



## Care Coordination in a Statewide System of Care: Financing Models and Payment Strategies

### Introduction

Care coordination is a vital part of the continuum of care for children and youth with special health care needs (CYSHCN) – children who have or are at increased risk for a chronic health condition that requires services of a type or amount beyond that required by children generally.<sup>1</sup> Care coordination has many different definitions, depending on the system of care that is using the term and the target population for the services. For this paper, we provide the following working definition: Care coordination for CYSHCN is a service that links CYSHCN and their families with appropriate services and resources in an effort to achieve good health.<sup>2</sup> Care coordinators link families to services across different delivery systems, help organize those services, provide logistical assistance and offer emotional support to families. It is important to note that this definition does not embrace the notion of the care coordinator as a gatekeeper or person who monitors service utilization.

Care coordination is of great importance to families of CYSHCN, health care providers, and state policy makers, particularly for families of children with complex conditions that entail multiple care needs. Fragmentation *within* service delivery systems (e.g., hospitals) and *across* delivery systems (e.g., medical care and special education) can impose a great burden on families, often creating confusion and delaying access to care. Surveys of families of CYSHCN repeatedly show the priority families place on care coordination and the benefit they derive from this service, particularly the empowering impact of care coordination on families' ability to use services effectively.<sup>3-5</sup>

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**Care coordination for children and youth with special health care needs is a service that links CYSHCN and their families with appropriate services and resources in an effort to achieve good health.**

When care coordination helps families address unmet needs, it has the potential to improve both the quality of care and adherence to treatment. This, in turn, helps providers deliver appropriate care. At its best, care coordination is an essential component of the medical home and can reduce medical inefficiency. Care coordination is also a vital asset to state policy makers, particularly Title V staff who are responsible for promoting statewide systems of quality care for CYSHCN. Care coordination connects a largely private health care system, which takes care of unique individual needs, with other providers in both private and public sectors, helping to create this system of care for CYSHCN.

One of the central roles of state Title V programs is to “facilitate the development of comprehensive, family-centered, community-based, culturally competent, coordinated systems of care for children with special health care needs.”<sup>6</sup> Despite the widely acknowledged value of care coordination, lack of financing makes it unavailable to most CYSHCN and their families. Studies consistently find that the lack of care coordination is an important area of unmet need for families.<sup>7, 8</sup> Over one fifth of families (22%) spend more than two hours per week of their own time coordinating care for their child and 4% spend more than ten hours per week coordinating care.<sup>9</sup> Furthermore, it is difficult for clinicians to provide care coordination services since these activities are not usually reimbursable.<sup>8, 10</sup> Few financing mechanisms are available to pay for care coordination and those that do exist are often earmarked for specific subgroups of CYSHCN, capped either at caseload figures or aggregate dollar amounts, or limited in their scope to a single setting or a short-term, grant-funded pilot project. Furthermore, most of the published literature describes models that are based in a single practice or provider network, or target a limited group of CYSHCN. Very little information is available about statewide models. Thus, advocates for expanded access to care coordination are constrained by lack of information about options for financing, and policy discussion of financing is constrained by uncertainty about the cost of the service.

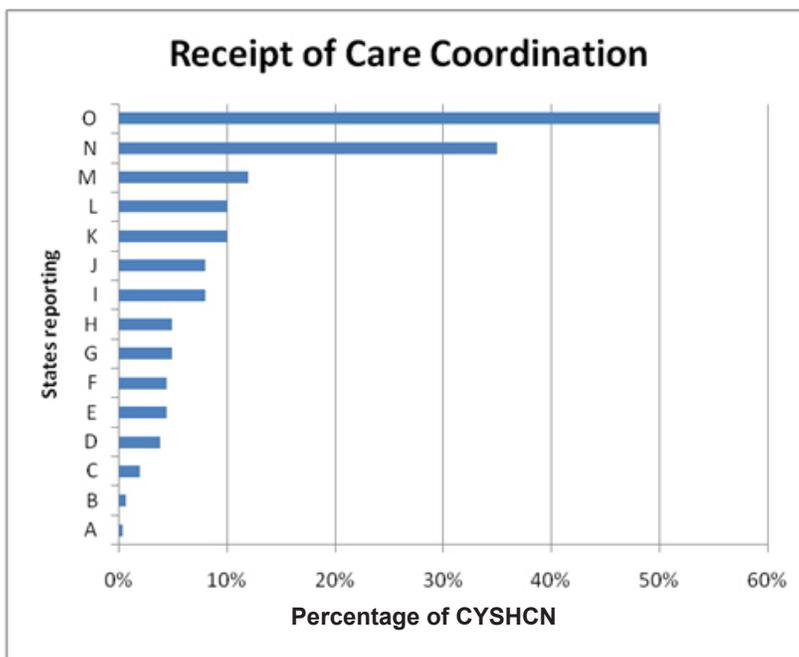
This policy brief provides (1) an overview of what states are currently doing to provide and finance care coordination for CYSHCN; (2) a model for estimating the costs of care coordination in any given state; and (3) suggestions for financing strategies. The information contained in this brief comes from a variety of sources, including the published and unpublished literature on care coordination, other policy briefs produced for the Maternal and Child Health Bureau of the Health Resources and Services Administration, U.S. Department of Health and Human Services, the National Survey of Children with Special Health Care Needs 2005-2006 (NS-CSHCN), and a 2010 Catalyst Center survey of state Title V programs.



## How do states currently finance and deliver care coordination for CYSHCN?

The Catalyst Center administered a survey to state Title V program administrators in the spring of 2010, asking questions about how services for CYSHCN, including care coordination, were delivered and financed in the state, and the role played by Title V programs in financing care coordination. Forty-two states responded to the survey. Responses varied widely, with some states reporting that they finance all the care coordination services that they are aware of. At the other end of the spectrum, two states reported that Title V did not finance any care coordination services but was responsible for monitoring the delivery and quality of care coordination services provided by others. The majority of care coordination was provided by social workers and nurses, but Hawaii reported using a nutritionist and an audiologist. In some states, such as Alaska and Rhode Island, care coordination is provided by patient navigators who are themselves parents of CYSHCN.

Only one third of the states responding to the survey were able to provide an estimate of the percentage of CYSHCN in the state who received care coordination services financed by Title V (or by any combination of payers) and another one third of states provided an estimate of the number of children who actually received services. In some cases, respondents simply assumed that all children who received any Title V service received care coordination, while other states provided very thoughtful answers about the actual number of children being served, the percentage of CYSHCN this represented in the state and the size of care coordination caseloads. Most states reported that less than one percent to ten percent of CYSHCN in the state received care coordination services, but three states estimated a higher percentage.



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A wide variety of agencies and organizations fund care coordination, including state departments of public health, mental health, developmental disabilities and education, Part C programs (Early Intervention), managed care organizations, foundations, medical practices and child welfare agencies. Nearly 80% of the states that responded to the survey were able to list other payers for care coordination services for CYSHCN, even if they were not certain how many children received services through these arrangements. Although care coordination was financed entirely through the Maternal and Child Health Block grant and state or county funds in some states, Medicaid was listed as an important major payer for care coordination by two thirds of the states. The states that reported a higher percentage of CYSHCN received care coordination also reported that some of that care was financed by Medicaid.

Caseload sizes ranged from under 100 children per care coordinator to 300+ children. In general, smaller caseloads were handled by nurses who provided more intensive services, and larger caseloads by social workers or parent navigators. Many of the coordination services were based in county health departments, but some were provided through medical homes or by managed care organizations. States hired their own staff to provide care coordination or contracted with private organizations for the service.

States mentioned a range of criteria for determining eligibility for care coordination services. Most frequently, eligibility for care coordination mirrored the diagnostic eligibility criteria for other Title V services in the state. Other eligibility criteria included income limits, eligibility for Supplemental Security Income (SSI), or a specified level of medical complexity. Finally, some states mentioned service or dollar limits for care coordination. For example, Michigan allows providers to bill \$300 per child per year for care coordination and \$1200 per child per year for children with more complex needs.

In these diverse state responses we found two common themes: the majority of states are only serving a fraction of their CYSHCN population, and none of the states has a statewide system of care coordination that is available to the full spectrum of CYSHCN who might need it. Given the limited resources for this service, there are categorical, diagnostic, income, or geographic eligibility restrictions in every state.

## **Who needs care coordination and how much do they need?**

While *any* CYSHCN may need care coordination at any time, most CYSHCN do not require care coordination all the time. For some CYSHCN, care coordination is not a necessary service, or may only be needed once to connect the family with services. For others, the need for care coordination may be episodic and occur at certain critical times – at birth; while diagnoses are being explored; during times of family crisis or youth transition to adult services; or during changes of provider, insurance or



eligibility rules. Still other CYSHCN may need care coordination on an ongoing basis. The need for care coordination is a seriously understudied topic; there is nothing in the published literature that offers insight into planning and financing a statewide system of care coordination. Several states requested assistance in looking at this issue when completing the survey mentioned above. The National Survey of Children with Special Health Care Needs (NS-CSHCN) provides some important information that serves as a starting point.<sup>9</sup>

The NS-CSHCN provides an estimate of the number of CYSHCN residing in each state. When the Catalyst Center asked states what percent of CYSHCN were currently receiving care coordination, the most comprehensive responses referenced the NS-CSHCN data as the denominator. However, the NS-CSHCN also provides information about how many families reported receiving help in arranging or coordinating care for their CYSHCN, and how many families reported they did not receive enough help. From this information, we can estimate the number of CYSHCN who neither received care coordination nor needed it. According to the NS-CSHCN, one third of CYSHCN (33.2%) received help arranging or coordinating care in 2005-2006, and another 13.7% of families reported receiving no help but needing it, for a total of 47% of CYSHCN who either received or needed care coordination. Thus, over half of all CYSHCN (53%) did not report needing help arranging or coordinating care at any given point in time.<sup>9</sup> Using these data, we can assume that a state should then plan for care coordination services that would touch, on some level, slightly fewer than half of their CYSHCN population during a year.

Examining these data more closely, there are some significant differences between the children whose families reported receiving or needing care coordination and those who did not. Children receiving or needing care coordination had a significantly greater number of health conditions (2.2% v. 1.7%), functional difficulties (3.2% v. 1.9%) and unmet needs (1.7% v. 1.4%) than those who did not report needing care coordination. These included health care needs that changed all the time, feeling anxious or depressed, chronic physical pain, difficulty swallowing or digesting food, and difficulty with coordination, learning, understanding or paying attention, communication, and behavior problems. In addition, children who needed care coordination were more likely to be uninsured or have public insurance, receive SSI benefits, and live in families with incomes below 100% of the federal poverty level (21% v. 12%). Their families were more likely to report difficulty using services (17% v. 5%) and less likely to report that their health insurance always met their needs (56% v. 64%).<sup>9</sup>

Boys were slightly more likely to need care coordination than girls, as were younger children and in particular, children receiving Part C Early Intervention services. There was a significant difference in race/ethnicity, with Black and Hispanic families more likely to report the use or need for care coordination services than White

(non-Hispanic) families. Finally, children using or needing care coordination services reported missing significantly more days of school (5.3% v. 4.0%), making more trips to the emergency room (4.6% v. 2.1%) and having more physician visits (21.0% v. 13.3%) in the past year than children who did not need care coordination.

These data suggest two things – first, that the scarce resources we currently use for care coordination are needed by and serving the more complex CYSHCN; and secondly, there is a substantial group of CYSHCN whose families do not report needing assistance. It is important to note one caveat about this second theme. The responses to the questions on the need for assistance with care coordination are based on parental self-report, and there may be some response bias based on demographics, parental knowledge of care coordination services, the availability of services and geographic region. For example, in looking at these data state by state, there is wide variation in both the percent of children currently receiving care coordination (from 23.3% to 42.4%) and the percent of families reporting no need for care coordination (from 49.8% to 61.5%). It is possible that these responses correlate with child need, but it is also possible that the responses reflect knowledge of and the availability of care coordination services in different states.

## **Assumptions about a Model Statewide System of Care Coordination**

Before conducting cost estimates, it is important to clarify some underlying assumptions about a statewide system of care coordination. First, we assume that the care coordinator in this model responds to the needs of the *child and family*, rather than the needs of a particular agency or organization even if the agency or organization is the payer or setting for the delivery of the service. Families, providers and policy-makers are all familiar with the pitfalls of having too many “case managers,” the child who has three or four different case managers or care coordinators from different agencies and the family is responsible for “coordinating the coordinators.” The most common problem in this scenario is no one, other than the family, is looking out for the whole child across different care settings. In the model and estimates proposed below, the care coordinator works on behalf of the child and family *across systems of care*.

A second assumption is that care coordinators will serve any CYSHCN, rather than children with a particular diagnosis. This includes children with serious emotional disturbances and children with dual or triple diagnoses, including children with conditions that have both physical and cognitive consequences, or children with any special need who require mental health services to deal with secondary depression.



This assumption also implies access to care coordination for children across a range of severity levels. Although the research and the NS-CSHCN data indicate that need for care coordination is associated with the severity of a child's condition,<sup>9, 11, 12</sup> families raising a child with less severe needs may need assistance if other stressors are impacting caregivers.

A third assumption is that there is more than one model for a statewide system of care coordination. Many different types of organizations currently provide care coordination services, including state agencies, managed care companies, hospitals, specialty clinics, home care providers, early intervention providers, private vendors and physician practices. While a medical home model may be the best option for housing a universal care coordination system because it is provider-based (and therefore assumed to be child- and family-centered) rather than insurance- or state agency-based (and therefore assumed to be organizationally centered), it is not the only model, and it will work only if there are a sufficient number of medical homes to provide this service to all CYSHCN in the state.

For the purposes of this paper, these are the major assumptions we use to estimate the cost of providing care coordination on a statewide basis. However there are other model considerations that will have an impact on costs, including the specific roles and responsibilities of the care coordinator, the systems involved in care coordination, the means of communication and linkage across systems, and overall performance expectations. A detailed description of these considerations is beyond the scope of this paper, but many state and community practices regarding these issues are described in a report produced by the National Academy for State Health Policy and the Commonwealth Fund.<sup>13</sup>

## Calculating the Cost of Care Coordination

The four main variables needed to arrive at the approximate costs of paying for a statewide system of care coordination include:

- The number of CYSHCN in the state who need care coordination services;
- The caseload per FTE care coordinator per year;
- The salary per FTE care coordinator per year; and
- The care coordination model and setting.

The number of CYSHCN who need care coordination in a state depends on (1) the size of the child population (ages 0-18) in the state, (2) the percentage of children with special health care needs, and (3) the percentage of those children who need care

coordination services. The size of the child population can be obtained from U.S. census data. Estimates of the percentage of children with special health care needs who have special health care needs in the state and who need care coordination services can be obtained from the NS-CSHCN.<sup>9</sup>

The caseload per FTE care coordinator is dependent on the model of care coordination. The Catalyst Center survey of state Title V directors found a wide variation in caseloads, ranging from 30 to 325 children, although most caseloads fell in the 120 to 175 range. For example, one model that employs nurses who conduct home visits and coordinate care across multiple specialties and care settings for medically complex children may have a caseload as low as 25-30 children.<sup>14</sup> The published literature contains scant information about caseload sizes, but program materials from medical home sites in South Carolina describe caseloads of 85 to 150 children using nurses and social workers.<sup>15, 16</sup> The Early Intervention program in Rhode Island provides care coordination using parents of children with special health care needs as coordinators, and their caseloads average 250 CYSHCN per coordinator.<sup>17</sup> Caseloads of larger numbers of children will provide fewer services per child than programs with smaller caseloads, but they may also include many children with limited need for care coordination most of the time.

Salary levels depend on the background of the care coordinator – nurse, social worker, paraprofessional (which includes family members working in an official capacity) – and the local labor market. A good source of state-specific salary information is the United States Department of Labor Bureau of Labor Statistics which publishes the Occupational Employment & Wage Estimates data on its website at [www.bls.gov/oes/current/oesrcst.htm](http://www.bls.gov/oes/current/oesrcst.htm).

To see how these parameters determine cost, let us use the state of Washington as an example. According to the 2000 census, there were 1,513,843 children under the age of 18 living in Washington. Of these, 13.7% reported having a special health care need through the NS-CSHCN. That translates to 207,396 children with special health care needs, of whom 47.7% use or need care coordination services. Thus, to provide care coordination services statewide the state of Washington needs to plan services for 98,928 CYSHCN. For simplicity's sake, we will round this off to 100,000.

# children in state of Washington	1,513,843
# CYSHCN (13.7% of children)	207,396
# of CYSHCN needing care coordination (47.7%)	98,928

Second, let us assume a medical home model for care coordination in Washington. The state has 500 pediatricians and 250 family practitioners who also provide care to children (750 physicians total). If each of these physicians provides care to 2000



children, then on average they each serve 131 CYSHCN who need care coordination services (2000\*13.7%\*47.7%). And if we further assume that each physician works in a two-physician practice, then we are talking about 375 practices (750/2), each serving about 262 (131\*2) CYSHCN. If the model calls for one care coordinator for every 250 CYSHCN, then the state would need 400 care coordinators (100,000/250), or approximately 1.1 FTE care coordinator per practice site (400/375).

Of course, in the real world CYSHCN are not distributed evenly across all practices, and some physicians work in large clinics while others are solo practitioners. However, this exercise provides us with a ballpark estimate of the number of care coordinators needed statewide if we assume an average caseload of 250 children per care coordinator.

What would this cost? The next step depends on who is providing the care coordination. In Washington, the average wage for a nurse is \$34.83/hour, a medical social worker is \$25.51, and a trained paraprofessional is \$14.18. Annual costs are obtained by multiplying the hourly wage by 2080 hours (40\*52). To this number we add 32% for fringe benefits and overhead and \$1,200,000 in systems oversight costs. The systems oversight costs include training for families and providers, quality assurance, certification, outreach and enrollment, information and referral, supervision and due process. The total cost of a statewide system of care coordination is thus estimated to be \$17 million to \$39 million for the entire state, depending on the staffing configuration. The chart below shows how this is calculated for the state of Washington:

Position	RN	MSW	Para
Hourly	\$ 34.83	\$ 25.51	\$ 14.18
Annual	\$ 72,446	\$ 53,061	\$ 29,494
Fringe and overhead @ 32%	\$ 23,183	\$ 16,979	\$ 9,438
Cost Per Coordinator	\$ 95,629	\$ 70,040	\$ 38,933
For 400 coordinators	\$ 38,251,699	\$ 28,016,102	\$ 15,573,043
Systems oversight	\$ 1,200,000	\$ 1,200,000	\$ 1,200,000
<b>Total Cost</b>	<b>\$ 39,451,699</b>	<b>\$ 29,216,102</b>	<b>\$ 16,773,043</b>

## Payment Strategies

The preceding gives us a picture of how a state might estimate the total cost of global access to care coordination for all of its CYSHCN. When we turn to strategies to meet that cost, we need to look both at specific payment mechanisms and at payment sources. There are several mechanisms that can be used to pay for care coordination services. These include:

- Unit rates for blocks of care coordination time (e.g., payment per 15 minutes of service);
- Unit rates for different types of care coordination service (e.g., \$X for an intake, \$Y for care plan development; \$Z for care coordination visit);
- Capitation rates (e.g., \$X per child per month);
- Global rates (e.g., \$Y per child per year or \$X, \$Y or \$Z per child per year based on child's level of need);
- Pay for performance bonus payments that reimburse health plans or providers for meeting certain quality standards related to care coordination;
- Budget line item or grant funds for staff positions, fringe benefits, and overhead costs with an expectation that staff serve a specific number of CYSHCN per year.

Using the staffing cost data from the Washington example above, and a financing strategy similar to the one in Michigan where providers can bill \$300 per year to provide care coordination for less medically complex children and \$1200 per year for more medically complex children, a payer could contract for care coordination services as follows. Assuming that a social worker would provide the care coordination for less medically complex children at an annual cost of \$70,040 per FTE including fringe benefits and overhead, they would need to serve a caseload of 233 CYSHCN in order to meet costs. A paraprofessional could only need a caseload of 130 children to meet costs. Registered nurses would need a caseload of 319 children; however if the RNs provided the care coordination for more medically complex children at \$1200 per child, they would only need a caseload of 80 children to meet costs.

Using a financing strategy from Ohio as an example, where providers can bill for up to 32 hours of care coordination services per year for a CYSHCN, care coordinators would need to maintain a minimum caseload of 65 children (more, if the maximum number of hours is not billed out) and bill payers at \$46/hour for RNs, \$34/hour for social workers and \$19/hour for paraprofessionals. The chart below shows how these costs are calculated, using both the Michigan and the Ohio examples:

Position	RN	MSW	Para
Hourly rate	\$ 34.83	\$ 25.51	\$ 14.18
Annual	\$ 72,446	\$ 53,061	\$ 29,494
Fringe & overhead @ 32%	\$ 23,183	\$ 16,979	\$ 9,438
Cost per FTE	\$ 95,629	\$ 70,040	\$ 38,933
Hourly rate adjusted for fringe and overhead	\$ 46	\$ 34	\$ 19
Caseload size @ \$300/child/year	319	233	130
Caseload size @ \$1200/child/year	80	58	32
Caseload size @ 32 billable hours/child*	65	65	65

\*if every child receives the maximum number of hours

Another payment strategy is to use CPT codes to bill for specific types of services. The Medical Home Crosswalk to Reimbursement, developed by McManus, Kohrt et al., provides a listing of CPT codes that could be used to bill an insurer on a fee-for-service basis, for services provided by a medical home.<sup>18</sup> Many of these codes could be used for different aspects of care coordination, such as 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 (99371-3); and care plan oversight (99374-80).<sup>18</sup>

## Funding Sources

The current status of state budgets may preclude the allocation of new funding for care coordination in many states for the time being, but new opportunities may arise with changes in the economy or as health care reform advances and some services now covered by Title V are reimbursed by insurance. Thus, it is important to consider the different options for funding sources. Most Title V programs pay for some care coordination services through block grants and/or state funds, but a growing number are turning to Medicaid as a funding source for Medicaid-eligible children. Several states have crafted shared payment strategies, partnering with Medicaid and using the Early Periodic Screening Diagnosis and Treatment (EPSDT) benefit or targeted case management to provide care coordination for CYSHCN who receive Medicaid benefits, thereby reserving state and block grant dollars for other non-Medicaid-eligible children. For example, Michigan Title V funds the state match for Medicaid-funded care coordination services, and New Mexico has hired 50 social workers who provide care coordination through pooled Title V and Medicaid dollars. Florida Title V operates a Medicaid Managed Care organization that provides care coordination for CYSHCN. Rhode Island provides Title V funding for parent coordinators who

are placed in medical home practices to provide care coordination. Other potential contributors are private insurance companies and other state agencies. For example, New Hampshire partners with a private insurance company, Anthem Blue Cross, to provide care coordination services for their CYSHCN.

In the Washington state example above, 34% of CYSHCN are enrolled in the Medicaid program and they represent 36% of the children needing care coordination. If 36% of the total costs are covered by Medicaid, and the federal government contributes to half of that, then the cost to the state is reduced by \$3 million to \$7 million.

Another potential source of funds could be generated from savings that accrue from avoiding duplication and waste or from accessing care in a timely fashion. For example, hospital costs for CYSHCN are nearly four times as high as for other children, and physician costs are nearly double.<sup>19</sup> Most of this care is medically necessary, but averting an occasional hospitalization or shortening a length of stay can generate significant savings. One study of a care coordination program for medically complex children in Wisconsin found 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 (Gordon et al., 2007). Savings from reduced inpatient admissions or days could be reallocated to provide funding for care coordination by either public or private capitated managed care systems or could be re-budgeted to care coordination in a state budget process that reimbursed for care on a site-by-site basis rather than on a per-child basis.

**Whether financing comes from reimbursement or purchased service mechanisms, a key issue in broadening access to care coordination is likely to be assuring the cost effectiveness of proposed models.** No state has yet implemented a statewide system of care coordination for CYSHCN, but there is enough experience to offer lessons regarding the importance of limiting the costs and engaging partners to share in them. In terms of limiting costs, few models rely entirely on nurses. Many are successful in implementing a team or tiered approach to care coordination, reserving nurses for the most medically complex children or for times of medical crisis in others and relying for the most part on social workers and paraprofessionals.



## Conclusion

Although advances are being made, care coordination is still a patchwork quilt in most states, with gaps based on insurance coverage (private v. public), diagnosis (physical v. developmental v. behavioral condition), primary care site (grant-funded site or not), geography, and timing; and care coordination services that are uneven in scope, depth and duration. However, as the medical home movement advances, as stakeholders press for shared financial responsibility, as the components of federal health care reform are implemented and as research continues on the cost effectiveness of care coordination programs, progress can and should be made.

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## About the Catalyst Center

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