

## Next Steps Toward Care Coordination: Perspectives from the California Advocacy Network for Children with Special Health Care Needs

### Abstract

In 2012, members of the California Advocacy Network for Children with Special Health Care Needs were asked in an online survey to identify the most pressing issues that the Network should address. By a large margin, respondents chose improving care coordination.

The follow-up survey discussed here was conducted in early 2013 to solicit members' more detailed perspectives on care coordination and how to improve it. Of the 100 Network members who responded, two-thirds (65%) identified California's fragmented system of care as the main barrier to effective care coordination. Members chose inadequate communication among health care providers and inadequate payment for care coordination as the second and third key barriers.

When asked what strategies might improve care coordination, respondents were divided among having a single care coordinator for each child (34%), training families to advocate for improved care coordination (31%), and educating medical practices about care coordination (31%). Respondents were divided about who should be primarily responsible for providing care coordination, with primary care practices chosen by 31%.

Some survey respondents also described their own experiences with care coordination, and provided information about programs that they found particularly effective.

These survey results document the need for improved care coordination in California, including reduced fragmentation, enhanced communication among providers and families, and development of a system to pay for care coordination services. The Lucile Packard Foundation for Children's Health, which sponsors the Network, is investing in programs and strategies to encourage these changes.

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### Background

Children with special health care needs (CSHCN) and their families face many challenges. Foremost among them is the fragmentation of the many programs and services upon which they depend.<sup>1</sup> Children with complex health problems typically interact with multiple systems including schools, hospitals, therapists, government agencies, and

community-based organizations. Navigating these many resources generally requires that families serve as the principal coordinator of their child's care, and financial coordinator to assure care is paid for.

External sources of care coordination are inconsistently available. According to the most recent national survey, nearly half of CSHCN in California do not receive effective care coordination.<sup>2</sup> The state ranks 46th in the nation on this measure. Providing care coordination

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<sup>1</sup> One in seven children in California has a special health care need, which is a "chronic physical, developmental, behavioral, or emotional condition" that requires "health and related services of a type or amount beyond that required by children generally". See McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P.W., Perrin, J.M., Shonkoff, J.P. & Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics*, 102(1): 137-140.

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<sup>2</sup> Child and Adolescent Health Measurement Initiative. (2010). Children with special health care needs: A profile of key issues in California. Palo Alto, CA: Lucile Packard Foundation for Children's Health.

services and support for families of CSHCN is one way to help alleviate families' stress and improve the quality of care for children in California. Effective care coordination holds the possibility of improving health outcomes for CSHCN, enhancing the quality of life of children and their families, and reducing health care costs.<sup>3,4,5</sup>

### The Advocacy Network

To address care coordination and the many issues confronting families of CSHCN, the Lucile Packard Foundation for Children's Health in 2011 established the California Advocacy Network for Children with Special Health Care Needs (the Network). In 2012, the Network comprised more than 500 members representing a broad constituency of families and professionals, including physicians, health care workers, county health program employees, teachers, social workers, and researchers. Network membership is open and available to anyone who wishes to [join](#).

In 2012, the Foundation conducted an Internet survey of Network members to better understand their priorities. Data from that initial survey identified improving care coordination as a primary goal for the Network going forward. In part as a response to that guidance from the Network, the Foundation has awarded several grants to explore care coordination issues and advance the system of care in this area. As a result of these grants, a deeper understanding of

care coordination including working models, existing challenges, and practical recommendations is evolving. One grant established the [California Community Care Coordination Collaborative](#), which provides a structured opportunity for coalitions in six counties to learn from one another, identify areas of shared need, discuss emerging challenges and connect with others engaged in improving care coordination services.

### 2013 Member Survey

After determining that improving care coordination was a priority for the Network, the Foundation conducted a brief follow-up survey focused specifically on care coordination. The follow-up, Internet-based survey was conducted among Network members in January and February of 2013 to investigate care coordination issues, including desired outcomes of care coordination, barriers to care coordination, strategies to address care coordination and who should be responsible for providing it. Care coordination was defined for the survey as a "...family-centered, assessment-driven, team-based activity guided by an individualized care plan designed to meet the needs of children and youth while enhancing the care-giving capabilities of families".<sup>6</sup> Respondents were invited to complete the survey via an email invitation. Three email reminders were sent over a period of two months.

<sup>3</sup> Criscione, T., Walsh, K.K., & Kast, T.A. (1995). An evaluation of care coordination in controlling inpatient hospital utilization of people with developmental disabilities. *Mental Retardation*, 33: 364–373.

<sup>4</sup> Liptak, G.S., Burns, C.M., Davidson, P.W. & McAnarney, E.R. (1998). Effects of providing comprehensive ambulatory services to children with chronic conditions. *Archives of Pediatrics & Adolescent Medicine*, 152: 1003–08.

<sup>5</sup> Palfrey, J.S., Sofis, L.A., Davidson, E.J., Liu, J., Freeman, L. & Ganz, M.L. (2004). The Pediatric Alliance for Coordinated Care: Evaluation of a medical home model. *Pediatrics*, 113(5 Suppl): 1507–16.

<sup>6</sup> Antonelli, R.C., McAllister, J.W. & Popp, J. (2009). Making care coordination a critical component of the pediatric health system: A multi-disciplinary framework. New York City, NY: The Commonwealth Fund.

## Survey Results

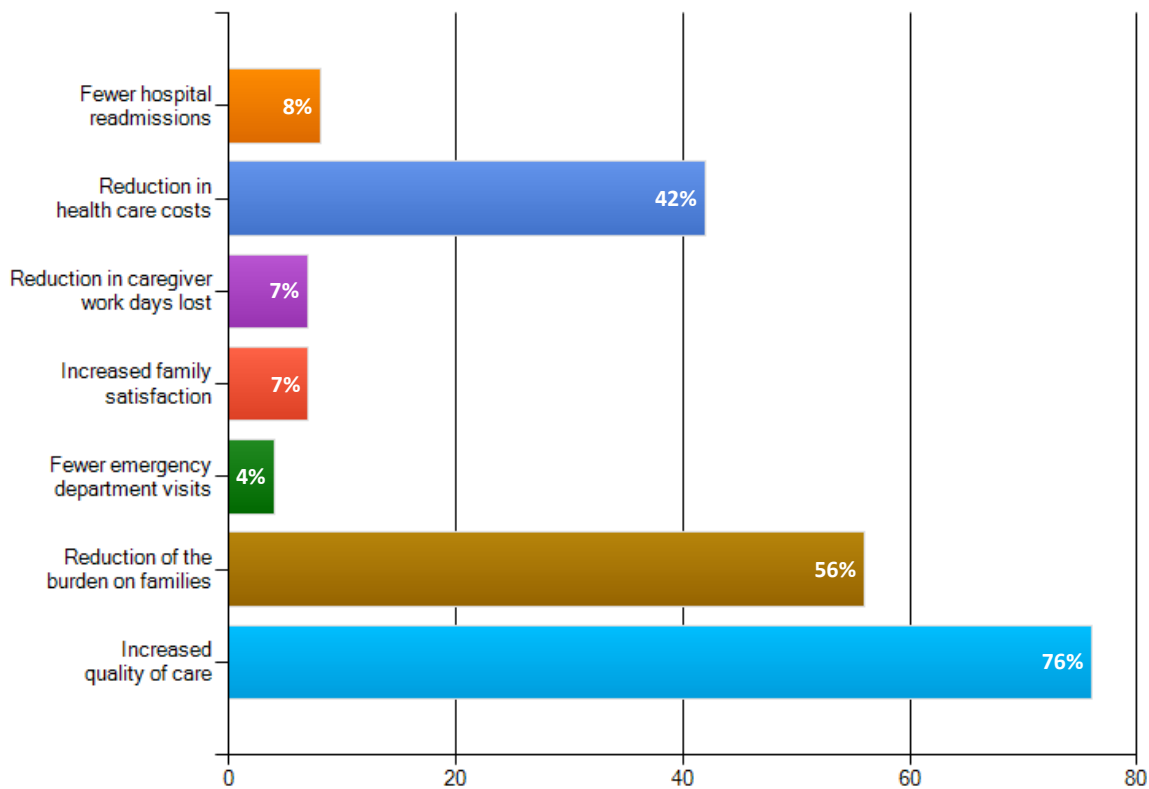
Of the 500 Network members invited to complete the survey, 100 completed it, for a response rate of 20%. There were no missing data among the completed surveys. Respondents identified themselves as county or state health agency employees (20%), non-profit employees (17%), families (16%), and pediatricians (11%). Other respondents included child health advocates, health service providers, researchers, and insurance company employees.

## Reasons for coordinating care.

Respondents were asked to consider the two most important reasons for coordinating care for CSHCN, aside from improving patient outcomes. Respondents identified increasing the quality of care (76%) and reducing the burden on families (56%) as the most important reasons. In addition, reducing health care costs was a commonly chosen response, with 42% of respondents choosing it.

Figure 1.

Aside from improving patient outcomes, what are the TWO most important reasons for coordinating care for CSHCN?

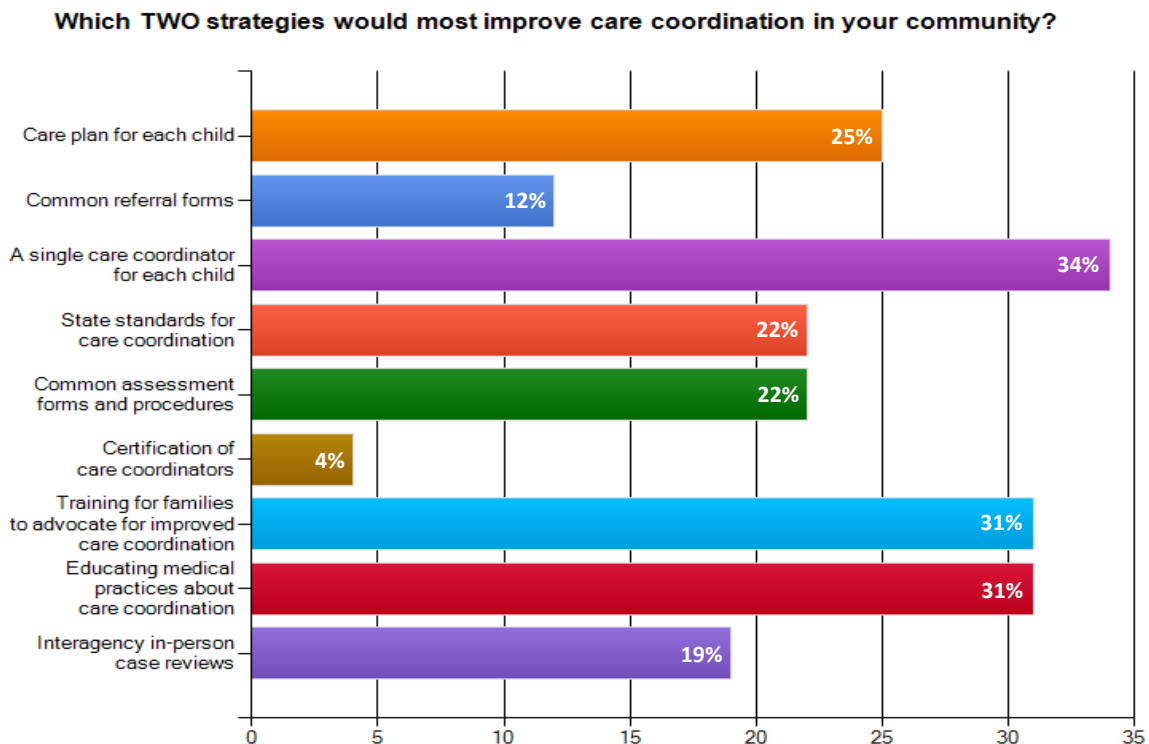


### **Strategies to improve care coordination.**

Respondents were asked to pick two strategies that would most improve care coordination in their communities. The options were drawn from the care coordination literature and shared experiences of Network members. Options included care coordination activities at the individual and practice levels, as well as broader systems approaches. A third of the respondents

(34%) identified a single care coordinator for each child as the strategy that would most improve care coordination in their community. Almost a third of respondents said that training for families to advocate for improved care coordination (31%) or educating medical practices about care coordination (31%) also would be appropriate strategies.

**Figure 2.**



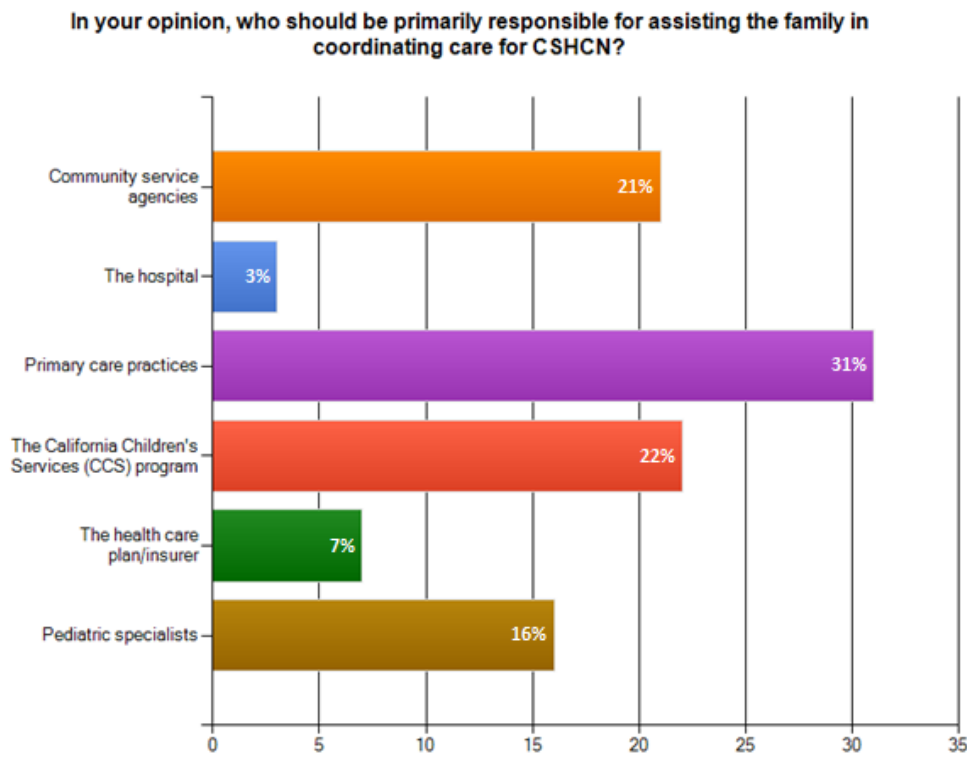
**Responsibility for care coordination.**

Respondents were asked to consider who should be primarily responsible for assisting families in coordinating care for CSHCN. Responses to this question were mixed, with about a third designating responsibility to primary care practices (31%). A fifth of respondents said that the California Children's Services (CCS) program (22%) should be responsible, while a fifth cited community service agencies (21%). An additional 16% responded that pediatric specialists should be responsible for care coordination.

It is interesting to note what different groups of respondents said about where responsibility for care coordination should rest. Of the families who responded to the survey (n=14), 43% said that primary care physicians should be responsible for care coordination. Among the

pediatricians who responded (n=11), over half (55%) also chose primary care physicians. Of the seven health service providers who took the survey, 43% suggested that California Children's Services should be responsible. The opinions of county and state agency employees (n=20) were mixed; 35% agreed that the primary care physician should bear the responsibility while 40% said that California Children's Services should be responsible. Respondents who identified themselves as non-profit agency employees (n=17) also gave mixed responses; 35% said community service agencies should be responsible, 30% said primary care physicians should take on care coordination and an additional 24% said that specialists should be responsible.

**Figure 3.**

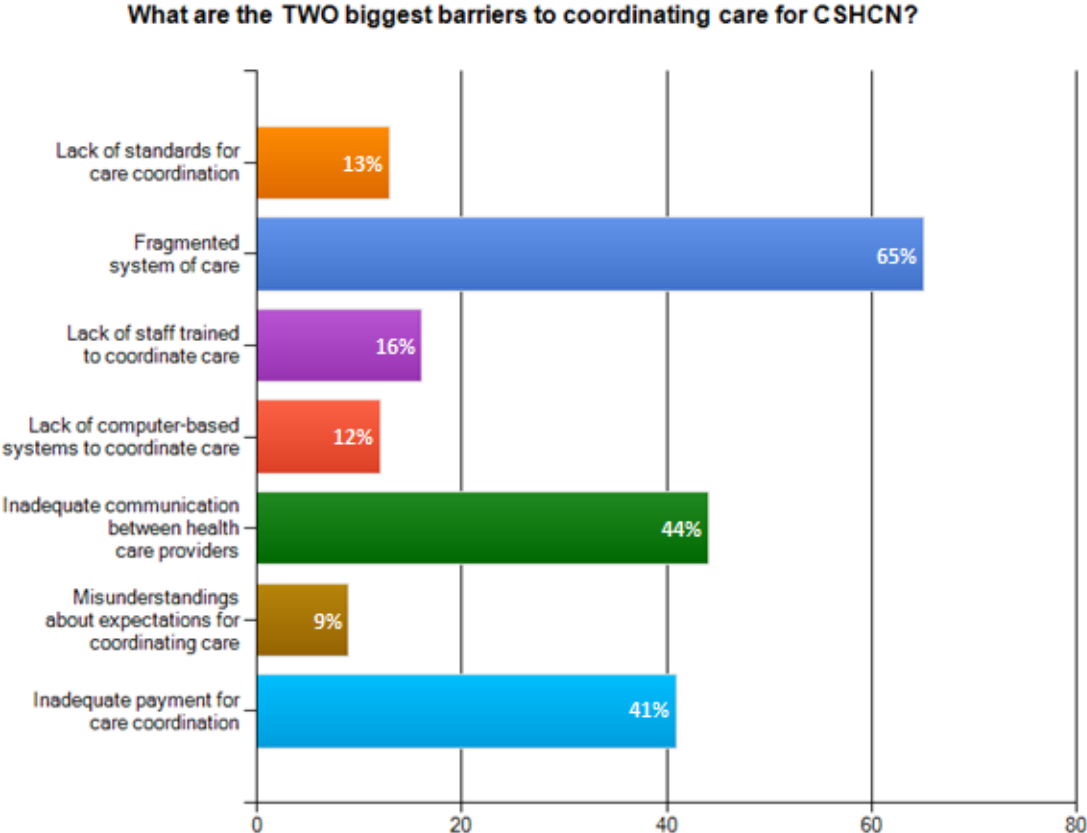


**Barriers to coordinating care for CSHCN.**

Respondents also were asked to consider the two biggest barriers to coordinating care for CSHCN. A majority of respondents selected the fragmented system of care (65%). Respondents

also identified inadequate communication between health care providers (44%) and inadequate payment (41%) as significant barriers to care coordination.

Figure 4.



### **Model care coordination programs for CSHCN in California.**

At the close of the survey, 28 respondents provided information about programs they said currently provide effective care coordination for CSHCN in California. The Foundation will release a separate document with information on these programs.

Half of the respondents also provided commentary about their experiences with care coordination for CSHCN. Four themes emerged. Examples of the sentiments provided by select respondents are included verbatim in italics.

#### **One size does not fit all for care coordination.**

The first theme was that care coordination must be individually tailored. *“Care coordination is not a ‘one size fits all’ proposition. Care coordination should be stratified and targeted at the needs of the patient.”* This theme was evident in the variety of answers regarding strategies for care coordination and who should be responsible for it. This theme reflects the heterogeneous nature of CSHCN and the varied needs of children and their families, as well as the care coordination principle of individualization.<sup>7</sup>

#### **Overcoming silos of care for CSHCN**

Many respondents also touched on a second theme, that care coordination must overcome the fragmentation of California's system. *“Reduction of the ‘silos’ (CCS, Medi-Cal, private insurance, school, Regional Centers, etc.) that California has created in managing this population is vital. You cannot manage the medical health of the child if you do not manage the social/emotional and community issues*

*affected by the child's chronic health care need. These services cannot be managed by a single person or even a single institution.”* This theme illustrates the systemic problems underlying the need for care coordination.

#### **Improving reimbursement for care coordination.**

Several respondents addressed the third theme, that the reimbursement structure for care coordination must be improved. *“[Care coordination for children with special health care needs] is an important, time intensive process that should be reimbursed by health care plan/insurer. The cost to provide such care coordination is far less expensive than the cost of hospital readmissions and duplicative care that occurs in a fragmented system.”*

#### **Making care coordination simple, easy and accessible.**

*“For care coordination to be effective for both the family and providers, services need to be easily accessible, family friendly, and in the family's language.”* This theme may underlie statewide data that almost half of families of CSHCN report that they do not receive effective care coordination. Accessibility is also recognized as a core characteristic of effective care coordination.<sup>8</sup>

<sup>7</sup> Massachusetts Consortium for Children with Special Health Care Needs, Care Coordination Workgroup. (2005). Care coordination: Definition and principles. Retrieved from <http://www.mchlibrary.info/databases/>.

<sup>8</sup> Ibid.



## Discussion

Effective care coordination can provide substantial benefits, including improved quality of care, reduced stress on families, and lower health care costs. The results of this survey indicate that there is much to be done to improve care coordination for CSHCN and their families in California. The current system needs structural changes to overcome fragmentation, to improve communication among and between providers and programs, and to create a rational and adequate payment system for coordination services. The survey results also highlight the importance of tailoring care coordination services to the individual child and family based on the complexity of their needs. An effective system will depend on multiple and complementary strategies developed at the local, state and national level.

While families always will be the child's [principal care coordinator](#), survey results suggest that this responsibility is shared with primary and specialty care practices and with public and private health plans and systems,

including CCS and community agencies. Families will need support from all of these partners to strengthen their capacity to coordinate their child's care. Medical practices also may need specific guidance and support to provide coordinated care, especially when serving children and families with special health care needs.

Addressing these complex issues requires collaboration among a breadth of individuals and organizations. The Lucile Packard Foundation for Children's Health is contributing to these efforts by sponsoring the Network, and by awarding grants to improve care coordination, including establishment of the [California Community Care Coordination Collaborative](#). The Foundation also publishes a bi-monthly [newsletter](#) about policy relating to children with special health care needs, and supports research on the subject.

For more information on the Foundation's work in this area, [see our website](#).

**ABOUT THE FOUNDATION:** The Lucile Packard Foundation for Children's Health works in alignment with Lucile Packard Children's Hospital and the child health programs of Stanford University. The mission of the Foundation is to elevate the priority of children's health care through leadership and direct investment. The Foundation is a public charity, founded in 1997.

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