Care coordination has the potential to improve care and reduce costs for children with special healthcare needs (CSHCN) enrolled in Medicaid. CSHCN are defined broadly as children who “have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” This group includes children with the most intensive and challenging healthcare needs, increasingly referred to as children with medical complexity. In addition to accounting for a large proportion of Medicaid spending, CSHCN are at risk for preventable hospitalizations and emergency care resulting from poor coordination among families, medical care providers, schools, and other community-based programs.

The pediatric community has emphasized the importance of care coordination for CSHCN for decades, but limited infrastructure and accountability have slowed implementation. This issue has become even more salient in Medicaid as state policy makers look to use resources more efficiently and shift more Medicaid-enrolled CSHCN into managed care plans. However, states provide Medicaid managed care organizations (MMCOs) with little guidance on how to implement effective care coordination programs for CSHCN. Furthermore, despite an extensive literature on care coordination for CSHCN, it is challenging to draw conclusions about design features of effective programs because existing studies often lack methodological rigor and vary widely in their underlying conceptual frameworks.

Given the paucity of reliable evidence on children’s programs, how should states and MMCOs design and implement care coordination for CSHCN? Research on care coordination interventions for Medicare beneficiaries is a potential source of insights. Although CSHCN and elderly Medicare beneficiaries may have very different healthcare and nonhealthcare needs, the goals and design elements of care coordination programs may be similar. In contrast to the CSHCN literature, there is a rigorous evidence base on care coordination for Medicare enrollees, including numerous experimental and quasi-experimental analyses of care coordination demonstrations.
This study describes 6 attributes of care coordination programs associated with improved outcomes among Medicare beneficiaries with chronic illnesses that are applicable to children with special healthcare needs (CSHCN) in Medicaid managed care. These findings may help managed care decision-makers implement and improve care coordination programs for CSHCN by:

- Identifying children who might benefit from care coordination.
- Specifying program goals and metrics.
- Developing requirements for care coordinators’ activities while allowing them to draw on their clinical expertise and judgment.
- Identifying other professionals (eg, clinical pharmacologists) who should team with care coordinators.

funded by federal agencies and other organizations.20-29 We sought to identify characteristics of successful Medicare care coordination programs and the extent to which they might be applicable to Medicaid-enrolled CSHCN, with the goal of providing actionable recommendations for state policy makers and MMCOs.

**METHODS**

For this study, we reviewed evidence on Medicare care coordination programs to describe the attributes of successful programs and then assessed the applicability of those findings to CSHCN in Medicaid. Regardless of whether these studies used the terms care coordination or care management, we focused on programs that perform coordination functions, such as organizing or linking multiple services and engaging the patient.30

We began our review of the Medicare literature with research syntheses that described findings across multiple federally funded care coordination demonstrations for community-dwelling Medicare fee-for-service beneficiaries. The syntheses were derived from randomized controlled trials and quasi-experimental analyses.30,31,32 We supplemented these syntheses with additional studies of care coordination programs targeted to Medicare beneficiaries that had equally strong research designs and were published in the last 10 years. These were primarily identified through summary articles on other care coordination programs targeted to Medicare beneficiaries in primary care practices which were included in a recent National Academy of Medicine workshop, “Models of Care for High-Need Patients.”22,33-35 We reviewed the original research cited in the syntheses and summary articles for additional detail on program characteristics and outcomes, as needed.

Second, we conducted an environmental scan of the Medicare financing and eligibility mechanisms through which states may provide care coordination to CSHCN, and we examined the extent to which existing programs rely on or interact with Medicaid managed care. We began the scan by reviewing articles that described existing programs and additional materials on the programs contained in those compilations.36,40-42 We also performed internet searches for Medicaid, children, and care coordination (or care management or care management), using several search terms for care coordination because it is not defined in Medicaid regulations and, in practice, exists in Medicaid under multiple programs.43 We also reviewed Medicaid law and federal guidance for clarification of the financing and eligibility options available to states interested in providing care coordination through Medicaid managed care.

Finally, we translated common characteristics of successful Medicare care coordination programs into program design considerations for CSHCN in Medicaid. Adapting evidence from Medicare for pediatric populations requires attention to unique characteristics of children’s health, such as the need for parental support, developmental trajectories, and differences in treatments for serious illnesses compared with such treatments in adults. We then refined our recommendations with the help of experts in children’s healthcare. We gathered feedback from 11 outside experts, including 5 Medicaid medical directors, 3 practicing pediatric clinicians, 1 former managed care executive, and 2 policy professionals well-versed in the research on Medicaid, care coordination, and CSHCN.

**RESULTS**

We reviewed 30 publications, including syntheses, summary articles, and individual studies of Medicare care coordination programs. Twenty-four of these publications reported evidence on impacts from rigorous studies and were included in this study. Nearly all of the Medicare care coordination programs used nurses as care coordinators. The goals of the Medicare care coordination programs were to reduce beneficiaries’ need for emergency department (ED) and inpatient care and to lower overall Medicare spending. Several studies also reported effects on mortality,22-24,29,44 patient functional status,26-28,29,51 patient satisfaction,26,43 and provider job satisfaction.43 We refer readers to summary articles for descriptions of the various care coordination interventions.22,23,31-35,38,39

We identified 6 design elements common among programs that were successful in reducing healthcare utilization or Medicare spending. Each of these has potential value for care coordination programs for CSHCN in Medicaid, but each requires adaptation to account for differences between the populations, funding sources, and programmatic constraints. In the remainder of this section, we discuss these 6 program design considerations and their relevance to CSHCN in Medicaid, noting particular challenges in adapting evidence from Medicare for pediatric populations. We provide additional detail in the eAppendix (available at ajmc.com).

1. **Identify and target specific subgroups.** Medicare care coordination programs that had positive impacts tended to focus on specific subpopulations. These included beneficiaries with...
particular chronic conditions and comorbidities and those projected to have high medical care use and spending.\textsuperscript{12,21,25–29,44–46}

Even among programs with favorable overall effects, impacts were often concentrated in, or larger for, a higher-risk subpopulation of their enrollees.\textsuperscript{20,27,28,37} Similarly, among care coordination interventions that did not demonstrate overall impacts, several had positive effects for a subset of higher-risk enrollees.\textsuperscript{20}

States and MMCOs may well benefit from strategies similar to those used in many Medicare programs to identify beneficiaries with either high recent utilization of EDs or inpatient care or high predicted future medical care spending, in addition to or instead of condition-based criteria. In the Medicaid context, social determinants of health and behavioral health comorbidities are additional factors that may help states and MMCOs identify children who are at especially high risk.

Medicaid-specific programmatic and care delivery factors may also drive, or limit, the targeting of care coordination programs for children. Several states combine Medicaid managed care with other Medicaid financing and eligibility pathways to care coordination that inherently target medically complex populations (eg, managed long-term services and supports for children covered by 1915[c] waivers and targeted case management delivered through managed care). States may also limit certain programs, such as targeted case management and home- and community-based benefits, to specific geographic areas, which may preclude targeting to all CSHCN who would benefit from care coordination. Likewise, the settings in which CSHCN receive care may inform targeting decisions. For example, CSHCN who receive care at tertiary care hospital outpatient clinics may be an easily identifiable high-risk target population, although targeting such CSHCN may exclude those who live far away from the selected clinics. In contrast, it may require more effort (eg, examination of diagnoses in encounter data) to identify CSHCN treated by primary care providers in the community who are most likely to benefit from care coordination.

2. Set clear goals for outcomes that are feasible to achieve within the time period examined. Few Medicare care coordination programs led to significantly lower Medicare spending.\textsuperscript{21,23,25,44} although some programs’ care coordination costs were offset by reductions in spending on inpatient or ED care.\textsuperscript{20,21,23} More commonly, interventions showed evidence of reduced hospitalizations,\textsuperscript{20,22,23,25,27,28} ED use,\textsuperscript{22,25,27,28} mortality,\textsuperscript{22,24,29,44} and other types of utilization,\textsuperscript{23,44,46} as well as improved functional outcomes\textsuperscript{27,28} and process of care quality measures.\textsuperscript{23,27,28}

These findings underscore the importance of specifying explicit goals in advance and developing logic models that connect care coordination activities to intended outcomes. States and MMCOs whose goals focus on improved well-being and functional status should not be surprised if their care coordination efforts actually increase net Medicaid spending. For states and MMCOs whose goals focus on reducing utilization and Medicaid spending, care coordination may initially increase healthcare utilization and spending before reducing the use of avoidable expensive services. Moreover, some positive outcomes of care coordination for CSHCN in Medicaid will not accrue to Medicaid programs, such as increases in parents’ labor force participation or children’s eventual success as independent adults. States and MMCOs must be realistic about expected outcomes specific to CSHCN and the time periods necessary to achieve them.

Our findings also point to the importance of defining the operational parameters of care coordination programs, such as caseloads, specific activities, and interactions with patients and family members. Defining these processes, and potentially specifying them in state Medicaid managed care contracts, provides an opportunity to subsequently measure them. In turn, measurement allows states and MMCOs to identify factors contributing to program outcomes.

3. Encourage active engagement between care coordinators and primary care providers. Among Medicare care coordination programs that demonstrated positive outcomes, care coordinators were either embedded in practices as part of the primary care team or developed close working relationships with primary care physicians.\textsuperscript{20,21,23,29,30,44,46} Among interventions in the Medicare Coordinated Care Demonstration that had positive outcomes, care coordinators either had already worked with the primary care physicians or accompanied patients to primary care visits to establish a relationship. These care coordinators were able to effectively communicate with providers, sharing important and timely information while making limited demands on providers’ time.\textsuperscript{20} Having a personal relationship with the care managers was also associated with physicians having greater trust in, respect for, and willingness to work with the care coordinators. Care coordination interventions that did not involve collaboration with primary care providers generally did not demonstrate positive outcomes.\textsuperscript{20,31}

Medicaid policy makers and MMCOs may wish to facilitate active care coordinator–primary care physician collaboration by reimbursing primary care practices for part of the cost of hiring dedicated care coordination staff. MMCOs that designate patient-centered medical homes may wish to support this staff investment as part of the medical home model. MMCOs that employ care coordinators to work across practices can also specify care coordination functions and performance requirements to ensure that the coordinators actively engage with the practices that they support.

4. Require some in-person contact between care coordinators and patients. Most care coordination programs that demonstrated positive outcomes involved substantial in-person contact between care coordinators or managers and patients, in
addition to periodic telephone calls. In-person care included meeting patients at the primary care office (either during the primary care visit or separately) or making in-home visits and assessments, as well as visits during inpatient stays.\textsuperscript{20,22,26-28,30,31,35,45,46} The single exception to this was a Health Buddy intervention that involved primarily electronic contact between patients and nurse care managers over a telephonic device.\textsuperscript{24,44} Nearly all other telephone-only interventions for Medicare beneficiaries failed to generate favorable effects on utilization or costs.\textsuperscript{31}

Medicaid policy makers and MMCOs may want to develop requirements for ongoing, periodic in-person visits. These visits may help to build strong relationships and trust among patients, their families, and care coordinators. In-person visits may also build strong patient engagement and capacity for self-management. For example, nurses may use techniques such as motivational interviewing during in-person visits to understand how they can guide caregivers to improve management of their child's condition and, as appropriate, self-management by the child. State Medicaid programs and MMCOs need to develop oversight mechanisms to ensure that coordinators operationalize such requirements in a satisfactory way. In particular, requirements for in-person visits should not impose additional travel burdens on families; instead, they should emphasize seamless integration of care coordination with existing appointments or patients' home routines.

5. Facilitate information sharing. Care managers or coordinators in several Medicare programs that showed positive impacts had access to the data in patients’ medical records, patient registries, and real-time data on ED use and hospital admissions to facilitate interventions during and not after crises.\textsuperscript{22,27,28} In other successful programs, the care managers served as information hubs in the absence of timely ED and inpatient data, coordinating the flow of information among multiple providers.\textsuperscript{20} Other programs noted that lack of timely information on hospital and ED use was a barrier to greater improvement in outcomes.\textsuperscript{25}

One potential mechanism for information sharing is the use of a shared electronic health record (EHR) by primary care providers, specialists, and care coordinators. Interoperable EHRs may increase the effectiveness of care coordination; however, these are rare. In the absence of EHRs that are well configured for care coordination, states and MMCOs may need to develop or support other ways for care coordinators to facilitate information sharing between providers. For example, some states have established limited health information exchanges that allow for near real-time notification of ED visits and hospitalizations that could be used by care coordinators.

6. Supplement care coordinators’ capabilities with those of other clinical experts, as relevant. Many interventions with positive impacts involved other professionals to help care coordinators address patients’ needs related to medication management, behavioral health, and nonmedical services.\textsuperscript{20,22,27,28,31} For example, in several programs, social workers addressed unmet behavioral health care needs in tandem with care coordinators’ efforts. This likely increased patients’ abilities to engage with care coordinators and increased the effectiveness of the programs.\textsuperscript{22,27}

Ensuring that care coordinators can help link patients to other clinical experts (eg, dieticians for children with feeding tubes and social workers for children with behavioral health problems) may be particularly important for CSHCN in Medicaid. Many CSHCN require services from medical, behavioral, and pharmacy providers, as well as services from other important entities (eg, early intervention programs or schools, juvenile justice systems, and social service agencies). States and MMCOs may want to leverage these clinical experts and deploy them as shared resources for care coordinators, regardless of whether the care coordinators are employed by practices, MMCOs, or other organizations. However, variation in the supply of pediatric providers, and in the social services available at the local and state levels, will affect care coordinators’ ability to marshal resources in this way.

DISCUSSION

This study describes 6 evidence-based program design elements from Medicare care coordination programs that provide potentially useful insights to help improve care coordination for CSHCN in Medicaid managed care. The available research on care coordination programs for CSHCN is limited as a source of evidence on effective care coordination practices, but the extensive Medicare literature can help address this gap. Based on these findings and discussions with experts in the field, state policy makers and MMCOs should consider the following when designing care coordination programs for CSHCN: 1) identifying and targeting high-risk patients, 2) clearly articulating what outcomes programs are likely to improve, 3) encouraging active engagement between care coordinators and primary care providers, 4) requiring some in-person contact between care coordinators and patients, 5) facilitating information sharing among providers, and 6) supplementing care coordinators’ expertise with that of other clinical experts.

As noted, adoption of these recommendations must be considered in light of some noteworthy differences between Medicare beneficiaries and Medicaid-enrolled CSHCN, such as the different constellations of diseases and conditions that they face and the types of services that they need.\textsuperscript{46} Care coordination efforts for CSHCN should also account for programmatic differences between Medicare and Medicaid. For example, it may be especially challenging for care coordinators to engage primary care providers in the Medicaid context due to Medicaid’s relatively lower payment rates for primary care services.
It is also important to note that the Early and Periodic Screening, Diagnostic, and Treatment benefit package, which provides a potential vehicle for states to cover care coordination services for CSHCN in Medicaid, does not automatically provide any specific care coordination services or reimbursement for such services. States seeking to implement or improve care coordination for CSHCN via managed care must take care to include adequate funding for care coordination services in MMCO capitation rates, and state MMCO contracts should identify precisely how MMCOs will pay for and deliver care coordination services to CSHCN.

An important design issue that was outside the scope of this study was the extent to which behavioral health care for CSHCN should be integrated within care coordination programs traditionally focused on physical health. Policy makers are increasingly recognizing the importance of addressing behavioral health needs in parallel with physical health needs for patients across the age spectrum. Several Medicare care coordination programs implemented team-based interventions that included social workers to address behavioral health needs or to facilitate referrals to more qualified behavioral health providers.22,27,28 Starting in 2017, Medicare began reimbursing primary care providers for behavioral health integration services based on the psychiatric collaborative care model,48 a model that was also effective in several pediatric populations with depression.59,50 However, the optimal balance between integration of behavioral health services within the primary care setting versus care coordination with behavioral health specialists for pediatric populations is an outstanding question.

Limitations

The review of the Medicare literature that informed this study was comprehensive but not systematic. We conducted a thorough search of references contained in the research syntheses and summary articles (a “snowball” strategy) and by pursuing references recommended by experts. This methodology was less structured than a systematic review but has been shown to serve as an effective strategy in searches of complex evidence.41 From our perspective, this strategy was also more efficient than a systematic review, particularly because there were many recently published syntheses and summary articles on care coordination. Nevertheless, it is possible that we excluded some relevant studies with this method.

Another limitation is that we were unable to assess which combination of the 6 characteristics of effective care coordination programs relevant to CSHCN in Medicaid is necessary or sufficient for a program to lead to positive outcomes. The combination of characteristics required for “successful” care coordination programs for CSHCN may differ depending on program goals.

Finally, all of the successful Medicare care coordination programs used nurses as care coordinators, due to the complex medical conditions of the patients. This suggests that achieving desired outcomes for beneficiaries, who almost always have complex healthcare needs, tends to require care coordinators with the clinical knowledge of nurses. Although this is likely true for some CSHCN, others may have needs that are best addressed by nonclinical care coordinators or by a combination of clinical and nonclinical experts on the care coordination team.

CONCLUSIONS

There is no one-size-fits-all design for implementing a care coordination program for CSHCN, given the diversity of conditions and medical needs, familial capacity to coordinate care, locally available resources and funding, and social determinants of health among Medicaid-eligible children. States and MMCOs may want to implement some of the 6 design elements presented here in different ways for different populations within the same state. Setting specific goals for care coordination programs—for example, emphasizing improved well-being and functional status or reduced utilization and spending—may also require placing relatively greater emphasis on certain design elements. Policy makers and MMCOs should continue to look for rigorous evidence on care coordination programs for CSHCN and consider conducting their own evaluations to assess program effects and the elements of programs that contribute to them. Similarly, there is no single perfect Medicaid financing or eligibility mechanism by which states can provide care coordination to CSHCN. As Medicaid leaders consider the options for care coordination programs, they may wish to combine traditional sources of funding for Medicaid managed care with others that target particular groups of CSHCN. Ultimately, no matter how states choose to implement care coordination for CSHCN, the evidence discussed here can help states and MMCOs develop successful programs, set appropriate expectations for outcomes, and better meet the needs of the CSHCN under their care.

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Author Affiliations: Mathematica Policy Research, Chicago, IL (KAS), Ann Arbor, MI (KWVB, JSZ, RH), Washington, DC (HTI), Princeton, NJ (RSB).

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of data (KAS, KWVB, JSJ, HTI, RSB); drafting of the manuscript (KAS, KWVB, JSJ, RSB); critical revision of the manuscript for important intellectual content (KAS, KWVB, JSJ, HTI, RSB); obtaining funding (KAS, HTI, RSB); administrative, technical, or logistic support (RHB); and supervision (KAS, RSB).

**Address Correspondence to:** Kate A. Stewart, PhD, MS, Mathematica Policy Research, 333 11th St, 6th Floor, Washington, DC 20009-2540. Email: kstawart@mathematica-mpr.com

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**REFERENCES**


**eAppendix.** Learning From Medicare Care Coordination Programs: Program Design Considerations to Maximize Success of Care Coordination Programs for CSHCN in Medicaid

<table>
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<th>Program Design Considerations Based on Insights From Literature on Medicare Care Coordination Programs</th>
<th>Relevance to CSHCN in Medicaid</th>
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<tr>
<td><strong>1. Target specific subgroups.</strong> Successful Medicare care coordination programs typically targeted care coordination to high-risk beneficiaries.</td>
<td>• For care coordination programs for CSHCN in Medicaid managed care, it is important to first articulate whether the eligible population should reflect the broader population of CSHCN per the federal Title V definition, which includes children “at risk” of having a chronic condition, or children with medical complexity (who may be in specialty plans that serve only populations with special health needs). This important distinction does not exist in Medicare. While children with medical complexity comprise a subgroup of all CSHCN, children in either group may include high-cost utilizers who may benefit from care coordination.</td>
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<td>• Whether focused on the broader population of CSHCN or subset of children with medical complexity, states and managed care plans may want to consider targeting care coordination services to children based on the presence of specific conditions. This may facilitate delivery of evidence-based care and enumeration of goals and metrics, which in turn facilitates measurement of whether care coordination had beneficial outcomes. However, this targeting strategy may miss many CSHCN who are high utilizers of expensive medical care services and may greatly benefit from care coordination services. Thus, states and plans may want to consider strategies similar to those used in many Medicare programs to identify beneficiaries with either high recent utilization of EDs or inpatient care, or high predicted future medical care spending, in addition to or instead of condition-specific criteria.</td>
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<tr>
<td><strong>2. Set clear goals for outcomes that are feasible to achieve in the time period examined.</strong> Several Medicare care coordination programs aimed to and were successful in reducing hospitalizations or ED</td>
<td>• Program goals may be multifaceted, encompassing reduced Medicaid spending, improved health, functioning, and/or quality of life, improved quality of care and patterns of service utilization, and improvements in parental outcomes, such as reductions in stress and lost time from work.</td>
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visits over a designated time period. Several were associated with lower mortality and/or improvements in healthcare use or functional status. Few were associated with reductions in net Medicare spending once the cost of the care coordination was included.

| **But they must be specific and the connections between goals and program activities must be clear.** |
| **For some outcomes, the care coordination–related investments in CSHCN may not be realized for many years. Thus, the timeline to observe impacts must be appropriate to the outcomes studied.** |
| **For programs trying to reduce Medicaid spending, care coordination may initially increase healthcare utilization and associated spending before reducing use of avoidable, expensive services.** |
| **As part of goal-setting activities, states and plans may also want to set interim goals related to care coordinators’ caseloads, activities, and interactions with patients, and measure these interim outcomes to better understand why care coordination programs may or may not be meeting their ultimate goals.** |

3. **Ensure care coordinators actively engage with primary care providers.** Effective Medicare programs facilitated strong, trusting working relationships between care coordinators and primary care providers, often embedding care coordinators in practices.

| **The literature on care coordination for CSHCN finds some programs with care coordinators embedded in clinics or practices, but others where care coordinators worked independently, separate from patients’ medical care providers. Both types of models showed positive impacts, although the quality of the analytic methods varied across studies, making it difficult to determine whether close collaboration between care coordinators and providers is more or less critical for pediatric populations.** |
| **To the extent that states and plans want to encourage active collaboration between care coordinators and providers, they can consider various models for financing and delivery, such as having the Medicaid program or managed care plan fund the care coordinators and related staff, and either embed the coordinators (in large practices) or share care coordinators across smaller practices. Alternatively, states or plans may consider funding primary care practices to hire their own care coordination staff.** |

4. **Require at least some in-person contact between care coordinators and patients.** Effective Medicare programs involved in-person contact between care coordinators and patients in addition to other forms of contact.

| **States and managed care plans should consider developing requirements for ongoing, periodic in-person visits, either in the office or at home, to build strong relationships and trust between patients and care coordinators. For example, states or plans could set requirements for in-person contact in addition to telephonic care coordination, and could also develop oversight** |
mechanisms to ensure that coordinators operationalize such a requirement in a satisfactory way.

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<tr>
<th>5. Facilitate information sharing.</th>
<th>Several Medicare care coordination programs either shared real-time data between medical providers and care coordinators or designed the program so that care coordinators had access to EHRs and patient registries.</th>
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<tr>
<td>• Use of a shared EHR between primary care providers, specialists, and care coordinators may greatly facilitate information sharing and the effectiveness of care coordination. Incentivizing providers’ use of interoperable HIT may benefit CSHCN who do and do not receive formal care coordination services. Alternatively, in the absence of EHRs and/or interoperable EHRs, programs may still find ways for care coordinators to facilitate information sharing between providers through, for example, patient registries and other existing databases.</td>
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<tr>
<th>6. Supplement care coordinators’ capabilities with other clinical experts, as relevant.</th>
<th>Several successful Medicare programs used care coordination teams that included clinical pharmacists, behavioral health experts, and staff to assist patients in accessing social services to leverage expertise in multiple domains.</th>
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<td>• Ensuring that care coordinators have access to other clinical experts (for example, dieticians for children with feeding tubes) to facilitate care coordination may be particularly effective for CSHCN in Medicaid, given the need to coordinate care among medical, behavioral and pharmacy providers and other important entities (for example, early intervention programs or schools, juvenile justice systems, and social service agencies). As with the relationship between care coordinators and primary care physicians, it is important that care coordinators develop active, trusting relationships with these other clinical experts to maximize effectiveness of the collaboration.</td>
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CSHCN indicates children with special healthcare needs; ED, emergency department; EHR, electronic health record; HIT, health information technology.

aThere is no one definition of care coordination. For this study, we focused on programs that perform coordination functions such as organizing or linking multiple services and engaging the patient regardless of whether these studies use the terms “care coordination” or “care management.”

bThe definition of high-risk varied across studies. Example definitions of “high-risk” include beneficiaries with selected chronic conditions; beneficiaries with multiple, recent hospitalizations and/or ED visits; beneficiaries with high hierarchical condition category scores; or various combinations of these criteria.