



HEALTH MANAGEMENT ASSOCIATES

*Care Coordination for
California's Children and Youth with Special
Health Care Needs:
Building Blocks from other States*

PREPARED FOR THE
LUCILE PACKARD FOUNDATION FOR CHILDREN'S HEALTH

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Abstract

For the more than one million children and youth with special health care needs (CYSHCN) in California, care coordination can be critical for linking them and their families to needed medical, developmental, behavioral, educational, and social services, and for providing logistical assistance and emotional support. A review of care coordination programs around the country revealed that while there is no single accepted model for care coordination, the essential building blocks are similar across programs: eligibility guidelines and determination, services and standards, payment/reimbursement mechanisms, financing, and oversight/monitoring. These represent decision points for California policymakers, officials, and other stakeholders as they consider ways to improve care coordination for CYSHCN. This report presents options for each building block based on seven care coordination programs in six other states, considerations given California’s unique environment, and lessons from other programs about key “ingredients” for an effective, sustainable care coordination system.

Introduction

For the more than one million children and youth with special health care needs (CYSHCN) in California, care coordination can be critical for linking them and their families to needed medical and non-medical services, and for providing logistical assistance and emotional support. By definition, CYSHCN have a chronic physical, developmental, behavioral, or emotional condition that requires more than routine health and related services.¹ These children and their families face myriad challenges: coverage and access to needed pediatric specialists can be inadequate or inconsistent, and navigating the various health and non-health systems can be confusing and frustrating. As a result, CYSHCN often receive fragmented or duplicative services and typically have many more unmet medical needs than other children.² Low-income, minority, and uninsured children are at particular risk for poor coordination of services.³

Coordination of care is also important to providers and policymakers, who are interested in ensuring that vulnerable children with complex needs receive appropriate, timely, high-quality services in a cost-effective manner.⁴ According to the American Academy of Pediatrics (AAP), “optimal outcomes for children and youth, *especially those with special health care needs*, [require] interfacing among multiple care systems and individuals...Coordination of care across settings permits an integration of services that is centered on the comprehensive needs of the patient and family, leading to decreased health care costs, reduction in fragmented care, and improvement in the patient/family experience of care.”⁵

California has a long history of caring for CYSHCN. Established in 1927, the California Children's Services (CCS) program (now the state's Title V program for CYSHCN) provides diagnosis and treatment, medical case management, and physical and occupational therapy services for children under the age of 21 who have a CCS qualifying condition and meet financial eligibility criteria. The majority of CCS-eligible children are dually enrolled in Medi-Cal (California's Medicaid program) and receive benefits unrelated to their CCS condition (typically primary and preventive care) through their Medi-Cal managed care plan; about 15% are “CCS-only” without other health coverage or with limited health coverage. For CYSHCN enrolled in Medi-Cal managed care who are not eligible for CCS, the plans are responsible for both primary and specialty care.

The CCS program is administered as a partnership between the California Department of Health Care Services (DHCS) and county health departments. The state sets the overall administrative policy and direction for CCS and conducts activities such as provider enrollment and oversight of provider payment. County activities include eligibility determination, service authorization, and case management.

¹ Lucile Packard Foundation for Children's Health website: <http://lpfch.org/cshcn>

² M. L. Mayer, A. C. Skinner, and R. T. Slifkin, “Unmet Need for Routine and Specialty Care: Data from the National Survey of Children with Special Health Care Needs,” *Pediatrics*, 2004 113: 109–115

³ Antonelli, R.C., McAllister, J.W., and Popp, J. “Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework.” The Commonwealth Fund, May 2009; D. Denboba, M. G. McPherson, M. K. Kenney et al., “Achieving Family and Provider Partnerships for Children with Special Health Care Needs,” *Pediatrics*, 2006 118: 1607–1615; D. Rosenberg, C. Onufer, G. Clark et al., “The Need for Care Coordination Among Children with Special Health Care Needs in Illinois,” *Journal of Maternal Child Health*, 2005 9: 41–47.

⁴ Calatyst Center. “Care Coordination in a Statewide System of Care: financing Models and Payment Strategies,” October 2010.

⁵ American Academy of Pediatrics. “Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems,” *Pediatrics* 2014;p.e-1451.
<http://pediatrics.aappublications.org/content/133/5/e1451.full.html>

Under current state law, treatment of a CCS condition is a “carve-out” service and thus is not covered under most Medi-Cal managed care plans; however, the statutory provision mandating the CCS “carve-out” expires in December 2015.⁶ In recent years, DHCS has made several attempts to address increasing expenditures while also improving the quality of care for CCS enrollees. DHCS has implemented a CCS pilot project in San Mateo County. While other changes to CCS have not moved forward to-date, DHCS appears to remain committed to redesigning the CCS program and has indicated they will be starting a stakeholder process. In addition to case management provided by county entities for CCS enrollees, there are several other entities conducting some type of care coordination. They include care management from the state's Regional Centers, county mental health programs, DHCS, local schools, and managed care organizations, as well as hospitals, specialty clinics, home care providers, and physician practices. This multiple and largely disjointed care coordination approach is based on categorical programs run by different organizations and departments such as CCS, developmental disabilities, mental health, and special education. Even within DHCS a child may have different care coordinators for CCS and for certain home health services. That is, care coordination in California is not developed as a single, child-centered program, which may result in duplication and confusion, with less than optimal outcomes.

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There is a wide range of views about the current state of care coordination for children in California. Some stakeholders view the state-county CCS partnership system as a model that should be adopted by other states. Others find the current system lacking, with inconsistent quality and access across counties and insufficient funding. Care coordination under the CCS program is done by medical professionals while care coordination under managed care is generally done by non-medical personnel. CYSHCN families' experience with Medi-Cal managed care is also inconsistent, given variation in delivery systems, health plan experience with special populations, and managed care models.⁷

The Lucile Packard Foundation for Children's Health (LPFCH) asked Health Management Associates (HMA) to examine programs of care coordination for CYSHCN in other states and to identify decision points and options that could be considered in California. This issue brief delineates for policymakers, local providers, and consumer advocates the key building blocks of a care coordination policy/program, describes how other states have designed these elements, suggests considerations for California given its history and health care landscape, and presents some lessons from other programs that may help in building or improving care coordination for CYSHCN in California.

⁶ California Welfare & Institutions Code, Section 14094.3.

⁷ Jee, J. and Nagarajan, J. “Identification and Assessment of Children and Youth with Special Health Care Needs in Medicaid Managed Care: Approaches from Three States,” National Academy for State Health Policy, February 2014.

HMA conducted structured interviews with program officials and staff of seven care coordination programs in six other states. The programs were selected based on literature reviews and discussions with researchers and experts on children's healthcare that suggested these were innovative and/or successful care coordination programs. Through these telephone interviews, HMA explored program design, operations, and lessons learned.

Care Coordination Approaches in Six Other States

The table below presents an overview of seven state care coordination programs in six states examined for this report.⁸

Program	State	Program Summary
Children's Medical Services (CMS) Network	Florida	Serving CYSHCN for more than 56 years, the program became a specialized managed care plan in 1996 to serve CYSHCN enrolled in Medicaid and CHIP. Children are assigned to a CMS Network primary care provider and receive ongoing support from CMS Network care coordinators within the local CMS Network field offices, as well as comprehensive medical and behavioral health services. (CYSHCN who are not eligible for Medicaid or CHIP receive limited services).
Rare and Expensive Case Management (REM) Program	Maryland	Medicaid managed care members of all ages who have specified diseases and conditions receive case management in addition to the full set of Medicaid fee-for-service (FFS) benefits and other medical and non-medical benefits.
Community Care of North Carolina (CCNC)	North Carolina	CCNC is the state's Medicaid care management program in which 14 regional networks match members with primary care practices and provide care coordination for children deemed high cost or otherwise in need of coordination services.
Child Health Accountable Care Collaborative (CHACC)	North Carolina	CHACC provides regional, network-based patient coordinators for children with complex conditions to promote communication and coordination among subspecialty providers, primary care providers, and families.
Comprehensive Evaluation Diagnosis Assessment Referral Re-evaluation (CEDARR)	Rhode Island	Case management is provided to Medicaid-eligible CYSHCN through CEDARR Health Homes as a core benefit, along with a continuum of home- and community-based clinical services and full Medicaid benefits.
South Carolina Solutions (SCS)	South Carolina	SCS manages the state's Medicaid program for medically complex children, providing care coordination under a medical home network model. Nurse care coordinators assist with transitions from the hospital to community and coordinate chronic, preventive, specialty, and social services.
Vermont Blueprint for Health (Blueprint)	Vermont	Children and adults, regardless of payer or diagnosis/condition, who receive treatment in a participating patient-centered medical home receive community-based, team-based care coordination services.

⁸ HMA also examined the SickKids Care Coordination Program & Norman Saunders Complex Care Initiative (SickKids) in Toronto, Ontario, Canada, and the Program of All-Inclusive Care for the Elderly (PACE) in various states; however, because of lack of adaptability to California, this Issue Brief does not include the findings from those programs.

Decision Points and Considerations for Building a Care Coordination Program

A review of care coordination programs around the country revealed that there is no single accepted model for care coordination or even a consensus on the definition of care coordination or its essential services, who should receive them, who should provide them and how providers would be paid, or how they would be funded. However, the essential building blocks of care coordination programs are similar; they include eligibility guidelines and determination, services and standards, payment/reimbursement mechanisms, financing, and oversight/monitoring. Each building block has numerous components, and for each component there are design options – presenting decision points for policymakers and program planners and administrators. Below we discuss each building block and present options based on the models we examined in other states. We also present issues for decision-makers to consider as they weigh options for care coordination components in California. Appendix A presents more detailed information about how each of the other states addresses the key decision points, and Appendix B includes sample assessment tools, disease criteria, care guidelines, and standards.

Eligibility

Among the care coordination programs examined, eligibility is generally based on criteria related to residence, age, eligibility/enrollment in an existing health coverage program, and condition or diagnosis (see Appendix A-Table 1). Most programs require residence in the state and living in a community (non-institutional) setting. Programs specifically for children in Florida, North Carolina, and Rhode Island use the upper limit of 21 years of age, while South Carolina uses age 18. Care coordination programs in Maryland and Vermont include individuals of all ages.

The clinical or diagnostic criteria vary in the level of specificity; options include:

- Child is documented as having at least one among a specific list of diagnoses;
- Child meets Maternal and Child Health Bureau definition as “hav[ing] or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require[s] health and related services of a type or amount beyond that required by children generally”; and/or
- Referral from a clinician.

Most programs require the child to be enrolled in Medicaid or Medicaid managed care, but some programs allow for participation by children served by CHIP and the safety net. Vermont's program allows participation by children covered by all payers, including Medicaid, Medicare, and commercial insurance.

Mechanisms for screening potentially eligible individuals take on varying levels of sophistication across programs and are often used in combination to determine eligibility (see Appendix A-Table 2). Eligibility is assessed and determined both at the program or local level and state level. Two of the most common ways that a child reaches a care coordination program is through referral by a clinician or self-referral by the family. A number of programs employ screening tools that are either proprietary or derived from existing tools that are designed to assess a child's full spectrum of needs and conditions. In some cases they stratify the individuals according to risk factors, which then determine the level of services offered.

The assessments often draw on supporting medical documentation, clinician referral, and medical history and focus on a range of physical, behavioral, developmental, and/or emotional conditions. Examples of screening tools are provided in Appendix B.

Since access to care coordination in Vermont is not based on diagnosis, no diagnostic screening is conducted for patients in participating practices. In North Carolina, predictive modeling based on claims data is used to identify high-cost/high-utilizing children whose care has the potential for improvement through CCNC and/or CHACC. Hospitalizations and medications are two data points captured and used to identify patients. However, the program was unable to identify patients by using claims data during the nine months following the state's transition to a new claims processing system, when data was not made available to CHACC. To address the lack of data and the limitations of the claims database in capturing certain patients, CHACC is working to develop a model that identifies patients before claims are available, including newborns and referrals made prior to the point where patients incur high costs or experience high utilization of services.

Eligibility Considerations for California

As noted above, in some states eligibility for care coordination programs is not restricted to children. While California has a precedent for separate programs for children, other models successfully operate to serve both children and adults, with responsibility for care coordination centralized under a single entity. Focusing on children and youth allows a program to specialize in meeting needs and providing services that are often specific to younger populations (such as engaging a network of pediatric subspecialists). However, the advantage of expanding beyond children and youth is to bring essential care coordination to a larger, vulnerable adult population and to prevent children with complex needs from "aging out" of critical care coordination. This "life-course perspective" acknowledges that early-life experiences can shape health across an entire lifetime. Obviously this more encompassing approach increases the care coordination costs, but it also enhances the potential for care coordination to reduce utilization of services and overall costs in the long run.

California could consider building upon existing requirements for CCS eligible conditions to include behavioral and/or developmental conditions, in line with more inclusive eligibility requirements used in some other states. Such an expansion would require partnering with state, county and regional center agencies that currently provide behavioral health and developmental disability services, with a resulting restructuring of existing systems. This could potentially lead to a merger of the CCS program with these other programs either organizationally or functionally with services being organized around the child rather than around the type of condition the child has.

There is also an opportunity for California to develop additional mechanisms for eligibility screening that rely on data analytics to identify children at risk for becoming high utilizers. North Carolina's system of predictive modeling, despite some limitations, functions to trigger assessments and care coordination that could pre-empt potentially costly services.

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Care Coordination Services and Standards

The American Academy of Pediatrics defines pediatric care coordination as “a patient-and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the care giving capabilities of families. Care coordination addresses interrelated medical, social, developmental, behavioral, educational and financial needs to achieve optimal health and wellness outcomes.”⁹ While the AAP recently released a framework listing care coordination functions and competencies¹⁰, the services that comprise care coordination, the individuals who perform care coordination, and the tools and standards for care coordination vary across the seven programs examined, depending on the system of care or program and the target population (see Appendix A-Table 4).

Across the programs examined, members consistently receive an assessment to identify their specific needs, typically upon enrollment and at certain intervals thereafter. Assessment processes and tools include clinical screening tools (including IFIND intake assessment tool, risk stratification tools); medical record reviews; and functional assessments by the caregiver. Risk stratification determines the level of acuity and needs, which then dictates the level of services and care coordination for the individual.

In addition to the assessment, care coordination typically involves the management of multiple medical services and the integration of physical care needs with behavioral health, social services, and supports. Across the seven programs, care coordination includes a combination of the following activities:

- care plan development, monitoring, and modification;
- communication and coordination among care team (both interdisciplinary and multidisciplinary)¹¹;
- regular telephone, home visit, and/or office-visit contact with the patient and family;
- patient and family education and health promotion;
- family support groups;
- assistance in obtaining covered (and often non-covered) benefits;

⁹ Pediatrics, 2014.

¹⁰ Ibid.

¹¹ An interdisciplinary care team is a group of qualified professionals that support the care planning and coordination of services for members and engages directly with members and their PCP. A multidisciplinary team is composed of a PCP and the patient's specialists who share patient information but do not meet directly.

- referrals to community-based services and resources;
- medication review and management (e.g., check that patients are filling prescriptions and taking medications appropriately);
- tracking and contacting of patients who are overdue or miss appointments or tests (may include review of patient claims); and
- follow-up with patients on their personal health management goals.

Assessments and care coordination activities are typically conducted by a care coordinator/manager or case manager whose role is defined by the state or program. In some programs, a nurse conducts the assessment and some or all follow-up care coordination activities are conducted by a trained non-clinician. Credentials and training requirements for the care coordinator role vary across programs and may include licensed clinicians such as registered nurses, social workers, mental health counselors, and family therapy counselors who have requisite years of experience providing healthcare case management services. Some programs use administrative staff or parents, with training, to provide certain care coordination tasks.

States have also established care coordination standards for the assessment and care plan processes, staffing ratios, and physician practice participation. Standards among the state programs examined include the following:

Assessment and care plan development: Providers of care coordination are required to contact members, usually starting with an initial assessment, within a certain time after enrollment, and to develop the care plan within a specified period of time.

Patient contacts: Many programs require that the care plan be reviewed and updated and that the family be contacted at certain intervals, such as every month or every six months.

Care coordinator caseloads: Staffing ratios vary widely according to the characteristics of the target population. Programs focused on children with special health care needs have caseloads as low as 40 and up to 60 (South Carolina); the lowest caseloads are found in special needs populations such as foster care children, where the ratio is 22 to one for nurses and 25 to one for social workers (Florida). Care coordinators serving children and adults with complex medical needs take on about 80 to 100 cases (Maryland), while community health teams of five full time staff are assigned to a population of 20,000 patients in the general population in Vermont – though the vast majority are healthy community members and only a very small portion need and/or seek care coordination from the teams. Other programs maintain a goal of one to two care coordinators assigned to a primary care practice with 300 to 400 patients (CMS-Florida) or have developed typical caseloads of 40 patients per clinician and 50 patients per care coordinator (CEDARR-Rhode Island).

Physician practice standards: Certain medical home characteristics and/or team approaches are required for participating providers in some state programs. Practices in Vermont are required to obtain NCQA Patient Centered Medical Home (PCMH) designation as a condition for participation and for receipt of care coordinator payments. In Maryland, a model waiver program funded through the “Katie Beckett Waiver” utilizes an interdisciplinary care team model to provide monthly care planning meetings

with the child's physician.¹² In CEDARR (RI), existing care coordination services were cross-walked with health home services in transitioning the program to a CMS-recognized Health Home. The Health Home teams consult, coordinate, and collaborate on a regular basis with the child's primary care physician/medical home and other providers to provide six standard health home services: comprehensive care management, care coordination, health promotion, comprehensive transitional care, individual and family supports, and referral to community and social support services.

Service/Standards Considerations for California

Medi-Cal managed care plans are currently required to identify and refer CCS-eligible children to the local CCS program, and to conduct an initial health assessment to assess acute, chronic, and preventive service needs, and needs for coordinating with other community resources and agencies.¹³

An assessment mechanism that establishes eligibility while stratifying the risk and acuity of eligible children across different levels is a patient-centered way to match resources to each child's needs.

Other states' approaches to care coordination services and standards for CYSHCN offer some new considerations for California in establishing program guidelines and standards. An assessment mechanism that establishes eligibility while stratifying the risk and acuity of eligible children across different levels is a patient-centered way to match resources to each child's needs. It also has implications for staffing, services, and costs. California could consider establishing minimum levels of service and standards for each level of acuity, with different staffing ratios, assessment targets and timelines, care coordinator credentials and training, and types of benefits and services to be coordinated. Further, California should assess the role that county CCS offices perform to determine how much of its activities are care coordination versus service authorization and to determine if a greater emphasis should be placed on care coordination activities.

Implementing a core minimum set of services for care coordination would help standardize and ensure comparable quality in care coordination across counties. This should include protocols for communication across medical providers – including subspecialists who play a critical role in the care of CYSHCN – and with behavioral health providers, social and community supports, and parents/caregivers. Mechanisms should be established for secure electronic sharing of diagnoses, treatment plans, and instructions for primary care providers and caregivers.

¹² Rhode Island has a Katie Beckett Waiver, also known as the Deeming Waiver or the 2176 Model Waiver. This creates an eligibility category that allows certain children under age 19 who have long term disabilities or complex medical needs to become eligible for Medicaid coverage. Katie Beckett eligibility enables children to be cared for at home instead of in an institution. With Katie Beckett, only the child's income and resources are used to determine eligibility. Approximately 40% of kids enrolled in CEDARR are commercially covered, with Medicaid serving as secondary coverage; the other 60% are enrolled in Medicaid managed care.

¹³ Jee and Nagarajan, 2014.

Payment/Reimbursement for Care Coordination

The method, mechanism, and rates for reimbursing the providers of care coordination (both individual care coordinators and the entities responsible for the service) are key design features. Reimbursement mechanisms are in part tied to the model or system of care, particularly regarding which entities are responsible for conducting the services. The six states examined present varied approaches to paying care coordinators (Appendix A-Table 5), including the following:

Salaried: Care coordinators are salaried employees (nurses, social workers, administrative staff, etc.) of local Medicaid primary care networks (CCNC-North Carolina), a Medicaid managed care plan (SCS- South Carolina), the state (CMS-Florida), or vendors under contract with any of the prior entities (REM-Maryland). Care coordination staff employed directly by a state agency are paid through a budget line item or grant funds for staff positions, fringe benefits, and overhead costs. The MCOs and vendors employing care coordinators are typically reimbursed by the state, through Medicaid capitated or PMPM (per member per month) payments or federal grant payments (CHACC-NC).

Per member per month (PMPM)/capitation: The care coordination entity is paid on a per member per month basis for all covered services including care coordination or for care coordination only. The rates may vary depending on patient acuity or medical home status. For example, REM (Maryland) care coordination vendors are paid from \$90 to \$267 PMPM, depending on the level of care required, after \$386 for the initial month. CCNC (North Carolina) physician practices are paid \$2.50 PMPM (or \$5 PMPM if the member is aged, blind or disabled for some care extra tasks such as 24-hours-a-day/7-days-a-week availability and coordination with community network staff. Vendors are typically paid per client while physicians receive a PMPM for all of their patient panel though only some use care coordination.

Global rates: A variation on PMPM, global payments reimburse a set amount per child per year, which could vary based on diagnosis, level of need, or complexity

Per unit: Care coordinators charge unit rates for blocks of care coordination time. For example, CEDARR (Rhode Island) providers bill Medicaid for care coordination services using CPT code H2021 (with modifiers) based upon 15 minutes of effort; it is a HCPCS¹⁴ code for “community-based wrap around services based on an intensive case management model facilitated by a single care coordinator/case manager with a single plan of care.”¹⁵ Others have developed lists of CPT codes that could be used to bill insurers for medical home services including various care coordination activities.¹⁶

¹⁴ Healthcare Common Procedure Coding System

¹⁵ <http://www.nd.gov/dhs/services/medicalsev/medicaid/archives/12-provider-updates.html>

¹⁶ For example, the American Medical Association added codes 99487-9 for care coordination for patients with complicated, ongoing health issues within a medical home, accountable care organization, or similar model. (Pediatrics, 2014.) In The Medical Home Crosswalk to Reimbursement, McManus, et al, developed a list of CPT codes that could be used to bill an insurer fee-for-service for medical home care coordination activities, including: Home visits (99341-99350); Prolonged services in an outpatient setting without direct patient contact (99358-9); Team conferences with interdisciplinary team (99361-2); Telephone calls to patient that involve active management of a problem including communication with a pharmacy, lab, social worker, home care provider, therapist, or other physician (99371-3); and Care plan oversight (99374-80). (“Care Coordination Toolkit: Proper Use of Coordination of Care Codes with Children and Youth with Special Health Care Needs (CYSHCN)” Center for Infants and Children with Special Needs. Cincinnati Children’s Hospital Medical Center and The National Center of Medical Home Initiatives for CSHCN, March 2006.) <http://www.medicalhomeinfo.org/downloads/pdfs/carecoordinationtoolkit06.pdf>

Payment/Reimbursement Considerations for California

Currently the CCS program reimburses county staff on an administrative basis based upon the county's allowable cost. State CCS offices are funded and reimbursed through the state budget. CCS care coordinators are typically salaried employees, and medical personal receive 75% federal funding for their medical related care coordination. Medi-Cal managed care plans are reimbursed for their care coordination through their managed care rate. The CPT codes for care coordination are not covered benefits in California; that is, the state does not directly reimburse private providers for care coordination.¹⁷ Managed care plans reimbursement to providers varies significantly both by plan and geography. Plans often pay physicians a PMPM rate per month that includes all primary care including care coordination. Generally plans that reimburse physicians on a fee for service basis cover the same benefits as those covered by Medi-Cal fee for service.

Designing a new or modified care coordination system in California would involve considering current and new options for reimbursement for the services. The payment mechanism could depend on the model and system of care. If counties or Medicaid MCOs are responsible for providing the coordination services, these entities could have flexibility to conduct and pay for care coordination through their employed staff (salaried), through vendors (PMPM or per unit), or through arrangements with PCPs (PMPM or per unit). The state could reimburse the care coordination entity through capitated payments, PMPM, per unit, or global payments for a population within a certain geographic area. Under a more centralized state-based system, the state government might contract with vendors at the local level.

Any of these payment mechanisms could be combined with a pay for performance approach that provides bonuses if care coordination quality standards, health goals, and/or cost reductions are achieved.

The rates for care coordination, to both the entities and individuals responsible for care coordination, must be adequate to ensure appropriately trained and monitored care coordinators and tools and communication venues for providing effective coordination. Further, regardless of the payment mechanisms, California policymakers and administrators could work to improve the coordination among various programs and systems that have responsibility for care coordination and thereby reduce redundancy and better serve families.

Any payment mechanism could be combined with a pay for performance approach that provides bonuses if care coordination quality standards, health goals, and/or cost reductions are achieved.

¹⁷ Counties, schools, mental health, regional centers and other government related providers are reimbursed for targeted case management.

Financing

Sustainable financing of care coordination is perhaps the greatest challenge faced by states and providers. Some states are funding care coordination through one vehicle such as a Medicaid waiver, while others (e.g., Florida and Vermont) are patching together multiple funding sources (See Appendix A-Table 6). A review of the states examined and the available literature¹⁸ suggest the following options for financing care coordination for children with special health care needs.

Financing Sources Used in Six States
Medicaid waiver: Section 1915(b), 1915(c) 1115
Medicaid administrative funds
Medicaid Early Periodic Screening Diagnosis and Treatment (EPSDT) benefit
Medicaid Targeted Case Management (TCM)
Health Home State Plan Amendment
Center for Medicare and Medicaid Innovation (CMMI) grant
Title V Maternal and Child Health Block Grants
Other state agencies
Commercial insurers
Tobacco Settlement Trust Funds
Title XX Social Services Block Grant (SSBG)
Title XXI CHIP funds (for CHIP-eligible children)
Hospital fees
Sliding scale family payments
ARRA and HITECH Act funds (for HIT-related costs)

Medicaid via waiver: While care coordination is not a standard Medicaid benefit, states provide and pay for such services through Section 1915(b) or 1915(c) and 1115¹⁹ waivers. This strategy draws in federal funds, though states must still finance the state portion through general funds or other sources. Most of the programs highlighted have been funded at least in part through Medicaid waivers. For example, Florida's CMS is funded primarily through a Medicaid 1915(b) managed care waiver, with the state portion comprising general revenue and tobacco settlement trust funds. Maryland began REM in 1997 with a Medicaid managed care 1115 waiver, with the state portion included in the annual state Medicaid budget. South Carolina started coordinating care for medically complex children through a long-term care 1115(c) waiver, and in 2012 implemented a five-year 1915(c) waiver to provide care coordination and other services for medically complex children. Vermont's Community Health Teams are funded largely by Medicaid through a Global Commitment to Health Medicaid 1115(a) waiver; the state portion flows from general funds.

¹⁸ Catalyst Center, 2010.

¹⁹ Section 1115 Research and Demonstration waivers allow for pilot testing of new models such as managed care or medical homes that may include care coordination services; 1115(c) waivers allow coverage of long term care services in community settings; 1915(b) and (c) waivers allow coverage of additional services from cost savings and choice counseling for managed care plans.

Medicaid administrative funds, Medicaid Early Periodic Screening Diagnosis and Treatment (EPSDT) benefit or Targeted Case Management (TCM): For CYSHCN who receive Medicaid benefits, states have provided case management as an “administrative” activity or cited the EPSDT federal requirements (e.g., CEDARR-RI services were provided under the EPSDT mandate). Also, states may add an optional Targeted Case Management (TCM) service to the State Plan to support care managers who address the needs of “super-utilizers,” without obtaining a section 1915(b) waiver.²⁰

Health Home State Plan Amendment: Through a Section 2703 Health Home State Plan Amendment, a state receives 90/10 federal match for two years for health home services that support care delivered by interdisciplinary teams with members including physicians, nurse care coordinators, nutritionists, social workers, and behavioral health providers. Rhode Island converted CEDARR to a Health Home in 2011; the enhanced federal match from 2011-2013 was reported to help bridge tough budget times for CEDARR and the state. Vermont is seeking a 90/10 federal match for health home services including care coordination.

Center for Medicare and Medicaid Innovation (CMMI) grants: North Carolina's CHACC is funded through a CMMI grant over a three-year period (awarded September 2012) that covers care coordination for children with complex/specialty care needs. Vermont's model includes funding through a CMMI medical home Multi-payer Advanced Primary Care Practice Demonstration to fund the Medicare portion of the program.

*Title V Maternal and Child Health Block Grants:*²¹ States may use Title V to fund local health departments to provide outreach, coordination, and referral services, or to develop shared funding strategies with Medicaid. CMS (FL) is funded in part through Title V MCH Block Grant Funds. Rhode Island uses Title V funding for parent coordinators who are placed in medical home practices to provide care coordination. Under health reform, as more people are covered through private insurance, some services now covered through Title V will be covered by commercial insurers, making additional funds available that could be used for care coordination.²²

Other state agencies: Where there are overlapping needs with departments or agencies responsible for behavioral health, education, or public health, there is potential to pool funds for care coordination. Vermont's Blueprint uses an inter-agency Memorandum of Understanding to tap some funds from its Department of Health to operate disease specific programs.

Commercial insurers: The Blueprint (Vermont) community health teams are funded through a multi-payer strategy that includes three major commercial insurers and Medicare in addition to Medicaid.

²⁰ Under Section 1915(g) of the Social Security Act, states may add an optional Targeted Case Management (TCM) service to the State Plan to support care managers that address the needs of “super-utilizers.” TCM services are reimbursed at the traditional state-specific federal match rate. An advantage of TCM is the authority for states to target case management activities to specific populations or within limited geographic regions without the need for the state to obtain a section 1915(b) waiver. <http://medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-07-24-2013.pdf>

²¹ The Title V Maternal and Child Health Program is a federal-state partnership administered by the Health Resources and Services Administration (HRSA) that promotes the health of mothers, women, children and youth, including children and youth with special health care needs and their families. Title V converted to a Block Grant Program in 1981. States and jurisdictions must match every \$4 of Federal Title V money that they receive with at least \$3 of State and/or local money; at least 30% of funds are earmarked for services for children with special health care needs. (<http://mchb.hrsa.gov/programs/titlevgrants/>)

²² In Michigan, Title V funds the state match for Medicaid-funded care coordination services, and New Mexico combined Title V and Medicaid dollars to hire 50 social workers who provide care coordination. (The Catalyst Center, 2010).

Rhode Island has a Katie Beckett Waiver, also known as the Deeming Waiver or the 2176 Model Waiver, which enables severely disabled children and adults to be cared for at home and be eligible for Medicaid based on the individual's income and assets alone (not counting income of legally liable relatives). About 40% of children enrolled in CEDARR are commercially covered with Medicaid serving as secondary coverage; the other 60% are enrolled in Medicaid managed care. Commercial insurers are starting to look at paying for care coordination, and the state is examining pilots for pediatric medical home.²³

Miscellaneous Financing Sources: Florida's funding for its CMS Network included some of the above sources plus Tobacco Settlement Trust Funds, the federal Title XX Social Services Block Grant (SSBG) program to states (transferred from Temporary Assistance for Needy Families [TANF] allotment²⁴) for early intervention, Title XXI CHIP funds (for CHIP-eligible children), some hospital fees (for newborn screening), and sliding scale payments (from non-Medicaid clients). Services not covered by Medicaid, including parent support, therapeutic camps, early intervention, genetic and nutritional counseling, are financed by the state General Revenue Fund. The Blueprint-VT is funded in part with federal funds for HIT under the ARRA and HITECH Act.²⁵

Financing Considerations for California

In California, budget shortfalls and competing priorities have made financing for care coordination and health care generally a difficult and divisive issue. California's CCS program is financed through a combination of state general fund, federal funds, and some county realignment funds. As has occurred with much of state government, the CCS administrative budget has gone through significant budget reductions that have affected the state's ability to conduct care coordination for the population it is responsible for and to do county oversight. Further, the counties' ability to do care coordination has been affected by the state budget shortfalls as well as some of the complexities and limitations of county realignment funding and high CCS costs that have put many counties over their required CCS maintenance-of-effort expenditure levels. Many California stakeholders argue that high-quality care coordination for CYSHCN, regardless of program structure or model, requires greater state-level leadership and commitment of resources.

Among the financing options described above, the Title V MCH block grant and TANF have reached their limits in California, and tobacco settlement funds were used for one-time budget savings so are not available. Policymakers and administrators could consider seeking Health Home funding that expands federal match to 90/10 for two years, allowing time for care coordination to provide some return on investment and for additional financing sources to be identified.

Another option is to shift responsibility to Medicaid managed care plans and include care coordination responsibility in the MCO capitation rates. If the capitation rate is not increased to cover the new services, however, there is risk that MCOs may cut services or quality, or that their own financial health would be threatened. Further, shifting care coordination that is now done by county medical

²³ New Hampshire partners with a private insurance company, Anthem Blue Cross, to provide care coordination services for their CYSHCN (The Catalyst Center, 2010).

²⁴ States may transfer up to 10% of federal TANF grants to the Social Services Block Grant (SSBG) for a wide range of benefits and services for families with children.

²⁵ The Health Information Technology for Economic and Clinical Health Act (HITECH) is part of the American Recovery and Reinvestment Act of 2009 (ARRA) federal stimulus plan. ARRA contains funding and incentives to promote health care information technology in general and the adoption of electronic health record (EHR) systems among providers.

professionals could shift this 75% federally funded activity to 50% federal funding. Some argue that care coordination (excluding CCS carve-out services) is already an MCO requirement in California.

Experiences of other states point to ways that California can limit costs of care coordination while not sacrificing quality. One strategy is to rely not solely on nurses but rather to use team approaches that utilize social workers, paraprofessionals, administrative staff, community health workers, and others for appropriate tasks. That is, a program can be designed to use more medically trained professionals for more complex cases or for crisis situations and to use lower-cost but trained staff for other services. However, California must also consider what types of personnel are eligible for higher federal matching rates.

To the extent care coordination can reduce duplication of management/coordination across different agencies and reduce utilization of hospitals, specialty services, and emergency rooms in the long term, California could potentially capture those savings and reallocate them to care coordination improvements or expansions. One study of a care coordination program for medically complex children in Wisconsin found that children who received services from pediatric nurse case managers had fewer hospitalizations, fewer hospital days, and higher outpatient clinic visits after enrollment in the program.²⁶

Oversight/Monitoring

In the programs examined, the states engage in varying levels of oversight and monitoring and performance-improvement activities. Most of the states require data reporting from the care coordination providers in order to assess quality, utilization, and cost (of care coordination specifically and/or overall services). Some states contract with an outside entity, such as a university, to conduct program evaluations while others utilize internal claims or other databases to obtain data submitted by providers, provider networks, and care coordination vendors.

Rhode Island, for example, has a robust Quality Monitoring and Oversight process for CEDARR to identify utilization trends, outcomes, unmet needs, and areas that require improvement on an individual or system level. It includes:

- Bi-monthly meetings with management of all four CEDARR Health Homes.
- Regular performance reporting submitted with state reviews of claims and utilization data on a quarterly basis.
- Quarterly site visits at each CEDARR Health Home.
- Annual chart reviews and family satisfaction surveys.

In Maryland, where vendors are contracted to provide care coordination services, the oversight and monitoring is also very data-driven. The state evaluates case management outcomes and service delivery by monitoring pre-determined performance measures as well as service utilization. Case management companies send activity logs and must respond when requirements are not met; case managers are required to report to the state any significant events relating to a REM participant. Some

²⁶ Gordon JB, Colby HH, Bartelt T, Jablonski D, Krauthoefer ML, Havens P. A. "Tertiary care-primary care partnership model for medically complex and fragile children and youth with special health care needs". Arch Pediatr Adolesc Med. Oct 2007;161(10):937-944.

of the case management vendors conduct their own surveys of members and families/caregivers. To monitor the Blueprint program overall (which includes care coordination via community health teams), Vermont utilizes existing tools such as CAHPS PCMH and NCQA recognition standards to assess the patient experience and patient centeredness, respectively, and monitors costs through a multi-payer all claims database. Most measures are publicly published annually, and the program is mandated to report to the legislature each year.

In North Carolina (CCNC and CHACC) and Florida (CMS), care coordination functions are relegated to regional networks, which are monitored by the state. For example, Florida operates its CMS program through 22 offices in eight regions statewide and a central office; two state bureaus oversee the administration and operational functions. CCNC (NC) has evolved to become an independent entity under the Office of Rural Health. CCNC's central office recently developed a set of fundamental expectations and core activities, in conjunction with medical directors and clinical directors, and collects quality measures and feedback measures quarterly; the state conducts a regular chart audit and other oversight.

Oversight Considerations for California

Regardless of the organization of the model, most states employ rigorous oversight with reporting of outcome measures and quality improvement activities and results by care coordination entities. In designing a care coordination program, California policymakers should similarly emphasize data-driven performance and outcomes assessment to meet program goals, whether coordination is delivered by the county, managed care organization, or vendor.

North Carolina and Florida illustrate the state's ability to monitor a program that is region-based, similar to California's CCS county-based program. Given recent budget reductions, California's ability to monitor CCS care coordination activities has been reduced. Stakeholders express concern about the consistency of care coordination between counties and say that in some cases the emphasis of the CCS offices is service authorization and not care coordination. Since there are multiple organizations in addition to CCS doing care coordination, it appears that California could make significant improvements in care coordination by better defining standards and organization roles and increasing its oversight and monitoring capabilities.

California policymakers should emphasize data-driven performance and outcomes assessment to meet program goals, whether coordination is delivered by the county, managed care organization, or vendor.

The state needs to weigh and find a balance in reporting requirements for effective quality control and improvement, without overburdening providers and care coordination entities. Further research into the quality improvements and cost savings in other programs should improve the design of oversight and monitoring activities for California.

Lessons and Conclusion

Other states' experiences with care coordination for CYSHCN suggest numerous ingredients that are needed for an effective, sustainable care coordination system:²⁷

- Acknowledgement that care coordination for CYSHCN, particularly those in Medicaid, is complex and requires much individualization; it is not amenable to a formula or one set of services or standards; risk stratification and levels of care are tools to enhance appropriateness of care.
- Ongoing efforts to enhance communication and collaboration among care providers (primary care, specialty care, children's hospitals) and with parents/caregivers and social/community services and supports; pediatric subspecialists play a critical role with medically complex cases and must be included in care planning and communication.
- Clear delegation of coordination responsibilities to reduce redundancy across systems (e.g., primary care, mental health, developmental disability, education), with flexibility depending on a child's needs. The care plan is a critical tool to coordinate communication; however, there needs to be compatibility across or ways to address disparate EHR/care coordination systems to reduce duplication of efforts by different providers.
- Resources for and commitment to use of data to identify trends and unmet needs of members.
- An assessment process and care plan document that is focused on outcomes with a realistic series of goals.
- Efforts to streamline administrative requirements in the reimbursement process.
- Identification of at-risk patients before they become high cost.
- Alignment with population-level interventions (vaccines, flu shots, prevention, outreach).
- Leadership to gain support for and implement policies and obtain funding for effective care coordination and population management.
- Workforce and tool development, and provider education to support effective care coordination.
- Commitment among policymakers and administrators for ongoing, sustained support.
- Efforts to measure and make adjustments to maximize cost effectiveness of proposed models, including in the design of care coordinator roles and responsibilities, communication and linkages across systems, and performance expectations.

²⁷ See Pediatrics, 2014 for additional recommendations for implementing care coordination for CYSHCN.
<http://pediatrics.aappublications.org/content/133/5/e1451.full.html>

California policymakers and stakeholders should consider these lessons whether redesigning or just tweaking its current care coordination for CYSHCN. The goal should be the Triple Aim—better care, better health, and lower costs—for California's CYSHCN and their families.

Appendix A. State Programs' Approaches on Building Blocks

Table 1. Eligibility Requirements

Program/State	Age	Diagnosis	Eligibility for existing program	Residence	Mandatory or Voluntary	Other Criteria/ Exclusions
Children's Medical Services (CMS) Network/Florida	<21 years	Clinical screening tools used to identify serious and chronic conditions in one of four domains: physical, emotional, behavioral, developmental	Medicaid, CHIP, or Safety Net (lack access to needed services and pay sliding fee scale)	Florida	Voluntary (plan option for Medicaid and CHIP)	
Community Care of North Carolina (CCNC)/North Carolina	<21 years	Chronic physical, developmental, behavioral, or emotional condition(s) requiring health and related services of a type and amount beyond that required by children generally	Medicaid	North Carolina	Mandatory, with choice to opt out	Foster children are auto-enrolled (covers nearly 90%)
Child Health Accountable Care Collaborative (CHACC)/North Carolina	<21 years	Two or more complex conditions; under care of two or more specialists; numerous hospitalizations; and/or numerous ED visits	Medicaid	North Carolina	Voluntary	Patients treated by a pediatric subspecialist in one of five participating academic medical centers or one of seven medical center with high volumes of children
Comprehensive Evaluation Diagnosis Assessment Referral Re-evaluation (CEDARR)/Rhode Island	<21 years	Broad definition based on federal Maternal and Child Health Bureau definition as the benchmark. ²⁸ Eligibility for enhanced federal match through the Health Home (health home)	Enrollment in Medicaid, including commercially insured children with Medicaid as secondary payer	Rhode Island	Voluntary	Child must live at home and not in a residential facility; children can receive services while temporarily in a facility, and discharge plan must

²⁸ The federal Maternal and Child Health Bureau defines Children with Special Health Care Needs as "children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally."

Program/State	Age	Diagnosis	Eligibility for existing program	Residence	Mandatory or Voluntary	Other Criteria/ Exclusions
		requires that the program assign a diagnosis.	(Katie Beckett waiver in Rhode Island) ²⁹			include discharge to home.
South Carolina Solutions (SCS)/South Carolina	<18 years	Meet Nursing Facility (NF) or Intermediate Care Facility for the Mentally Retarded (ICF/MR) criteria; meet Medical Eligibility Criteria that indicates the child has: <ul style="list-style-type: none"> - A serious illness or condition that is expected to last longer than 12 months and which generally makes the child dependent upon comprehensive medical, nursing, health supervision or intervention; and - Significant medication, hospitalization, therapy, nursing care, and specialist needs 	Medicaid	South Carolina	Voluntary	MR/DD children not eligible
Rare and Expensive Case Management (REM)/Maryland	All ages	Specific diagnoses, with age requirements, included on the REM Disease List	Medicaid Managed Care Program (HealthChoice) ³⁰	Maryland	Voluntary	Dual eligible individuals are not eligible
Vermont Blueprint for Health/Vermont	All ages	Not linked to diagnoses	All payers (Medicaid, Medicare, and Commercial)	Vermont	Voluntary	All patients in participating primary care practices are eligible for care coordination services

²⁹ Rhode Island has a Katie Beckett Waiver, also known as the Deeming Waiver or the 2176 Model Waiver. This creates an eligibility category that allows certain children under age 19 who have long term disabilities or complex medical needs to become eligible for Medicaid coverage. Katie Beckett eligibility enables children to be cared for at home instead of in an institution. With Katie Beckett, only the child's income and resources are used to determine eligibility. Approximately 40% of kids enrolled in CEDARR are commercially covered with Medicaid serving as secondary coverage; the other 60% are enrolled in Medicaid managed care.

³⁰ Dual eligibles are excluded from the REM program as they are carved out of HealthChoice.

Table 2. Eligibility Determination

Program/State	Referral/Assessment	Processing/Determination
Children's Medical Services (CMS) Network/Florida	Families applying for Florida KidCare are asked a series of questions regarding their child's medical, behavioral, and developmental status to determine whether screening for CMS is needed. ³¹	CMS nurses administer a clinical screening tool to determine clinical eligibility.
Community Care of North Carolina (CCNC)/North Carolina	Predictive modeling based on claims data is used to identify high-cost patients; and referrals from providers.	Networks and care managers contact identified patients and coordinated with the patients' providers. CCNC employs a risk stratification tool.
Child Health Accountable Care Collaborative (CHACC)/North Carolina	Referrals from NICU, PICU, specialty clinics, and primary care providers	CHACC care manager implements a broad assessment tool. Care managers have discretion to complete a partial or full assessment based on the screening criteria – at risk for needing services – and existing care coordination being provided.
Comprehensive Evaluation Diagnosis Assessment Referral Re-evaluation (CEDARR)/Rhode Island	Self-referral by the family; or referral by a provider, school, or other agency based on the child's need for services and assistance that CEDARR can provide	Licensed Clinician screens the child for eligibility during the initial meeting with the child and family. Licensed Clinicians in the CEDARR program must determine ongoing eligibility for home and community-based services provided through the CEDARR Family Centers.
South Carolina Solutions/South Carolina	Children are referred by a provider. The Medical Eligibility Assessment Tool is used to evaluate the child against medical complexity criteria, based upon diagnoses and subsets.	
Rare and Expensive Case Management (REM)/Maryland	Self-referral with referral form signed by a physician; or referred by a physician, MCO, specialty clinic, NICU, etc. All applicants require the REM referral, or application, and supporting medical documentation from the individual's provider.	Nurses within the Division of Children's Services of the Maryland Department of Health & Mental Hygiene; all application denials are reviewed by a physician.
Vermont Blueprint for Health/Vermont	All patients in participating practices and organizations are eligible for care coordination services provided by their primary	N/A

³¹ The following questions from the Florida KidCare application address a child's medical, behavioral, and/or developmental condition(s):

- (1) Is this child limited or prevented in any way in his or her ability to do the things most children of the same age can do?
- (2) Does this child need to get special therapy, such as physical, occupational or speech therapy, or treatment or counseling for an emotional, developmental, or behavioral problem?
- (3) Does this child need or use more medical care, mental health or educational services than is usual for most children of the same age?

Program/State	Referral/Assessment	Processing/Determination
	care provider and Community Health Team (CHT).	

Table 3. Care Coordination Services

Program/State	Services			
	Care Coordination	Medical	Behavioral Health	Non-Medical
Children's Medical Services (CMS) Network/ Florida	<ul style="list-style-type: none"> Individual care plan Annual assessment 	<ul style="list-style-type: none"> Medicaid: all Medicaid State Plan medically necessary services CHIP: mirrors Medicaid benefits Safety net: limited services (Rx, specialized services, diagnostic services, dental for cleft lip/palate) 	<ul style="list-style-type: none"> Mirrors Medicaid services for Medicaid and CHIP children Behavioral Health Network (B-Net): Slightly under 1,000 slots statewide for seriously mentally ill (SMI) children (Administered by Department of Children and Families) Institutional care is carved out (limited to up to 30 days) 	<ul style="list-style-type: none"> Genetic and Nutritional counseling Parent support Respite and pediatric palliative care (provided by Partners in Care): partnership with hospice agencies to provide access to art and play therapy, respite, and counseling services for 940 children with life-limiting illness not expected to live past age 21 (able to bill Medicaid FFS for services)
Community Care of North Carolina (CCNC)/North Carolina	<ul style="list-style-type: none"> Risk assessment Review of medications Ancillary services Home visits 	<ul style="list-style-type: none"> Medicaid benefits 	<ul style="list-style-type: none"> Carved out Delivered via MCO 	<ul style="list-style-type: none"> Family support groups Nutrition education Referrals to social services and supports
Child Health Accountable Care Collaborative (CHACC)/North Carolina	<ul style="list-style-type: none"> Assessment Care plan 			
Comprehensive Evaluation Diagnosis Assessment Referral	<ul style="list-style-type: none"> Required Health Home services with a Care Coordination component are collapsed under 	<ul style="list-style-type: none"> Full Medicaid benefits 	<ul style="list-style-type: none"> Medicaid benefits 	

Program/State	Services			
	Care Coordination	Medical	Behavioral Health	Non-Medical
Re-evaluation (CEDARR)/Rhode Island	<p>the broader service definition of "Health Needs Coordination"</p> <ul style="list-style-type: none"> ○ Education ○ Peer interaction ○ Family support groups ○ Navigation ○ Acquiring benefits • Initial Family Intake and Needs Assessment (IFIND) • Family care plan development and review • Family Care Coordination Assistance <ul style="list-style-type: none"> ○ Provision of specials needs resource information ○ System mapping and navigation ○ Resource identification ○ Eligibility assessment and application assistance ○ Peer support and guidance 			
South Carolina Solutions/South Carolina	<ul style="list-style-type: none"> • Identify resources for family in the community • Authorize respite care • Monthly review of educational topic with caregiver • Monthly review of care plan with caregiver and instructions for caregiver to ensure compliance • Monitor interventions and therapies provided 	<ul style="list-style-type: none"> • Comprehensive 	<ul style="list-style-type: none"> • Carved out • Comprehensive community based system 	<ul style="list-style-type: none"> • Emergency preparedness plans • Home modifications • CPR training • Home and community based services and supports • Transportation • Respite • Private duty nursing • Equipment maintenance • Education for family
Rare and Expensive Case Management	<ul style="list-style-type: none"> • Assessment of enrollee needs • Patient education 	<ul style="list-style-type: none"> • Comprehensive Medicaid FFS benefits 	<ul style="list-style-type: none"> • Carved out • Provided by an ASO 	<ul style="list-style-type: none"> • Coordinated by case managers and provided

Program/State	Services			
	Care Coordination	Medical	Behavioral Health	Non-Medical
(REM)/Maryland	<ul style="list-style-type: none"> Family support services Development of a treatment plan Coordination of provider services Follow-up on enrollee's progress 	<ul style="list-style-type: none"> Optional services such as shift home health aide 		through the Developmental Disability Administration and Division of Rehabilitation Services
Vermont Blueprint for Health/Vermont	<ul style="list-style-type: none"> Individual care coordination Outreach and population management Integration with community-based social and economic supports 	<ul style="list-style-type: none"> Based on patient's coverage 	<ul style="list-style-type: none"> Based on patient's coverage 	<ul style="list-style-type: none"> Connect patients with chronic care management, behavioral health, health and wellness coaching, social/economic services support Physical therapy Nutritional therapy Chronic disease self-management programs Wellness, Recovery and Action Plan (WRAP) Support and Services at Home (SASH) for elderly and disabled Medicare beneficiaries

Table 4. Care Coordination Standards

Program/State	Standards				
	Assessment and care plan	Staff ratio/caseload	Care coordinators	Medical home model/care team	Other
Children's Medical Services (CMS) Network/Florida	<ul style="list-style-type: none"> Clinical screening tool and medical records assessment Assessment conducted with the family in person or via phone Assessments used to develop care plan Individual care plan updated every six months 	<ul style="list-style-type: none"> No specific caseload requirement Goal is 1-2 care coordinators per primary care practice with 300-400 kids 250 to 450 cases based on number of care coordinators per office/ region Medical foster care program: 22:1 for nurses and 25: 1 for social workers 	<ul style="list-style-type: none"> Registered Nurses Social workers 	<ul style="list-style-type: none"> Each child is assigned a care coordinator Interdisciplinary team approach 	
Community Care of North Carolina (CCNC)/North Carolina	<ul style="list-style-type: none"> Risk stratification tool to assess major pediatric chronic conditions Rate level of care as heavy, medium, or light Care managers work through priority patient list based on risk stratification 	<ul style="list-style-type: none"> Based on the target and intensity of the target 	<ul style="list-style-type: none"> Registered Nurses 	<ul style="list-style-type: none"> Multidisciplinary team approach Behavioral health professional included for members with behavioral health condition Care managers embedded in primary care practices of larger networks or assigned to cluster of practices in smaller network Care managers required to enter data into CMIS 	<ul style="list-style-type: none"> Web-based care management system

Program/State	Standards				
	Assessment and care plan	Staff ratio/caseload	Care coordinators	Medical home model/care team	Other
Child Health Accountable Care Collaborative (CHACC)/North Carolina	<ul style="list-style-type: none"> Broad assessment tool 		<ul style="list-style-type: none"> Specialty Care Manager embedded in academic medical centers, tertiary hospitals, and specialty clinics Registered Nurses 		<ul style="list-style-type: none"> Patient management information tool used to communicate between specialist and PCP
Comprehensive Evaluation Diagnosis Assessment Referral Re-evaluation (CEDARR)/Rhode Island	<ul style="list-style-type: none"> IFIND intake assessment <ul style="list-style-type: none"> Completed within 30 calendar days of request by family Family care plan <ul style="list-style-type: none"> Completed within 30 days of the assessment Reviewed and revised annually Interim care plan (1-2 months) 		<ul style="list-style-type: none"> Licensed clinician: Licensed Social Worker, Licensed Mental Health Counselor, Licensed Marriage and Family Therapy Counselors, and Registered Nurses Licensed clinician required to contact family at least every six months Family service coordinator 	<ul style="list-style-type: none"> Health Home model 	
South Carolina Solutions/South Carolina	<ul style="list-style-type: none"> Proprietary tool to determine level of care Level of care reviewed quarterly 	<ul style="list-style-type: none"> Transitional assessments in hospitals: 45-50 cases per nurse Qualifying events assessments: ≤40 cases per nurse 	<ul style="list-style-type: none"> Monthly contact with patient and family Monitor claims monthly 	<ul style="list-style-type: none"> Interdisciplinary care team Behavioral health professional included in team for members with behavioral health condition 	<ul style="list-style-type: none">

Program/State	Standards				
	Assessment and care plan	Staff ratio/caseload	Care coordinators	Medical home model/care team	Other
		<ul style="list-style-type: none"> In home assessments: ≤60 cases per nurse 			
Rare and Expensive Case Management (REM)/Maryland	<ul style="list-style-type: none"> Assessment Interdisciplinary plan of care Care plan developed with family/caregiver input Level of care guidelines and assignment 	<ul style="list-style-type: none"> 80-100 members per case manager 	<ul style="list-style-type: none"> Registered Nurses Social workers Minimum contact requirements based on level of care Reporting requirements 	<ul style="list-style-type: none"> Multidisciplinary team Included primary care provider and variety of other providers 	<ul style="list-style-type: none"> Quality improvement and performance measures Electronic case management system
Vermont Blueprint for Health/Vermont	<ul style="list-style-type: none"> HRA not standardized across practices 	<ul style="list-style-type: none"> Five FTE serve 20,000 patients 	<ul style="list-style-type: none"> Nurses Varying job titles 	<ul style="list-style-type: none"> NCQA PCMH certification Community Health Team (multidisciplinary) Track patients who are overdue for tests Manage short-term care for high needs patients Check that patients are filling prescriptions and taking medications appropriately Follow up with patients on personal health management goals CHT meets at least weekly 	<ul style="list-style-type: none"> Web-based central health registry to capture all patient data

Table 5. Reimbursement Methodology and Process

Program/State	Reimbursement Methodology	Process for Paying Providers for Care Coordination	Billing for Care Coordination
Children's Medical Services (CMS) Network/Florida	<ul style="list-style-type: none"> CMS network care coordinators within the local CMS Network field offices are state-employed nurse care coordinators and social workers 	<ul style="list-style-type: none"> Salaried 	<ul style="list-style-type: none"> N/A
Community Care of North Carolina (CCNC)/North Carolina	<ul style="list-style-type: none"> CCNC care managers are employed by the (14) CCNC networks, which are private non-profit and contract with the state. The state provides operating expenses for staff and health care initiatives. The networks receive a management fee based on the number of Medicaid recipients enrolled with the network. In addition, practices that participate in CCNC are paid (2013) \$2.50 PMPM for program requirements that include 24 hour phone access and referral or authorization of services to other providers when the service cannot be provided by the PCP; \$5 PMPM if patient is ABD. (Medical services are reimbursed FFS). 	<ul style="list-style-type: none"> Most CCNC care managers are employed by the networks and are salaried; they do not receive incentive payments, but there are productivity expectations and goals 	<ul style="list-style-type: none"> Each CCNC network receives PMPM from the state based on monthly enrollment
Childhood Accountable Care Collaborative (CHACC)/North Carolina	<ul style="list-style-type: none"> Nurse case managers, administrative staff that make appointments and provide linkages under direction of the nurse, and some patient navigators that are not medically trained are salaried through the CHACC networks³² 	<ul style="list-style-type: none"> Salaried 	<ul style="list-style-type: none"> N/A
Comprehensive Evaluation Diagnosis Assessment Referral Re-evaluation (CEDARR)/Rhode Island	<ul style="list-style-type: none"> Providers are paid on a per 15-minute unit basis, with rates tied to the provider's qualifications: \$16.63 for the Licensed Clinician, \$9.50 for the Family Services Coordinator Changing to PMPM of \$70.93 (proposed), split between team members (pending CMS approval) 	<ul style="list-style-type: none"> Providers are paid directly by the state; no payment is made to the MCOs 	<ul style="list-style-type: none"> Providers bill Medicaid through MMIS for Care Coordination services, using CPT code H2021 (with modifiers for different reimbursement rates) based upon 15 minutes of effort per unit
South Carolina Solutions	<ul style="list-style-type: none"> \$214 PMPM for care coordination; half is paid to 	<ul style="list-style-type: none"> N/A 	<ul style="list-style-type: none"> N/A

³² CHACC networks are centered on each of five academic medical centers or seven tertiary children's hospitals, so they are not exactly a one-to-one ratio with the 14 CCNC networks.

Program/State	Reimbursement Methodology	Process for Paying Providers for Care Coordination	Billing for Care Coordination
(SMS) /South Carolina	primary care providers plus FFS		
Rare and Expensive Case Management (REM)/Maryland	<ul style="list-style-type: none"> The case management vendor is paid a monthly individual payment. The case rate is based on the member's level of care: \$385.55 for initial month; \$286.90 for level 1; \$171 for level 2; \$90.25 for level 3. Physician practices are not paid for care coordination 	<ul style="list-style-type: none"> The state (DHMH) reimburses the case management vendor 	<ul style="list-style-type: none"> N/A
Vermont Blueprint for Health/Vermont	<ul style="list-style-type: none"> Participating providers are paid FFS plus PMPM based on volume of patients attributed to the practice for Medicaid, Medicare and commercial payers Payment amount is based upon NCQA recognition level (\$1.20-\$2.49 PMPM) 	<ul style="list-style-type: none"> Payers send payments to the coordinating administrative entity in the community and distributed to participating practices 	<ul style="list-style-type: none"> N/A

Table 6. Financing of Care Coordination

Program/State	Financing	Sustainability
Children's Medical Services (CMS) Network/Florida	<ul style="list-style-type: none"> Funded through Medicaid 1915(b) managed care waiver with state portion comprised primarily of general revenue and tobacco settlement trust funds. Also funded in part by Title XXI CHIP funds (for CHIP-eligible children), Title V MCH Block Grant Funds, TANF/SSBG (for the early intervention program), hospital fees (for newborn screening program), sliding scale fees from families above certain income. Services not covered by Medicaid, including parent support, therapeutic camps, early intervention, genetic and nutritional counseling, are financed by the state General Revenue Fund. 	<ul style="list-style-type: none"> Title XXI dependent upon enrollment Uncertain re: MCH block grant dollars given federal cuts (e.g., the sequester)
Community Care of North Carolina (CCNC)/ North Carolina	<ul style="list-style-type: none"> CCNC is funded under a Medicaid 1915(b) waiver, for central functions such as data processing and program administration, and for case management services by the networks and practices. CCNC has a few multi-payer special projects. 	
Childhood Accountable Care Collaborative (CHACC)/North Carolina	<ul style="list-style-type: none"> \$9.3 million CMMI grant for the "Child Health Accountable Care Collaborative" (CHACC) over 3-year period (awarded September 2012). 	<ul style="list-style-type: none"> Program is expected to produce health care savings of approximately \$24 million over the life of the grant
Comprehensive Evaluation Diagnosis Assessment Referral	<ul style="list-style-type: none"> CEDARR has been in existence in RI since 2001, funded through Medicaid under EPSDT program authority (to provide the screening and treatment included in the federal requirement). From 2011-2013, it received Section 2703 Health Home State Plan Amendments 90% federal 	<ul style="list-style-type: none"> State funding is included in annual state budget since 2001

Program/State	Financing	Sustainability
Re-evaluation (CEDARR)/Rhode Island	<ul style="list-style-type: none"> match (about 95% of enrollees meet criteria); enhanced payment reported to help bridge difficult budget times for CEDARR As of October 1, 2013, the State resumed funding the full State share (48%), which has been included in the annual budget passed by the Legislature every year since 2001. RI is a Katie Beckett state, so about 40% of children enrolled are commercially covered with Medicaid serving as secondary coverage; the other 60% are enrolled in Medicaid managed care 	<ul style="list-style-type: none"> Commercial insurance starting to look at paying for care coordination. State is encouraging CEDARR sites to become credentialed with commercial insurers Looking at pilot for pediatric-based medical home
South Carolina Solutions/South Carolina	<ul style="list-style-type: none"> Began with a managed in long term care 1115(c) waiver, currently under Medically Complex Children 1915(c) waiver (2012-2017; Community Health Solutions of America (CHS) administers the program for the state under an umbrella medical home network model. 	
Rare and Expensive Case Management (REM)/ Maryland	<ul style="list-style-type: none"> REM started in July 1997 with the implementation of Medicaid managed care. Amidst concern that medically complex individuals would not get needed care under managed care, the state and a panel of providers led the effort as part of the overall work on the 1115 waiver. REM case management services are funded through the Maryland Medicaid Program and include federal funding 	<ul style="list-style-type: none"> The funding is included in the annual State Medicaid budget
Vermont Blueprint for Health/Vermont	<ul style="list-style-type: none"> Commercial payers, Medicaid and Medicare provide funding through PMPM payments to participating practices and organizations and funding for Community Health Teams that include care coordination when appropriate Medicaid global commitment waiver provides \$5 million per year for administration of program, salaries, evaluation, and grants at the local level. Budget covers : 3 chronic disease self-management programs (general, diabetes, pain management), wellness, recovery and action plan (WRAP) – mental health, CDC evidence based diabetes prevention program tobacco cessation Medicaid and private insurers (3 major commercial insurers) in Vermont split the costs of the community health teams and pay FFS for care; total support is provided at the rate of \$70,000 (approximately 1.0 FTE/ 4,000 patients). Medicare funding for provider payments and CHT support is provided through CMS' Multi-payer Advanced Primary Care Practice Demonstration (a CMMI grant) Prior to the demonstration, Medicaid funded the Medicare portion of provider payments and CHT support. Blueprint is also supported by federal funds for HIT (ARRA, HITECH Act) Some money from Department of Health through CDC to operate disease specific programs 	<ul style="list-style-type: none"> Evaluation has documented the return on investment (ROI) of the program for Medicaid and commercial payers – improved health outcomes and decreased costs The demonstration is scheduled to end July 2014. The state has submitted a formal request to OMB to extend it through December 2014. Extension is an option if the program meets cost neutrality requirements and is at the discretion of

Program/State	Financing	Sustainability
	<p>through an MOU</p> <ul style="list-style-type: none"> • The funds are fully matched • As part of the "Hub and Spoke" Health Home initiative, state is seeking a 90-10 FMAP rate for health home services. • Some private foundation funding, like for WRAP in 2010. 	<p>the Secretary of HHS. OMB has not yet responded. Funding is available through July 2014 or December 2014 if the extension is approved</p> <ul style="list-style-type: none"> • Uncertain whether Medicare will continue to participate once the Multi-Payer Advanced Primary Care Practice Demonstration ends. • The state is not in a position to fill in the funding once the demonstration ends.

Appendix B: Sample Assessment and Other Tools

South Carolina Medical Complexity Criteria – Assessment Tool

Medically Complex Children's Waiver
Medical Complexity Criteria – Assessment Tool

Signature _____
Date _____

SCORE

Applicant Name _____ DOB _____

Medicaid/CLTC Number _____ Age _____

Primary Diagnosis _____

Secondary Diagnoses _____

Therapeutic Foster Care _____ DSS Case
Worker _____

1. Medications in the child's plan of treatment are necessary throughout the day: This criterion is to be applied to the individual's need for medication administration and includes the frequency and clinical skill involved. The criteria specify the route of administration, frequency required and assessment for effectiveness.

Score	
3	<p>____ Requires administration of multiple medications via tracheostomy, nasenteric or lavage tube, G-tube or J-tube – administered 4 times per day or more often.</p> <p>or</p> <p>____ Requires scheduled (not PRN) nebulization treatments every 1-2 hours or more often to prevent exacerbation of the medical condition – requires frequent assessment of effectiveness of medications.</p>
2	<p>____ Requires administration of multiple medications via tracheostomy, nasenteric or gavage tube, G-tube or J-tube – administered 3 times per day.</p> <p>or</p> <p>____ Requires oral administration of multiple medications (6 or more scheduled, not PRN) that are administered 3 times per day or more often.</p> <p>or</p> <p>____ Requires scheduled (not PRN) nebulization treatments every 4-6 hours to prevent exacerbation of the medical condition.</p>
1	<p>____ Requires administration of scheduled medications via tracheostomy, nasenteric or gavage tube, G-tube or J-tube – administered 1-2 times per day.</p> <p>or</p> <p>____ Requires oral administration of multiple medications (6 or more scheduled) that are administered 1-2 times per day.</p>
0	<p>____ Requires administration of oral meds (less than 6 scheduled) 1-2 times per day.</p> <p>or</p> <p>____ Requires medication administration on a PRN basis including nebulization treatments for an episodic event.</p>

Scheduled Medications:

PRN Medications:

1. _____ 6. _____ 11. _____

2.	7.	12.
3.	8.	13.
4.	9.	14.
5.	10.	15.
2. There is a significant medical condition that requires hands on medical supervision and monitoring by a trained professional due to the high probability for health complications, or adverse reactions due to the complexity of the child's condition.		
3	<input type="checkbox"/> Frequent periods of acute exacerbation of the medically complex condition(s), which requires hospitalization 3 times per year or more often. or <input type="checkbox"/> 4 or more ER or 8 or more sick visits per year for acute exacerbation of the medically complex condition(s).	
2	<input type="checkbox"/> Less frequent periods of acute exacerbation of the medically complex condition(s) that requires hospitalization 2 times per year. or <input type="checkbox"/> 3 ER or 6 sick visits per year for acute exacerbation of the medically complex condition(s).	
1	<input type="checkbox"/> Occasional periods of acute exacerbation of the medically complex condition(s) that requires hospitalization 1 time per year through an ER visit. or <input type="checkbox"/> 2 ER or 4 sick visits per year for acute exacerbation of the medically complex condition(s).	
0	<input type="checkbox"/> Rare periods of acute exacerbation of the medically complex condition(s), which has not required sick visits in the past year.	
Dates:		
3. The child's condition requires complex and comprehensive hands on nursing care. The assumption is that the majority of care provided to the child is done by the trained parent/caregiver or Private Duty Nursing Services.		
3	<input type="checkbox"/> The child receives Total Parenteral Nutrition, requiring close monitoring of electrolytes. or <input type="checkbox"/> The child receives tube feedings continuously; or intermittently 4 times per day or more. or <input type="checkbox"/> The child's oral feedings take an hour or longer requiring positioning and suctioning. or <input type="checkbox"/> The child requires frequent monitoring of respiratory status at least every 1-2 hours. or <input type="checkbox"/> The child requires frequent neurological monitoring at least 3-4 times per day. or <input type="checkbox"/> The child requires urinary catheterization or ostomy care 4 times per day or more. <input type="checkbox"/> The child requires monitoring for skin integrity at least 2 times per day to prevent further	

	<p>skin breakdown of an existing wound.</p>
2	<p>___ The child has impaired oral motor function and requires monitoring for weekly episodes of gagging, choking, vomiting, or aspiration; or takes between 30 minutes to 1 hour to feed requiring hands on assistance.</p> <p>or</p> <p>___ The child receives tube feedings intermittently 3 times per day or less.</p> <p>or</p> <p>___ The child requires frequent monitoring of respiratory status every 3-4 hours.</p> <p>or</p> <p>___ The child requires neurological monitoring at least one time per day.</p> <p>or</p> <p>___ The child exhibits seizure activity at least 2 or more times a month while on optimal anticonvulsant therapy.</p> <p>or</p> <p>___ The child requires urinary catheterization or ostomy care 3 times per day.</p> <p>or</p> <p>___ The child requires daily monitoring of skin integrity to prevent skin breakdown.</p> <p>Notes:</p>
1	<p>___ The child has impaired oral motor function resulting in monthly episodes of gagging, choking, vomiting, or aspiration.</p> <p>or</p> <p>___ Oral feedings take less than 30 minutes to complete, but require hands on assistance to accomplish age appropriate eating skills, or which may require oral stimulation to swallow.</p> <p>or</p> <p>___ The child requires some daily respiratory monitoring which may include periodic CPAP ventilation.</p> <p>or</p> <p>___ The child needs some neurological monitoring or has exhibited seizure activity one time in the last 6 months.</p> <p>or</p> <p>___ The child requires urinary catheterization or ostomy care 2 times per day or less.</p> <p>or</p> <p>___ The child requires daily blood glucose monitoring.</p> <p>Notes:</p>
0	<p>___ The child has a history of impaired oral motor function and/or is able to eat with occasional episodes of gagging, and / or vomiting, but otherwise has oral feedings that are age appropriate.</p> <p>or</p> <p>___ The child requires PRN respiratory monitoring or may require oxygen for an episodic event.</p> <p>or</p> <p>___ The child is oxygen dependent with stable oxygen needs during the past 6 months requiring minimal intervention.</p>

	or ___ The child has no seizure activity during the past 6 months. or ___ The child does not require hands on nursing care.								
4. There are significant and complex medical conditions that require comprehensive medical supervision and coordination of multiple e medical providers (i.e., primary and specialty care physicians) due to multiple diagnoses, complexity of health conditions and high probability for health complications, due to the complexity and intensity of the child's conditions.									
3	___ Coordination and monitoring by primary care physician of 6 or more specialty care providers.								
2	___ Coordination and monitoring by primary care physician of 4 –5 or more specialty care providers.								
1	___ Coordination and monitoring by primary care physician of 2-3 specialty care providers.								
0	___ Coordination and monitoring by primary care physician and 1 specialty care provider.								
List Current Specialists: 1. _____ 5. 2. _____ 6. 3. _____ 7. 4. _____ 8.									
1. The child's daily routine is substantially altered by the need to complete specialized, and time-consuming treatments or the need for two or more types of prescribed therapeutic therapies provided by a licensed professional. This refers to medically appropriate and medically focused PT, OT, and Speech Therapies. It does not include recreational or behavioral therapies.									
3	___ The child receives multiple prescribed therapies by a licensed professional according to his/her treatment plan with a combined total greater than 5 times per week.								
2	___ The child receives multiple therapies according to his/her treatment plan with a combined total of 4-5 times per week.								
1	___ The child receives multiple therapies with a combined total of 2-3 times per week.								
0	___ The child receives a therapy according to his plan of care less than 2 times per week.								
Notes: <table> <tr> <td>medical therapies</td> <td>school based therapies</td> </tr> <tr> <td>PT</td> <td>PT</td> </tr> <tr> <td>OT</td> <td>OT</td> </tr> <tr> <td>ST</td> <td>ST</td> </tr> </table>		medical therapies	school based therapies	PT	PT	OT	OT	ST	ST
medical therapies	school based therapies								
PT	PT								
OT	OT								
ST	ST								

Maryland REM Level of Care Guidelines

LOC 1 Acutely Ill	LOC 2 Unstable	LOC 3 Stable
<p>Case Management level of intervention: The emergent change in the REM participant's medical condition or service utilization requires intensive case management intervention and follow-up.</p> <p>Examples</p> <p>REM participant has history (within past 6 mos.) of frequent hospitalizations and ER visits. Unstable clinical condition, an exacerbation of chronic illness or a newly diagnosed condition. Unstable psychosocial issues that have a significant negative impact on the health of the participant. History of highest service utilization. Participant receives new or on-going nursing services requiring intense CM assessment of the need for services.</p>	<p>Case Management level of intervention: The instability in the REM participant's medical condition or service utilization requires Case Management intervention on an ongoing basis to attain stable service/treatment plans.</p> <p>Examples</p> <p>REM participant has a history of exacerbations of medical issues requiring case management assessment of stability. Recently diagnosed with a new condition and that condition is stabilizing. Demonstrating understanding of condition but requires CM follow up to maintain level of understanding. Continues with high utilization of services, but appropriateness has been determined by CM and participant and participant/caregiver is demonstrating some level of independence in managing services. Participant sees multiple specialists. CM assistance is required with coordination of care between multiple specialists. Attendance at some of the appointments by the CM is required. Receives on-going nursing services not requiring intensive CM assessment of the need for services. (Includes those requiring the nursing assessment form every 12 months for participants receiving ongoing private duty nursing or SHHA services.) Has presented with obstacles to accessing services requiring CM intervention and coordination.</p>	<p>Case Management level of intervention: Case management intervention is required on an ongoing basis to monitor participant's stable service/treatment plans.</p> <p>Examples</p> <p>REM participant has a stable service/treatment plan. Requires ongoing monitoring of ability to access services. Requires on-going assessment of clinical stability. Receives on-going monitoring of routine specialty and primary care. Utilization of services is moderate, and appropriateness has been determined by CM. Participant/caregiver is demonstrating independence in managing services.</p>

Maryland REM Case Manager Minimum Contact and Reporting Requirements

Participant Level of Care	General Criteria	Documentation	Reporting Schedule (Minimum if no change in level of care)	Participant Contact	PCP Contact	Cost and Utilization Data Review
Assessment	New to REM	Assessment Form Interdisciplinary plan of care (IPOC) CM Plan Emergency Information Form	Initial assessment report completed within 30 calendar days of date referral sent to CM Agency and updated once every 12 months.	1. Phone contact within 24 hours 2. Face to face visit within 10 calendar days of receipt of referral.	Prior to first report	N/A
Level of Care 1	Acutely ill and/or history of highest service utilization requiring intensive CM assessment and coordination.	IPOC and CM Plan Assessment Report	Reviewed/updated and completed at least every 3 months from date of previous report. Once every 12 months	1. Phone contact every month. 2. Face to face visit every 3 months	Once every 3 months	Every 3 months
Level of Care 2	Unstable service and treatment plans requiring on-going CM assessment and coordination.	IPOC and CM Plan Assessment Report	Reviewed/updated and completed at least every 6 months from date of previous report. Once every 12 months	1. Phone contact every month. 2. Face to face visit every 6 months	Once every 6 months	Every 3 months
Level of Care 3	Stable service and treatment plans requiring periodic CM assessment and coordination	IPOC and CM Plan Assessment Report	Reviewed/updated and completed at least every 6 months from date of previous report. Once every 12 months	1. Phone contact every month. 2. Face to face visit once per 12 months.	Once every 6 months	Every 3 months

Maryland REM Rare and Expensive Disease List

ICD-9 Code	Disease	Age Group	Guidelines
042.	Symptomatic HIV disease/AIDS (pediatric)	0-20	<p>(A) A child <18 mos. who is known to be HIV seropositive or born to an HIV-infected mother and:</p> <ul style="list-style-type: none"> * Has positive results on two separate specimens (excluding cord blood) from any of the following HIV detection tests: <ul style="list-style-type: none"> --HIV culture (2 separate cultures) --HIV polymerase chain reaction (PCR) --HIV antigen (p24) <p>N.B. Repeated testing in first 6 mos. of life; optimal timing is age 1 month and age 4-6 mos.</p> <p>or</p> <ul style="list-style-type: none"> * Meets criteria for Acquired Immunodeficiency Syndrome (AIDS) diagnosis based on the 1987 AIDS surveillance case definition
V08	Asymptomatic HIV status (pediatric)	0-20	<p>(B) A child >18 mos. born to an HIV-infected mother or any child infected by blood, blood products, or other known modes of transmission (e.g., sexual contact) who:</p> <ul style="list-style-type: none"> * Is HIV-antibody positive by confirmatory Western blot or immunofluorescence assay (IFA) <p>or</p> <ul style="list-style-type: none"> * Meets any of the criteria in (A) above
795.71	Infant with inconclusive HIV result	0-12 months	<p>(E) A child who does not meet the criteria above who:</p> <ul style="list-style-type: none"> * Is HIV seropositive by ELISA and confirmatory Western blot or IFA and is 18 mos. or less in age at the time of the test <p>or</p> <ul style="list-style-type: none"> * Has unknown antibody status, but was born to a mother known to be infected with HIV
270.0	Disturbances of amino-acid transport Cystinosis Cystinuria Hartnup disease	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required.
270.1	Phenylketonuria - PKU	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required. Lab test: high plasma phenylalanine and normal/low tyrosine
270.2	Other disturbances of aromatic- acid metabolism	0-20	Clinical history and physical exam; laboratory
270.3	Disturbances of branched-chain amino-	0-20	

ICD-9 Code	Disease	Age Group	Guidelines
	acid metabolism		studies supporting diagnosis. Subspecialist consultation note may be required.
270.4	Disturbances of sulphur-bearing amino-acid metabolism	0-20	
270.5	Disturbances of histidine metabolism Carnosinemia Histidinemia Hyperhistidinemia Imidazole aminoaciduria	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required.
270.6	Disorders of urea cycle metabolism	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required.
270.7	Other disturbances of straight- chain amino-acid Glucoglycinuria Glycinemia (with methylmalonic acidemia) Hyperglycinemia Hyperlysinemia Pipecolic acidemia Saccharopinuria Other disturbances of metabolism of glycine, threonine, serine, glutamine, and lysine	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required.
270.8	Other specified disorders of amino-acid metabolism Alaninemia Ethanolaminuria Glycoprolineuria Hydroxyprolinemia Hyperprolinemia Iminoacidopathy Prolinemia Prolinuria Sarcosinemia	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required.
271.0	Glycogenosis	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required.
271.1	Galactosemia	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required.
271.2	Hereditary fructose intolerance	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required.
272.7	Lipidoses	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required.
277.00	Cystic fibrosis without ileus.	0-64	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required.
277.01	Cystic fibrosis with ileus.	0-64	Clinical history and physical exam; laboratory

ICD-9 Code	Disease	Age Group	Guidelines
			studies supporting diagnosis. Subspecialist consultation note may be required.
277.02	Cystic fibrosis with pulmonary manifestations	0-64	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required.
277.03	Cystic fibrosis with gastrointestinal manifestations	0-64	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required.
277.09	Cystic fibrosis with other manifestations	0-64	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required.
277.2	Other disorders of purine and pyrimidine metabolism	0-64	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required.
277.5	Mucopolysaccharidosis	0-64	Demonstration of deficient enzyme such as: alpha-L-Iduronidase, Iduronosulfate sulfatase, Heparan sulfate sulfatase, N-Acetyl-alpha-D-glucosaminidase, Arylsulfatase B, Beta-Glucuronidase, Beta-Galactosidase, N-Aacetylhexosaminidase-6-SO4 sulfatase.
277.81	Primary Carnitine deficiency	0-64	Clinical history and physical exam; laboratory or imaging studies supporting diagnosis. Subspecialist consultation note may be required.
277.82	Carnitine deficiency due to inborn errors of metabolism	0-64	Clinical history and physical exam; laboratory or imaging studies supporting diagnosis. Subspecialist consultation note may be required.
277.89	Other specified disorders of metabolism	0-64	Clinical history and physical exam; laboratory or imaging studies supporting diagnosis. Subspecialist consultation note may be required.
284.01	Constitutional red blood cell asplasia	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required.
284.09	Other constitutional aplastic anemia	0-20	
286.0	Congenital factor VIII disorder	0-64	
286.1	Congenital factor IX disorder	0-64	
286.2	Congenital factor XI deficiency	0-64	
286.3	Congenital deficiency of other clotting factors	0-64	
286.4	von Willebrand's disease	0-64	
330.0	Leukodystrophy	0-20	Clinical history and physical exam; laboratory or imaging studies supporting diagnosis. Subspecialist consultation note may be required.
330.1	Cerebral lipidoses	0-20	
330.2	Cerebral degenerations in generalized lipidoses	0-20	
330.3	Cerebral degeneration of childhood in other diseases classified	0-20	
330.8	Other specified cerebral degeneration	0-20	

ICD-9 Code	Disease	Age Group	Guidelines
	in childhood		
330.9	Unspecified cerebral degeneration in childhood	0-20	
331.3	Communicating hydrocephalus	0-20	Clinical history and physical exam; imaging studies supporting diagnosis. Sub specialist consultation note may be required.
331.4	Obstructive hydrocephalus	0-20	
333.2	Myoclonus	0-5	Clinical history and physical exam. Subspecialist consultation note may be required.
333.6	Idiopathic torsion dystonia	0-64	Clinical history and physical exam; laboratory or imaging studies supporting diagnosis. Subspecialist consultation note may be required.
333.7	Symptomatic torsion dystonia	0-64	
333.90	Unspecified extrapyramidal disease and abnormal movement disorder	0-20	Clinical history and physical exam; laboratory or imaging studies supporting diagnosis. Subspecialist consultation note may be required.
334.0	Friedreich's ataxia	0-20	Clinical history and physical exam. Neurology consultation note.
334.1	Hereditary spastic paraplegia	0-20	
334.2	Primary cerebellar degeneration	0-20	
334.3	Cerebellar ataxia NOS	0-20	
334.4	Cerebellar ataxia in other diseases	0-20	
334.8	Other spinocerebellar diseases NEC	0-20	
334.9	Spinocerebellar disease NOS	0-20	
335.0	Werdnig-Hoffmann disease	0-20	Clinical history and physical exam. Neurology consultation note.
335.10	Spinal muscular atrophy unspecified	0-20	
335.11	Kugelberg-Welander disease	0-20	
335.19	Spinal muscular atrophy NEC	0-20	
335.20	Amyotrophic lateral sclerosis	0-20	
335.21	Progressive muscular atrophy	0-20	
335.22	Progressive bulbar palsy	0-20	
335.23	Pseudobulbar palsy	0-20	
335.24	Primary lateral sclerosis	0-20	
335.29	Motor neuron disease NEC	0-20	
335.8	Anterior horn disease NEC	0-20	
335.9	Anterior horn disease NOS	0-20	
341.1	Schilder's disease	0-64	Clinical history and physical examination; supporting imaging studies and neurologic consultation note may be required.
343.0	Diplegic infantile cerebral palsy	0-20	Clinical history and physical exam. Neurology consultation note may be required.
343.2	Quadriplegic infantile cerebral palsy	0-64	(See next page for Guideline description)
344.00	Quadriplegia, unspecified	0-64	
344.01	Quadriplegia, C1-C4, complete	0-64	
344.02	Quadriplegia, C1-C4, incomplete	0-64	

ICD-9 Code	Disease	Age Group	Guidelines
344.03	Quadriplegia, C5-C7, complete	0-64	Clinical history and physical examination; supporting imaging studies and neurologic consultation note may be required.
344.04	Quadriplegia, C5-C7, incomplete	0-64	
344.09	Quadriplegia, Other	0-64	
359.0	Congenital hereditary muscular dystrophy	0-64	Clinical history and physical examination; supporting imaging studies and neurologic consultation note may be required.
359.1	Hereditary progressive muscular dystrophy	0-64	Clinical history and physical examination; supporting imaging studies and neurologic consultation note may be required.
359.21	Myotonic muscular dystrophy (Steinert's only)	0-64	Clinical history and physical examination; supporting imaging studies and neurologic consultation note may be required.
437.5	Moyamoya disease	0-64	Clinical history and physical examination; supporting imaging studies and neurologic consultation note may be required.
579.3	Short gut syndrome	0-20	Clinical history and imaging studies supporting diagnosis. Gastrointestinal subspecialist consultation note may be required.
582.0	Chronic glomerulonephritis with lesion of proliferative glomerulonephritis	0-20	Clinical history, laboratory evidence of renal disease. Nephrology subspecialist consultation note may be required.
582.1	Chronic glomerulonephritis with lesion of membranous glomerulonephritis	0-20	
582.2	Chronic glomerulonephritis with lesion of membranoproliferative glomerulonephritis	0-20	
582.4	Chronic glomerulonephritis with lesion of rapidly progressive glomerulonephritis	0-20	
582.81	Chronic glomerulonephritis in diseases classified elsewhere	0-20	
582.89	Other Chronic glomerulonephritis with lesion of exudative nephritis interstitial (diffuse) (focal) nephritis	0-20	
582.9	With unspecified pathological lesion in kidney Glomerulonephritis: NOS specified as chronic hemorrhagic	0-20	

ICD-9 Code	Disease	Age Group	Guidelines
	specified as chronic Nephritis specified as chronic Nephropathy specified as chronic		Clinical history, laboratory evidence of renal disease. Nephrology subspecialist consultation note may be required.
585.1	Chronic kidney disease, Stage I (diagnosed by a pediatric nephrologists)	0-20	
585.2	Chronic kidney disease, Stage II (mild) (diagnosed by a pediatric nephrologists)	0-20	
585.3	Chronic kidney disease, Stage III (moderate) (diagnosed by a pediatric nephrologists)	0-20	
585.4	Chronic kidney disease, Stage IV (severe) (diagnosed by a pediatric nephrologists)	0-20	
585.5	Chronic kidney disease, Stage V (diagnosed by a pediatric nephrologists)	0-20	
585.6	End stage renal disease (diagnosed by a pediatric nephrologists)	0-20	
585.9	Chronic kidney disease, unspecified (diagnosed by a pediatric nephrologists)	0-20	
585.6, V45.11	Chronic kidney disease with dialysis	21-64	Clinical history, laboratory, evidence of renal disease. Nephrology subspecialist consultation note may be required.
741.00	Spina bifida with hydrocephalus NOS	0-64	Clinical history and physical exam, imaging studies supporting diagnosis. Subspecialist consultation may be required.
741.01	Spina bifida with hydrocephalus cervical region	0-64	
741.02	Spina bifida with hydrocephalus dorsal region	0-64	
741.03	Spina bifida with hydrocephalus lumbar region	0-64	
741.90	Spina bifida unspecified region	0-64	
741.91	Spina bifida cervical region	0-64	
741.92	Spina bifida dorsal region	0-64	
741.93	Spina bifida lumbar region	0-64	
742.0	Encephalocele Encephalocystocele Encephalomyelocele Hydroencephalocele Hydromeningocele, cranial Meningocele, cerebral Menigoencephalocele	0-20	Clinical history and physical examination, radiographic or other neuroimaging studies. Neurology or neurosurgery consultation note may be required.
742.1	Microcephalus Hydromicrocephaly Micrencephaly	0-20	Clinical history and physical examination, radiographic or other neuroimaging studies. Neurology or neurosurgery consultation note
742.3	Congenital hydrocephalus	0-20	

ICD-9 Code	Disease	Age Group	Guidelines
742.4	Other specified anomalies of brain	0-20	may be required.
742.51	Other specified anomalies of the spinal cord Diastematomyelia	0-64	
742.53	Other specified anomalies of the spinal cord Hydromyelia	0-64	Clinical history and physical examination, radiographic or other neuroimaging studies. Neurology or neurosurgery consultation note may be required
742.59	Other specified anomalies of spinal cord Amyelia Congenital anomaly of spinal meninges Myelodysplasia Hypoplasia of spinal cord	0-64	
748.1	Nose anomaly - cleft or absent nose ONLY	0-5	
748.2	Web of larynx	0-20	Clinical history and physical examination. Radiographic or other imaging studies and specialist consultation note (ENT, plastic surgery) may be required.
748.3	Laryngotracheal anomaly NEC- Atresia or agenesis of larynx, bronchus, trachea, only	0-20	Clinical history and physical exam; laboratory or imaging studies supporting diagnosis. Subspecialist consultation note may be required.
748.4	Congenital cystic lung	0-20	
748.5	Agenesis, hypoplasia and dysplasia of lung	0-20	Clinical history and physical exam; laboratory or imaging studies supporting diagnosis. Subspecialist consultation note may be required.
749.00	Cleft palate NOS	0-20	
749.01	Unilateral cleft palate complete	0-20	Clinical history and physical examination. Supporting consultation note from ENT/plastic surgery may be required.
749.02	Unilateral cleft palate incomplete	0-20	
749.03	Bilateral cleft palate complete	0-20	
749.04	Bilateral cleft palate incomplete	0-20	
749.20	Cleft palate and cleft lip NOS	0-20	
749.21	Unilateral cleft palate with cleft lip complete	0-20	
749.22	Unilateral cleft palate with cleft lip incomplete	0-20	
749.23	Bilateral cleft palate with cleft lip complete	0-20	
749.24	Bilateral cleft palate with cleft lip incomplete	0-20	
749.25	Cleft palate with cleft lip NEC	0-20	

ICD-9 Code	Disease	Age Group	Guidelines
750.3	Congenital tracheoesophageal fistula, esophageal atresia and stenosis	0-3	Clinical history and physical exam; imaging studies supporting diagnosis. Subspecialist consultation note may be required.
751.2	Atresia large intestine	0-5	Clinical history and physical exam; laboratory or imaging studies supporting diagnosis. Subspecialist consultation note may be required.
751.3	Hirschsprung's disease	0-15	
751.61	Biliary atresia	0-20	
751.62	Congenital cystic liver disease	0-20	
751.7	Pancreas anomalies	0-5	
751.8	Other specified anomalies of digestive system NOS	0-10	Clinical history and physical exam; laboratory or imaging studies supporting diagnosis. Subspecialist consultation note may be required.
753.0	Renal agenesis and dysgenesis, bilateral only Atrophy of kidney: congenital infantile Congenital absence of kidney(s) Hypoplasia of kidney(s)	0-20	Clinical history, physical examination, radiographic or other imaging studies. Subspecialist consultation note may be required.
753.10	Cystic kidney disease, bilateral only	0-20	
753.12	Polycystic kidney, unspecified type, bilateral only	0-20	
753.13	Polycystic kidney, autosomal dominant, bilateral only	0-20	
753.14	Polycystic kidney, autosomal recessive, bilateral only	0-20	
753.15	Renal dysplasia, bilateral only	0-20	
753.16	Medullary cystic kidney, bilateral only	0-20	
753.17	Medullary sponge kidney, bilateral only	0-20	
753.5	Extrophy of urinary bladder	0-20	Clinical history, physical examination, radiographic or other imaging studies supporting diagnosis. Subspecialist consultation note may be required.
756.0	Musculoskeletal--skull and face bones Absence of skull bones Acrocephaly Congenital deformity of forehead Craniosynostosis Crouzon's disease Hypertelorism Imperfect fusion of skull Oxycephaly Platybasia Premature closure of cranial sutures Tower skull Trigonocephaly	0-20	
756.4	Chondrodystrophy	0-1	
756.50	Osteodystrophy NOS	0-1	
756.51	Osteogenesis imperfecta	0-20	Clinical history, physical exam; imaging studies supporting diagnosis. Subspecialist consultation note may be required

ICD-9 Code	Disease	Age Group	Guidelines
756.52	Osteopetrosis	0-1	Clinical history and physical exam; laboratory or imaging studies supporting diagnosis. Subspecialist consultation note may be required.
756.53	Osteopoikilosis	0-1	
756.54	Polyostotic fibrous dysplasia of bone	0-1	
756.55	Chondroectodermal dysplasia	0-1	
756.56	Multiple epiphyseal dysplasia	0-1	
756.59	Osteodystrophy NEC	0-1	
756.6	Anomalies of diaphragm	0-1	
756.70	Anomaly of abdominal wall	0-1	
756.71	Prune belly syndrome	0-1	
756.72	Omphalocele	0-1	
756.73	Gastrochisis	0-1	Clinical history, physical examination, imaging studies supporting diagnosis. Subspecialist consultation note may be required.
756.79	Other congenital anomalies of abdominal wall	0-1	
759.7	Multiple congenital anomalies NOS	0-10	Clinical history, physical exam; laboratory or imaging studies supporting diagnosis. Subspecialist consultation note may be required.
V46.1	Dependence on respirator	1-64	Clinical history and physical exam. Subspecialist consultation note required.