National Standards for Systems of Care for Children and Youth with Special Health Care Needs (CYSHCN) 2.0 Excerpts

System Domain 4: Medical Home

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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.

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.

Medical Home Management

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.
3. The medical home provider performs comprehensive health assessments.
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.
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.
8. The medical home serving CYSHCN has a process for keeping an updated record of and managing medications.
9. The medical home serving CYSHCN has a process for keeping an updated record of and managing medications.
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.
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.

Care Coordination

1. All CYSHCN have access to patient and family-centered care coordination that integrates physical, oral, mental health and community-based services.
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,
-have ongoing relationships with families, medical care providers, and other partners in care,
- 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,
- assist in managing care transitions of CYSHCN across settings and developmental stages, and
- 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, 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.
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.

Pediatric Specialty

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.
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.About 50% of surveyed Title V officials, and more than 60% of the surveyed Medicaid officials, indicated that this domain was one of the most useful domains of the National Standards for CYSHCN.

Examples of how states have used this domain:

Louisiana Title V used this domain to inform medical home strategies.

New Mexico is using this domain to strengthen medical homes with a focus on care coordination and improve understanding and impact of the delegated model of care coordination. New Mexico also incorporated features of this domain into its Title V action plan and strategies.

Aligned Quality Measures

Follow-up referral after positive developmental screen. Giving you the information you needed when you needed it?

Learning how to meet your own needs while caring for (child)? How well the child's doctors communicate (composite)

Care goal creation/planning (composite).

Team functioning/quality (composite).

For the National Standards for CYSCHN Click Here
For more Quality Measures related to the National Standards for CYSHCN Click Here
For more on how states have used the National Standards for CYSHCN Click Here