

Systems of Care for Children with Special Health Care Needs

About Technical Assistance Briefs. The MCH Evidence Center provides ongoing technical assistance (TA) to Title V agencies related to the emerging evidence base, strategies, and measures related to many topics interconnected with National Performance Measures and other critical topics in MCH. *Technical Assistance Briefs* are an outcome of these TA sessions that are designed to act as *conversation starters* in thinking about programs that can be developed to address issues that affect women, infants, children, adolescents, youth, families, and communities. These briefs are not meant to be comprehensive; full analyses of the NPM topic areas are provided in [Evidence Analysis Reports](#).

The Center makes these customized briefs available during TA and on the program website to identify evidence-based/informed strategies, promising practices, examples of ESMs from the field and peer-reviewed resources. Please [contact us](#) if you would like us to develop a similar report for topics that you are working on.

Initial Query for this Brief. Identify measures and best practices around Systems of Care for Children with Special Health Care Needs.

Evidence-Based Strategy Measures

ESM: Program Integration. These ESMs have been chosen by other states. You can review the ESMs to see if any resonate with your goals. Evidence Center staff are available to talk through how you could modify select ESMs to serve your needs.

State	ESMs
AS	ESM 11.1: Percent of Providers Serving Children with Special Health Care Needs report they are confident in providing services for this population
AR	ESM 12.4: Number of School District Special Education Teachers/Professionals attending professional development training that complete a Title V Health Care Transition Readiness Assessment Survey
CO	ESM 11.1: Percent of children with special health care needs ages 0-17 years who receive family-centered care
CT	ESM 15.1: The number of community organizations who help families understand what services are available and covered by insurance for all children including those with special health care needs
DC	ESM 11.1: Number of children and adolescents with and without special health care needs referred to a medical home
GA	ESM 12.1: Percent of youth/young adults enrolled in the Department's Title V program for Children and Youth with Special Health Care Needs (CYSHCN) that transfer to an adult provider.
GA	ESM 12.2: Number of stakeholders, state agencies, and community partners that collaborate with the Department to improve health care transition for youth/young adults with or without special health care needs.
HI	ESM 12.1: Degree to which the Title V Children and Youth with Special Health Needs Section promotes and/or facilitates transition to adult health care for Youth with Special Health Care Needs (YSHCN), related to Six Core Elements of Health Care Transition 2.0.
IA	ESM 11.1: Number of telehealth visits through Child Health Specialty Clinics

IA	ESM 12.1: Percent of youth ages 12–21 served by Child Health Specialty Clinics who have completed a transition checklist
KA	ESM 12.1: Percent of youth with special health care needs, ages 12 to 21, who have one or more transition goals achieved on their action plan by the target completion date
MA	ESM 12.1: Number of CYSCHN and their families who participate in health care transition planning activities.
ME	ESM 12.1: Number of families of 12-21 year olds with special health care needs who attend the Supported Decision-Making class
MH	ESM 12.1: Percent of youths with Special Health Care Need (CSHCN) enrolled in the non-medical related programs to receive services.
NE	ESM 11.1: The number of CYSCHN families who have contact with a Parent Resource Coordinator.
NJ	ESM 11.1: Percent of CYSHCN ages 0-18 years served by Special Child Health Services Case Management Units (SCHS CMUs) with a primary care physician and/or Shared Plan of Care (SPoC).
NC	ESM 11.1: Percent of children with special health care needs who received family-centered care
NH	ESM 12.1: Percent of young adults with special health care needs, ages 18-21, who identify an adult health care provider at discharge from the Title V program
NM	ESM 13.2.3: Percent of special needs children who had at least one dental visit during the last year.
PW	ESM 11.1: Increase the number of children with special health care needs and their families with a care coordination plan who are linked to primary healthcare services and community support
PA	ESM 11.11: Number of youth with special health care needs receiving evidence-based or -informed leadership development training through the Leadership Development and Training Program
TN	ESM 12.5: Number of youth with special health care needs trained as mentors
TN	ESM 12.6: Number of parents and youth with special health care needs who receive leadership and self-advocacy training
TX	ESM 12.1: Percent of families of transition age youth with special health care needs receiving professional help with their child’s transition to adulthood
UT	ESM 11.3: Percent of children with special health care needs population served by the Bureau who have documented care coordination follow up as part of a medical home model of care.
UT	ESM 12.1: Percentage of children with special health care needs who report the transition plans assisted them (report a change in knowledge, skills or behavior) in transitioning to adulthood.
UT	ESM 12.2: Percent of adolescents and youth with special health care needs ages 12-18 who receive a transition plan.
VI	ESM 11.1: Percent of children with and without special health care needs, ages 0 through 17, who have a medical home

Evidence-Based Strategies – What Works for Health

The following programs have been identified as effective models related to Systems of Care for Children with Special Health Care Needs:

Title	Link	Category
Behavioral health primary care integration	https://www.countyhealthrankings.org/take-action-to-improve-health/what-works-for-health/policies/behavioral-health-primary-care-integration	Scientifically Supported
Chronic disease management	https://www.countyhealthrankings.org/take-action-to-improve-health/what-works-for-health/strategies/chronic-disease-management-programs	Scientifically Supported
Medical homes	https://www.countyhealthrankings.org/take-action-to-improve-health/what-works-for-health/strategies/medical-homes	Scientifically Supported

Patient navigators	https://www.countyhealthrankings.org/take-action-to-improve-health/what-works-for-health/strategies/patient-navigators	Scientifically Supported
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Evidence-Based Strategies – Innovation Hub

The following programs have been identified as effective models related to Systems of Care for Children with Special Health Care Needs:

Title	Link	Category
Innovative Approaches: Community Systems Building Grants for Children and Youth with Special Health Care Needs (CYSHCN)	https://amchp.org/wp-content/uploads/2021/05/NC-IA-Implementation-Handout_Final-1.pdf	Best
Rhode Island Department of Health Internship Program for Youth with Special Healthcare Needs	https://amchp.org/wp-content/uploads/2021/05/RIDOH-Intership-Program.pdf	Promising
Family Voices of California Project Leadership	https://amchp.org/wp-content/uploads/2021/05/InnovaSta-CA-Family-Voices-Leadership-Project_Updated-6.18.2020.pdf	Promising
Oregon Care COOrdination Program (CaCoon)	https://amchp.org/database_entry/oregon-care-coordination-program-cacoon/	Promising
Washington Statewide Leadership Initiative Coalition	https://amchp.org/wp-content/uploads/2021/05/Washington-Statewide-Leadership-Initiative-Coalition_IH-Practice-Handout_Promising.pdf	Promising
Family Navigator Network	https://amchp.org/wp-content/uploads/2021/05/Family-Navigator-Network_Practice-Handout-Emerging.pdf	Emerging
Expanded eligibility for WV CYSHCN through enhanced screening	https://amchp.org/wp-content/uploads/2021/09/Spring-2021_WV-CYSHCN_Practice-Handout-Emerging.pdf	Emerging
Parents as Detailers for Learn the Signs. Act Early.	https://amchp.org/wp-content/uploads/2021/05/Parents-as-Detailers-for-Learn-the-Signs-Act-Early.pdf	Emerging
Child Development Clinic Services	https://amchp.org/wp-content/uploads/2021/10/Child-Development-Clinic-Services-Practice-Handout-Emerging-1.pdf	Emerging
Virtual programming and mental health support for CYSHCN families	https://amchp.org/wp-content/uploads/2021/09/New-Jersey_Practice-Handout-CuttingEdge.pdf	Cutting-Edge
Shared Plans of Care for Children and Youth with Special Healthcare Needs (CYSHCN)	https://amchp.org/wp-content/uploads/2021/09/2021_Colorado_Shared-Plans-of-Care-Care-for-CYSHCN_Evaluation-Handout.pdf	Policy Evaluation

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Access other resources at <https://www.mchevidence.org>

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