Standards for Systems of Care for CYSHCN:

1. Children and families of CYSHCN are active, core partners in decision making in all levels of care.
2. All services and supports for CYSHCN are implemented and delivered in a culturally competent, linguistically appropriate, and accessible manner to best serve CYSHCN and their families. All written materials provided to CYSHCN and their families are culturally appropriate, provided in the primary language of the CYSHCN and their family, and in a manner and format appropriate for children and their parents or caregivers who have limited English proficiency, lower levels of literacy, or sensory impairments.
3. Insurance coverage for CYSHCN is accessible, affordable, comprehensive, and continuous.[11]
4. All care provided to CYSHCN and their families is evidence-based where possible, and evidence-informed and/or based on promising practices where evidence-based approaches do not exist.

Table of Contents: Core Domains for System Standards

System Standards

Children are screened early and continuously for special health care needs.

Identification

1. The state system should have a definition for CYSHCN.[12]
2. Upon enrollment and transfer between insurance coverage (e.g., public and private), a mechanism for identifying CYSHCN is in place.[13]

Screening

3. CYSHCN receive periodic, developmentally appropriate, and recommended comprehensive screenings according to the Bright Futures guidelines.[14]
4. Screening results are documented and coordinated with the medical home.[15]
5. State newborn screening information is delivered to providers and parents in a timely fashion, and arrangements for necessary follow-up services are documented. If indicated, repeat screening results and follow-up are communicated by the hospital or state program to the newborn's health plan, medical home, and specialty providers. [16]
6. The child's health plan and medical home have a documented plan and process to demonstrate follow-up with a hospital or state health department when newborn screening results are not received.[17]

Assessment

7. CYSHCN are provided a documented initial health assessment within 90 days[18] of enrollment in a health plan.
8. Screening efforts, results, and referrals for further assessment are documented and coordinated with the child's medical home and health plan.[19]

Referral/Follow-up

9. Following a screening and assessment, CYSHCN are referred to needed services including pediatric specialists, therapies, and other service systems.[20]
10. Protocols and documentation methods are in place for the child's medical home to follow-up with the child and family to ensure referred services were accessed and to provide any assistance in accessing needed care, regardless of the original entity conducting a screening and referral.[21]

Related National Principles and Frameworks

► Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents, American Academy of Pediatrics[22]
► Draft Structure and Process Measures for Integrated Care for People with Dual Eligibility for Medicare and Medicaid, National Committee for Quality Assurance[23]

System Domain
Eligibility and Enrollment in Health Coverage

System Standards

1. Outreach activities to enroll children into insurance coverage include strategies designed and proven to be effective in reaching CYSHCN and their families.[24]
2. A comprehensive member services program with specialized staff is available to provide information and assistance to CYSHCN and their families in areas including: covered and non-covered services; additional or supplemental insurance coverage options; eligibility and enrollment questions; navigating the medical and community system of care available for CYSHCN;[25] enrollee status; complaints and grievances; and selection of primary care provider, specialists, or medical homes with experience in serving CYSHCN.[26]
3. Information and materials related to insurance program eligibility and enrollment processes are provided in such a manner as to be easily understood by the enrollee's family.[27]
4. Continuity of care is ensured during periods of enrollment and transition, such as changes in or temporary loss of insurance coverage.[28]
5. Written policies and procedures are in place at the system level for transitioning CYSHCN between non-network and network providers, including communication with the medical home and family.[29]
6. 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.[30]

System Standards

1. The system has the capacity and processes in place to ensure CYSHCN have geographic and timely access to primary and specialty services, including in-network and out-of-network providers; physical, mental and dental health care providers; pediatric primary care and pediatric subspecialists; children's hospitals; pediatric regional centers where available; and ancillary providers.[31]

2. Reasonable access requirements and wait times are in place for routine, episodic, urgent, and emergent physical, oral, and mental health and habilitative services. Same-day appointments are made available for urgent care services.[32]

3. Transportation assistance is provided to families with difficulties accessing needed medical services.[33]

4. Satellite programs, electronic communications, and telemedicine are used to enhance access to specialty care and regional pediatric centers of excellence, where available, and other multidisciplinary teams of pediatric specialty providers.[34]

5. Written policies and procedures are in place that describe how CYSHCN choose and/or are assigned to a primary care provider (PCP) and how they may change their PCP.[35]

6. Pediatric specialists who have a demonstrated clinical relationship as the clinical coordinator of all care for the child, including health supervision and anticipatory guidance, are able to serve as a primary care provider (PCP).[36]

7. A documented process is in place for how to access pediatric specialists (face-to-face or via telemedicine) specified in a child's plan of care. (See Care Coordination domain for specifics on plans of care)

8. All health insurance programs cover medically necessary services, which are defined as services for "the prevention, diagnosis, and treatment of an enrollee's disease, condition, and/or disorder that results in health impairments and disability; the ability for an individual to achieve age-appropriate growth and development; the ability for an enrollee to attain, maintain, and retain functional capacity; and the opportunity for an enrollee receiving long term services and supports to have access to the benefits of community living, to achieve person centered goals, and live and work in the setting of their choice.".[37,38]

9. Comprehensive 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. [39,40,41,42]

10. Authorization processes take into account the unique needs of CYSHCN and are simplified to promote access to services.[43]

11. Families of CYSHCN are able to access second opinions from qualified health care providers without restrictions to such opinions.[44]

Related National Priciples and Frameworks

The National Association of Insurance Commissioners (NAIC) defines habilitation services as "health care services that help a person keep, learn, or improve skills and functioning for daily living."[116]

System Standards

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

1. All CYSHCN have a medical home capable of providing or coordinating services to meet the child's medical, dental, and social-emotional needs.[45]
2. The medical home provides team-based care that is led by a primary care clinician and/or pediatric subspecialist and in which the family is a core member.[46]

Related National Priciples and Frameworks

► AAP Medical Home Policy Statement[47]
► Joint Principles of the Patient Centered Medical Home[48]
► Medical Home Index (Six Domains), Center for Medical Home Improvement[49]
► Family-Centered Care Assessment for Families (FCCA-F), National Center for Family Professional Partnerships[50]
► Standards and Guidelines for NCQA's Patient-Centered Medical Home (PCMH) 2017, NCQA[51]

Pediatric Preventive and Primary Care *(as part of the medical home)*

System Standards

1. Care focuses on overall health, wellness, and prevention of secondary conditions.[45]
2. CYSHCN receive recommended immunizations according to the Advisory Committee on Immunization Practices (ACIP).[46]

Related National Priciples and Frameworks

Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents, American Academy of Pediatrics[53]

Medical Home Management

System Standards

1. The medical home provides access to health care services 24 hours, seven days a week.
2. The medical home utilizes scheduling systems that recognize the additional time involved in caring for CYSHCN.[54]
3. The medical home provider performs comprehensive health assessments.[55]
4. Pre-visit assessments are completed by the medical home with the family to ensure the medical home team has comprehensive data on the child/family and provides care in an appropriate manner.[56]
5. Accommodations for special needs, such as provision of home visits versus office visits are made available by the medical home.
6. The medical home conducts activities to support CYSHCN and their families in self-management of the child's health and health care.
7. The medical home develops, maintains, and updates a comprehensive, integrated plan of care that includes patient/family identified goals.[57] (See standards for care coordination).
8. The medical home serving CYSHCN has a process for keeping an updated record of and managing medications.[58]
9. The medical home integrates care with other providers and ensures that information is shared effectively with families and among and between providers.
10. The medical home conducts effective transitions of care between primary and specialty services, facilities, and providers and institutional settings to ensure preference for health services and sharing of information across systems.[59]
11. The medical home performs care tracking, including sending of proactive reminders to families and clinicians of services needed, via a registry or other mechanism.[60]

Care Coordination *(as part of the medical home and integrated with community-based services)*

System Standards

1. All CYSHCN have access to patient- and family-centered care coordination that integrates physical, oral, mental health and community-based services.[61]
2. To provide optimal coordination and integration of services that are needed by the child and family, care coordinators:
   ► serve as a member of the medical home team,[62,63]
   ► have ongoing relationships with families, medical care providers, and other partners in care,[64]
   ► use biopsychosocial assessments to help families articulate goals and priorities for care which take into account social determinants that impact the health of their child,[65]
   ► assist in managing care transitions of CYSHCN across settings and developmental stages, and[66]
   ► provide appropriate resources to match the health literacy level, primary language, and culture of CYSHCN and their family.[67]
3. A plan of care is jointly developed, shared, and implemented among the CYSHCN and their family, primary care provider and/or the specialist serving as the principal coordinating physician and members of the health care team.[68]

4. Family strengths are respected in the delivery of care, extended family members are included in decision-making according to the family's wishes and family-driven goals are incorporated into the plan of care.[69]

Related National Principles and Frameworks

► Definition of Care Coordination[70] (See Appendix A)
► National Quality Forum Framework for Care Coordination[71] (See Appendix A)
► The Functions of Care Coordination[72] (See Appendix A)
► 2013 Special Needs Plans Structure and Process Measures (See SNP Element 1), National Committee for Quality Assurance (NCQA)[73]
► Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs: Report and Implementation Guide[74]
► Patient and Family Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems[75]

Pediatric Specialty Care *(integrated with the medical home and community-based services)*

System Standards

1. Comprehensive specialty services, including behavioral health services, acute services in a 24-hour clinical setting, intermediate services, and outpatient services and community support services are made available by specialty providers when needed.[76]
2. The system encourages shared management of CYSHCN between pediatric primary care and specialty providers through payment models or other policies that promote improved integration among multiple systems.[77]

System Standards

CYSHCN and their families are provided access to comprehensive home and community-based supports.

1. Agreements are in place between the health systems and community agencies including family organizations, public health, education, Early Intervention (Part C), Special Education, child welfare, mental health, and home health care organizations and are structured to:
    - ► promote family support through linking families to family organizations and other services and supports,
    - ► promote shared financing, where appropriate,
    - ► establish systems for timely communications and appropriate data sharing,
    - ► ensure access and coordination of services
    - ► promote collaboration between community-based organizations and agencies, providers, health care systems, and families, and
    - ► specify responsibilities across the various providers, and community-based agencies[78]

Related National Priciples and Frameworks

- ► Ease of Use Framework[79] (See Appendix A)
- ► Standards and Guidelines for NCQA's Patient-Centered Medical Home (PCMH) 2014, NCQA

Respite Care

System Standards

1. Respite services, both planned or emergency, are available to all families and caregivers of CYSHCN.[80]
2. Families and caregivers of CYSHCN are screened for respite care needs, made aware of available respite services in their community, and have a system in place for ensuring timely referrals for families of CYSHCN with emergency respite needs.
3. Families are informed and helped to access available respite services which may be provided in a variety of settings, on a temporary basis, including the family home, respite centers, or residential care facilities.[81]
4. When out-of-home respite services are needed, transportation is available to help a child and family access these services.

Related National Priciples and Frameworks

National Respite Guidelines: Guiding Principles for Respite Models and Services. ARCH National Respite Network and Resource Center[82]

Palliative and Hospice Care

System Standards

1. Curative and palliative care (also known as concurrent care) are both available and offered to families of CYSHCN at the same time.
2. Palliative and hospice care utilizes family-centered models of care that respect the CYSHCN and their family's preferences, values, and cultural beliefs, and provide family access to psychosocial screening and referrals to needed supports and services.

Related National Priciples and Frameworks

Guiding Principles for Pediatric Palliative Care, National Hospice and Palliative Care Organization (NHPCO)[83] (See Appendix A)

Home-Based Services

System Standards

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 professionals who have experience in pediatric care.[84]

System Standards

Youth with special health care needs receive the services necessary to make transitions to adult care.

Pediatric Health Care Setting:
1. **Transition Policy:** A policy about the system's approach to transition is developed and in place at all levels of the system, including privacy and consent information at age 18 and age of transfer. It should be developed with consumer input and shared and discussed with youth and families beginning at ages 12-14 and regularly reviewed as part of ongoing care.[85]
2. **Transition Readiness:** A standardized, scorable tool to determine youth's understanding of self-care and use of health care, initially done with youth and caregiver at age 14 and periodically reassessed by the pediatric provider.
3. **Transfer of Care:** The system should be sure providers make the following documents available to the youth's new provider who serves adult patients (adult provider): a) cover letter, b) final transition readiness assessment, c) updated plan of care, d) updated medical summary and emergency care plan, and e) if needed, legal documents, condition fact sheet, and additional provider records. There should also be a process in place to confirm with the adult provider residual responsibility for patient care until the young adult is seen in the adult care setting.
4. **Transfer Completion:** The system should ensure that there is communication with the adult provider confirming transfer and offering pediatric consultation assistance as needed. The system should contact the young adult/caregiver confirming transfer of care and eliciting feedback on experience with transition process.

Adult Health Care Setting:
1. **Young Adult Transition and Care Policy:** The system should have a policy/statement about the practice's approach to accepting and partnering with new young adults, developed with consumer input and shared and discussed with young adult at first visit and regularly reviewed as part of ongoing care.
2. **Orientation to/Integration into Adult Practice:** The system should identify and list adult providers interested in caring for new young adult patients and be sure there is a young-adult friendly process for welcoming and orienting new young adults into the adult providers' practices and identifying any special needs and preferences. The system should document if the adult providers received the transfer documents.
3. **Initial Visit:** The system should develop an initial visit plan that includes: addressing the young adult's concerns about transfer, clarifying adult approach to care, conducting self-care assessment, reviewing young adult's health priorities as part of a current plan of care, and updating and sharing medical summary and emergency care plan.
4. **Ongoing Care:** The system should communicate with pediatric practices confirming transfer into the adult practice and need for pediatric consultation assistance and assist young adults with connections to adult specialists and other support services, provide ongoing development of self-care skills and care management, and elicit feedback from the young adult about their experience with their health care.

► AAP/AAFP/ACP Clinical Report on Transition[86]
►Six Core Elements of Health Care Transition (Version 2.0)[87] (See Appendix A)

System Domain
Health Information Technology

System Standards

1. Electronic health information should be accessible, retrievable, and available across systems and meet meaningful use requirements.[88]
2. Medical homes have the capacity for electronic health information and exchange, including maintenance of clinical information.[89]
3. Families have easy access to their electronic health information.
4. Documented processes exist for exchanging health information across care settings, including an agreement about exchanging information, the types of information to be exchanged, time frames for exchanging information, and to what extent referrals are made electronically.[90]

Source: United States Breastfeeding Committee

System Standards

1. The state, health plans, providers, and insurers have a specific and ongoing quality assurance (QA) and quality improvement (QI) process in place. This includes:
   ► families of CYSHCN are represented on the primary care provider QI teams and health plan QI teams
   ► periodic monitoring of network provider capacity to ensure the full continuum of children's physical, oral, and mental health needs are met on a timely basis
   ► promotion of geographic accessibility to needed services[91]
   ► periodic monitoring of utilization of care, appropriateness of care, and compliance with all system standards for CYSHCN[92]
   ► conducting experience of care surveys with families of CYSHCN and youth (including targeted feedback from relevant racial/ethnic and language groups) to obtain feedback and assess their experiences with care[93]
   ► assessment of out of pocket expenses, lost work burden, and other sources of stress on families, and
   ► assessment of child outcomes, including measures of health and functional status.
2. Child medical record reviews include a representative sample of CYSHCN so that the experiences of this population are reflected in QA and QI activities.
3. The utilization review and appeals processes for CYSHCN includes members of a child's integrated care team when requested by the family.[94]

Related National Priciples and Frameworks

2013 Special Needs Plans Structure and Process Measures
(SNP Element 2), National Committee for Quality Assurance (NCQA)[95]

System Domain	Existing National Principles and/or Frameworks
SCREENING, ASSESSMENT, AND REFERRAL	
	Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents[96]
ACCESS TO CARE	
	Core Set of Children's Health Care Quality Measures for Medicaid and CHIP (Child Core Set)[97]
MEDICAL HOME	
NCQA Goals:[98] 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:[99] 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	**Joint Principles of the Patient-Centered Medical Home:**[101] 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.

System Domain	Existing National Principles and/or Frameworks

MEDICAL HOME (continued)

Medical Home Index Domains:[100]
1. Organizational Capacity
2. Chronic Condition Management
3. Care Coordination
4. Community Outreach
5. Data Management
6. Quality Improvement/Change

► 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.

System Domain	Existing National Principles and/or Frameworks

PEDIATRIC AND PREVENTIVE PRIMARY CARE (as part of the medical home

Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents[102]

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."[103]

National Quality Forum Framework for Care Coordination:[104]
► 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:[105]
► Needs assessment for care coordination and continuing care coordination engagement
► Care planning and communication
► Facilitating care transitions (inpatient, ambulatory)
► Connecting with community resources and schools
► Transition to adult care

The Functions of Care Coordination:[106]
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 minimum 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.

System Domain	Existing National Principles and/or Frameworks
CARE COORDINATION (continued)	

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.
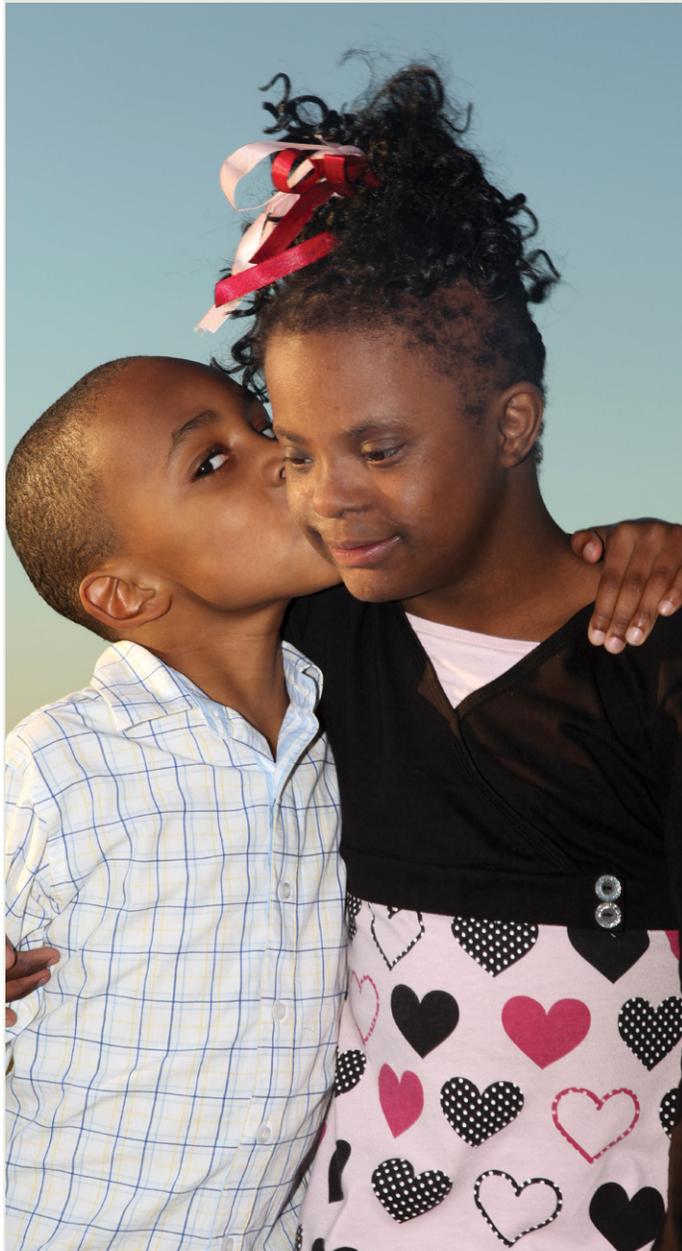
A Shared Plan of Care:[107]
► Addresses the physical, oral, and mental health problems identified as a result of the initial and ongoing evaluation and describes the implementation and coordination of all services required by the CYSHCN and their family.
► Identifies the strengths and needs of the child and family; incorporates and states their goals with clinical goals; and guides the roles, activities, and functions of the family, and the care team.
► 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.
► Is maintained and updated with evaluative oversight and should be used to make timely referrals and track receipt of services.
► Is routinely evaluated and updated in partnership with the family as needed, but no less frequently than every six (6) months.
► 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.
► Is maintained and updated with evaluative oversight and should be used to make timely referrals and track receipt of services.

The Ten Steps for Implementation of a Shared Plan of Care:[108]
Step 1. Identify who will benefit from having a care plan.
► Select criteria to identify the children and families who would benefit from having an accessible, comprehensive, integrated, and shared plan of care.

System Domain	Existing National Principles and/or Frameworks

CARE COORDINATION (continued)

Step 2. Discuss with families and colleagues the value of developing and using a comprehensive and integrated plan of care.
► Talk with the patient and family about the value of a shared plan of care and their central role in its dynamic development and use; share with them that other families have recommended this as a helpful strategy.
► Review with colleagues your understanding of the family perspective, including the importance of communication and collaboration; link the plan of care conceptually with better health care, population health, and costs per capita.

Step 3. Select, use, and review multi-faceted assessments with the child, youth and family.
► Use findings to frame child and family needs, strengths, resources, and circumstances.

Step 4. Set shared personal (child and family) and clinical goals.
► Work together to agree upon clinical goals of care, specific child and family goals, and their relative order of priority.

Step 5. Identify other needed partners and link them into the plan of care process — subspecialists, community resource providers and others.
► Clarify who the "lead team" is (locus of care coordination) for the family, other team members, and partners.

Step 6. Develop the plan of care "Medical Summary" and merge with "Negotiated Actions" in step 7.
► For some children, an emergency plan of care, necessary legal documents, and additional rare condition fact sheets, or other specific guidance, should be attached.
► Merge with Negotiated Actions dimensions (Step 7).

Step 7. Establish the plan of care "Negotiated Actions" and merge with the "Medical Summary" in step 6.
► Negotiate accountability for each action.
► Ensure that anticipated transitions are addressed, including between school levels, hospital to home, and pediatric to adult-focused health care.

Step 8. Ensure that the plan of care is accessible, retrievable, and available.
► Make the plan of care available in real time for families and practice staff.
► Use it at each health care encounter and/or contact with the child and family.

Step 9. Provide tracking, monitoring and oversight for the plan of care.
► Regularly review contents and progress with the family, modify data and goals as necessary, while updating actions and accountabilities.

System Domain	Existing National Principles and/or Frameworks

CARE COORDINATION (continued)

► At least annually, or according to each individualized plan, reassess the circumstances of the child and family including their physical, mental, cognitive, social, functional and environmental health status, and determine the use of and need for additional resources and supports, similarly revising the plan.

Step 10. Systematically use the plan care model process as a life course and a population health approach.

COMMUNITY-BASED SERVICES AND SUPPORTS

Ease of Use Framework:[109]

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

System Domain	Existing National Principles and/or Frameworks

COMMUNITY-BASED SERVICES AND SUPPORTS (continued)

    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.[110]

National Respite Guidelines: Guiding Principles for Respite Models and Services[111]

Principles of Quality Respite Care:[112]

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.

System Domain	Existing National Principles and/or Frameworks
RESPITE CARE (continued)	
	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:[113]
	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.

System Domain	Existing National Principles and/or Frameworks
TRANSITION TO ADULTHOOD	
Sample tools to implement and evaluate 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)**[114] **Customizable packages available for:** Transitioning Youth to Adult Health Care Providers (for use by pediatric, family medicine, and med-peds providers):[115] 1. Transitioning to an Adult Approach to Health Care Without Changing Providers (for use by family medicine and med-peds providers) 2. Integrating Young Adults into Adult Health Care (for use by internal medicine, family medicine, and med-peds providers)
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]

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