

# Summary: 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**

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These standards represent the consensus of a consortium of public and private organizations participating in the first-ever national, collective effort to detail the components of a high quality system of care for CYSHCN. They are intended for use or adaptation by a wide range of stakeholders at the national, state and local levels. The standards were developed by the Association of Maternal and Child Health Programs with support from the Lucile Packard Foundation for Children's Health.

More information:

<http://www.lpfch.org/publication/standards-systems-care-children-and-youth-special-health-care-needs>

<http://www.amchp.org/programsandtopics/CYSHCN/Pages/default.aspx>



# Standards for Systems of Care for CYSHCN

## SCREENING, ASSESSMENT, AND REFERRAL

### 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.
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.
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.
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.
5. All children, including CYSHCN, receive periodic, developmentally appropriate, and recommended 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.
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 received, barriers to care, and, where feasible, assistance in addressing barriers to obtaining needed follow-up.

# Standards for Systems of Care for CYSHCN

## 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.
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 services, navigating the medical and community system of care available for CYSHCN, enrollee status, complaints and grievances, and selection of a primary care provider or other such medical home with experience in serving CYSHCN.
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.

## 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.
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.
3. Freedom of choice in selecting a primary care provider and written policies and procedures describing how enrollees choose and are assigned to a PCP, and how they may change their PCP is in place.
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.

## 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. 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.
3. Perform comprehensive health assessments.
4. Promote an integrated, team-based model of care coordination.
5. Develop, maintain, and update a comprehensive, integrated plan of care that has been developed with the 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 (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.
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.
10. Provide care that is effective and based on evidence, where applicable.

### 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 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.
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.
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.
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.

# Standards for Systems of Care for CYSHCN

## MEDICAL HOME cont'd

### 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:
  - serve as a member of the medical home team
  - assist in managing care transitions of CYSHCN across settings and developmental stages
  - provide appropriate resources to match the health literacy level, primary language, and culture of CYSHCN and their family
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. The plan of care:
  - 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
  - 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
  - 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

### 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.
2. Where needed, systems such as satellite programs, electronic communications, and telemedicine are used to enhance access to specialty care, regional pediatric centers of 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 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 clinical setting, intermediate services, and outpatient services and community support services are provided.

# Standards for Systems of Care for CYSHCN

## COMMUNITY-BASED SERVICES AND SUPPORTS

### Overall Systems Standard:

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:
  - promote family support through linking families to family organizations and other services and supports
  - promote shared financing
  - establish systems for timely communications and appropriate data sharing
  - ensure access and coordination of services for individual children and their families
  - promote collaboration between community-based organizations and agencies, providers, health care systems, and families
  - specify responsibilities across the various providers, and community-based agencies serving children and their families

### 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.

### 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.

### 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.

# Standards for Systems of Care for CYSHCN

## FAMILY PROFESSIONAL PARTNERSHIPS

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.
5. Care is delivered in culturally appropriate ways, respecting family desires for inclusion of extended family members in decision making.
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).
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.

# Standards for Systems of Care for CYSHCN

## TRANSITION TO ADULTHOOD

### 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. YSHCN are encouraged to learn about and engage in their health care as part of this process.
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.

### 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.

# Standards for Systems of Care for CYSHCN

## 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.
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 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.
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.

## 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:
  - families of CYSHCN as members of the primary care provider and health plan QI teams
  - 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
  - periodic monitoring of utilization of care by CYSHCN and their families, appropriateness of care for CYSHCN, and compliance with all system standards for CYSHCN
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.
  - 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
  - assessment of out of pocket expenses and lost work burden on families
  - assessment of child outcomes including measures of health and functional status

# Standards for Systems of Care for CYSHCN

## INSURANCE AND FINANCING

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.
2. Coverage and payment levels are adequate to facilitate access to 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.
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.
4. Comprehensive rehabilitative 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.
5. Rehabilitative 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.
6. Provider payment policies promote 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.
8. Families of CYSHCN may seek second opinions from qualified health care providers without restrictions to such opinions.
9. Performance or financial incentives are in place to promote medical homes and care coordination and enhance access to services and promote quality.

For more details and documentation on these standards, visit

<http://lpfch-cshcn.org/publications/research-reports/developing-structure-and-process-standards-for-systems-of-care-serving-children-and-youth-with-special-health-care-needs>

<http://www.amchp.org/programsandtopics/CYSHCN/Pages/default.aspx>