

Recommendation to the PIAC: Care Coordination Requirements & Standard for Children and Youth with Special Health Care Needs (CYSHCN) for ACC v2.0

Children and youth with special health care needs (CYSHCN) have unique needs that cannot be sufficiently met using more adult focused models. HCPF can further strengthen care coordination for CYSHCN in the next iteration of the ACC by adopting AMCHP care coordination and ensuring inclusion of system standards in RCCO plans:

Recommended Actions:

- A. Adopt the overall system outcomes for CYSHCN (whitepaper pg. 7)**
- B. Adopt the core domains & standards for System Standards (whitepaper pg. 7)**
 - a. Specific attention should be given to
 - i. **Medical Home**
 - 1. **Care Coordination**
 - a. **Community-Based Services and Supports:** ([pg. 18](#))
 - i. 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:
 - a. promote family support through linking families to family organizations and other services and supports
 - b. promote shared financing
 - c. establish systems for timely communications and appropriate data sharing
 - d. ensure access and coordination of services for individual children and their families
 - e. promote collaboration between community-based organizations and agencies, providers, health care systems, and families

- f. specify responsibilities across the various providers, and community based agencies serving children and their families
 2. Community based supports include respite services, both planned and emergency, are available to all families and caregivers of CYSHCN, as well as palliative and hospice care.
 - b. Transition to Adulthood**
 - i. Youth with special health care needs receive the services necessary to make transition to all aspects of adult life, including adult health care, work and independence.
 2. **Pediatric Speciality Care:** (integrated with the medical home and community-based services) ([pages 16-17](#))
 - a. Shared management of CYSHCN between pediatric primary care and specialty providers is permitted.
 - b. 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.
 - c. Physical health, oral health and mental health are coordinated and integrated.**
 - d. The system serving CYSHCN includes Title V CYSHCN programs,** LEND and UCEDD Centers for individual with developmental disabilities, where available.
 - e. 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.
- ii. **Quality Assurance and Improvement** ([pg.24](#))
 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:
 - a. families of CYSHCN as members of the primary care provider and health plan QI teams
 - b. 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
 - c. periodic monitoring of utilization

- d. care by CYSHCN and their families, appropriateness of care for CYSHCN, and compliance with all system standards for CYSHCN
 - e. 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
 - f. assessment of out of pocket expenses and lost work burden on families
 - g. 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.
- C. Require the identification and implementation of [#] of structure and process standards for each of the system domains (part B, above) by [year].**
- D.** Ensure use of existing National Principles and/or Frameworks (evidence based), as outlined in Appendix A: *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*
<http://www.amchp.org/programsandtopics/CYSHCN/Documents/Standards%20Charts%20FINAL.pdf>

Additional Desired Outcomes for CYSHCN Care Coordination:

- Creation and maintenance of shared plans of care between child serving providers
- Closing the feedback and referral loop between child serving systems (especially between Title V programs, HCP & the RCCO).
- Collaboration between community based services for families resulting in reduction in duplication of services, gap filling, and identification of roles and responsibilities.

Inclusion of Standards in Appendix A: 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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