



**California Advocacy Network for Children with Special Health Care Needs**  
**Survey Findings**  
**August 2012**

**Background**

One of every seven children in California has a special health care need that is a chronic physical, developmental, behavioral, or emotional condition that necessitates health and related services of a type or amount beyond that required by children generally.

Children with special health care needs in California reflect great racial, ethnic and socio-economic diversity, although children from low-income families are overrepresented among them. The complexity of their health problems, often combined with their families' circumstances, requires a health care system that provides unusually high quality, comprehensive, and coordinated care to meet their needs.

Even in the best economic times many children in California are not able to obtain this level of care, given the limits on available services and the lack of coordination among providers. A national survey<sup>1</sup> of parents of children with special health care needs found that the state ranks last in the nation on a minimum quality of care index. The index measured family reports about the adequacy of their child's health insurance, whether their child had a medical home, and if their child received one preventive care health visit in the last twelve months. One consequence of these shortcomings is that California's parents of children with special needs reported the highest rates of stress due to parenting, suggesting that there is substantial need in the state for enhanced access to family support services.

The Lucile Packard Foundation for Children's Health, thus, is guided by the belief that, "Children should have access to high-quality, culturally competent, family-centered health care when and where they need it, provided through a delivery system that recognizes their unique physical and developmental needs."

To foster improvements in the systems that serve children in California, the Foundation sponsored several convenings of families and health care experts who helped develop an "Enhanced Model of Care for Children with Special Health Care Needs." This model calls for unified eligibility criteria for programs, a medical home for every child, and consistent, evidence-based care principles and quality standards. The model envisions unified public and private payment to providers caring for children with special health care needs. This model serves as a long-term plan for the Foundation, but its success will require linking research and advocacy to support the process of system change.

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<sup>1</sup> The Child and Adolescent Health Measurement Initiative, *Children with Special Health Care Needs: A profile of key issues in California*, The Lucile Packard Foundation for Children's Health, 2010.

## **The Network**

Coordination among advocates for children with special health care needs is a necessary antecedent to changing programs and policies affecting these children and their families. Toward that end the Foundation created the California Advocacy Network (formerly the California Collaborative) for Children with Special Health Care Needs in 2011. Currently, the Network has more than 400 members representing a broad constituency of families and professionals (physicians, non-physician health care workers, and county health program employees, as well as teachers, social workers, private health plan employees, and health policy researchers) concerned with the system of care. Membership is open and available to anyone who wishes to join by completing a form on the [Foundation](#) website. The Network reflects the state's broad diversity geographically. Currently members come from 42 rural and urban counties across the state.

Following the creation of the Network, it became apparent through discussions with key leaders and previous reports commissioned by the Foundation that most stakeholders could identify significant issues for this population in several main areas: financing the costs of health care, breakdowns in public health insurance programs, and access to high quality pediatric care and specialty care. A series of small regional meetings with Network members and other key stakeholders was held around the state. These meetings confirmed the key challenges and offered a number of possible strategies for the Network to pursue. These included: working toward reforming the existing California Children's Services program, advocating for higher reimbursement rates for providers, and training families to become leaders and self-advocates.

## **Objectives and Methods**

With broad goals and strategies determined, the Foundation needed to develop priorities and identify specific, actionable next steps for its internal work and for the Network. A brief, Internet-based survey was designed to quantify the opinions of Network members. Respondents were asked to identify the issues that were most important for the Network to address, general issues and those specifically related to access, and the kinds of activities/tactics that were likely to be most successful for the Advocacy Network and for the Foundation. In May 2012, an announcement of the availability of the survey and access to it was sent via email to 430 Network members. Three subsequent email reminders were sent over a period of three weeks.

## **RESULTS**

Of the 430 recipients of the survey, 208 completed it, for a response rate of 48 percent. There were no missing data among the completed surveys. Among the survey respondents, families were under-represented by nearly half relative to the composition of the Network, but families, non-profit human services agency employees and county or state health agency employees represented the largest groups of respondents (Figure 1).

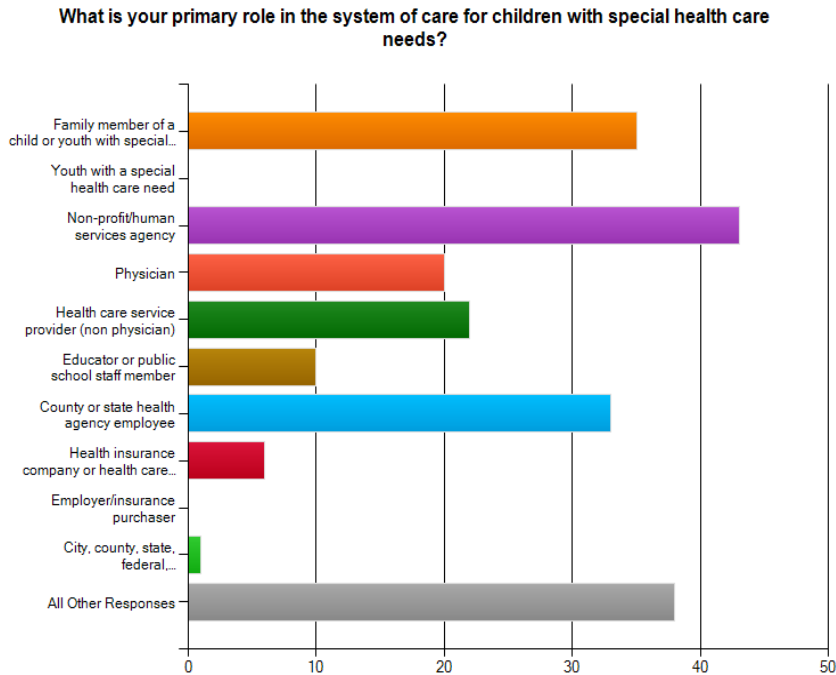


Figure 1.

**Priority Issues for the Network**

General Considerations: The range of possible activities in which the Network might engage is broad and the diversity of its members might be expected to yield conflicting results. However, there was strong preference among the respondents for efforts to improve care coordination for children with special health care needs (42%). (Figure 2).

Priorities did vary among categories of Network members. Care coordination was chosen as the top priority by members from non-profit human services agencies (56%) and non-physician health care service providers (50%). Expanding the California Children’s Services program to care for the whole care, not just specialty care for the whole child was

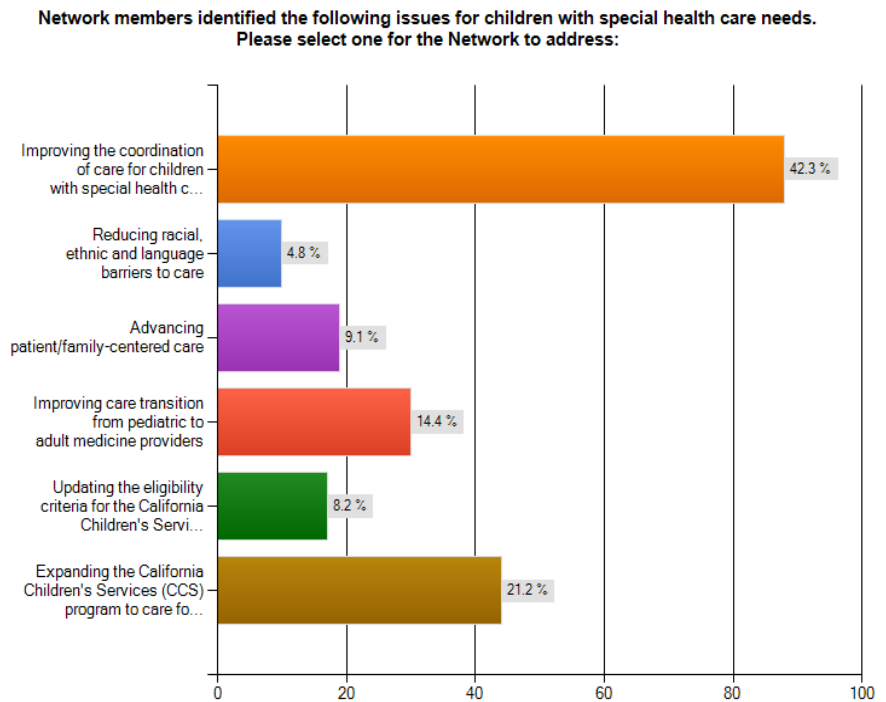


Figure 2.

identified as the second priority (21%). This is primarily a financing and policy issue concerning existing state health policy.

Families selected care coordination (29%) and improving care transition from pediatric to adult medicine providers (26%) as their highest priorities (Figure 3).

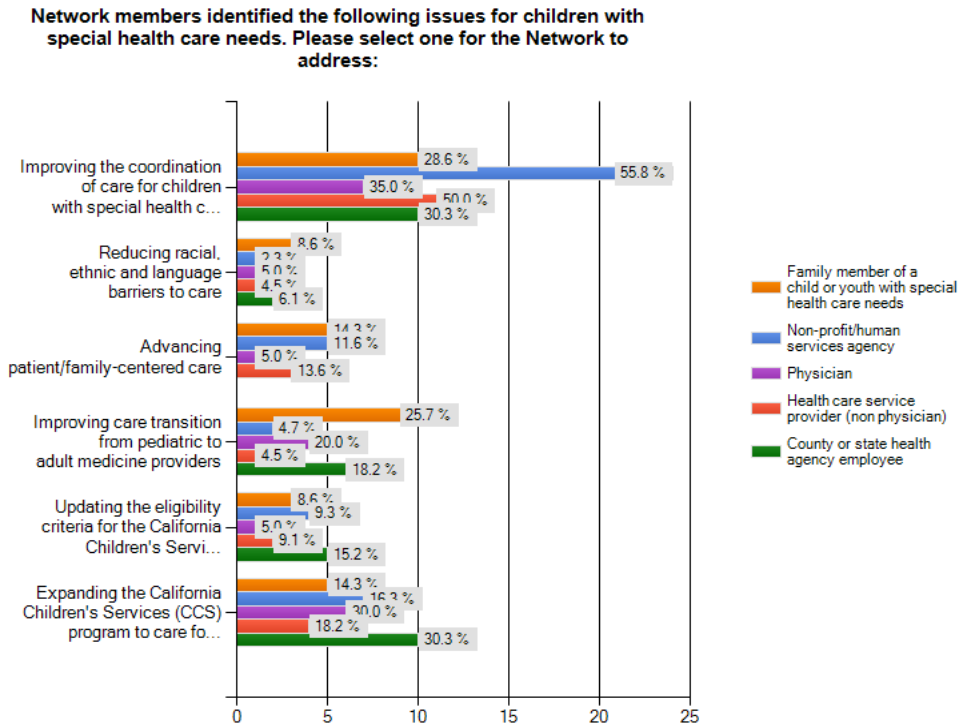


Figure 3.

**Strategies:** Having identified their priority issues for the Network's attention, respondents were then asked to suggest the kind of activity that would most effectively take advantage of the resources of a collaborative network. Among the various options, identifying and replicating best practices was the favored approach by 44 percent of the respondents; lobbying efforts, i.e., educating policymakers, was selected by only about half as many (21%) (Figure 4).

The Lucile Packard Foundation for Children's Health wants to support health care advocacy efforts for children and their families. Which Foundation activity would be most helpful? (Choose one)

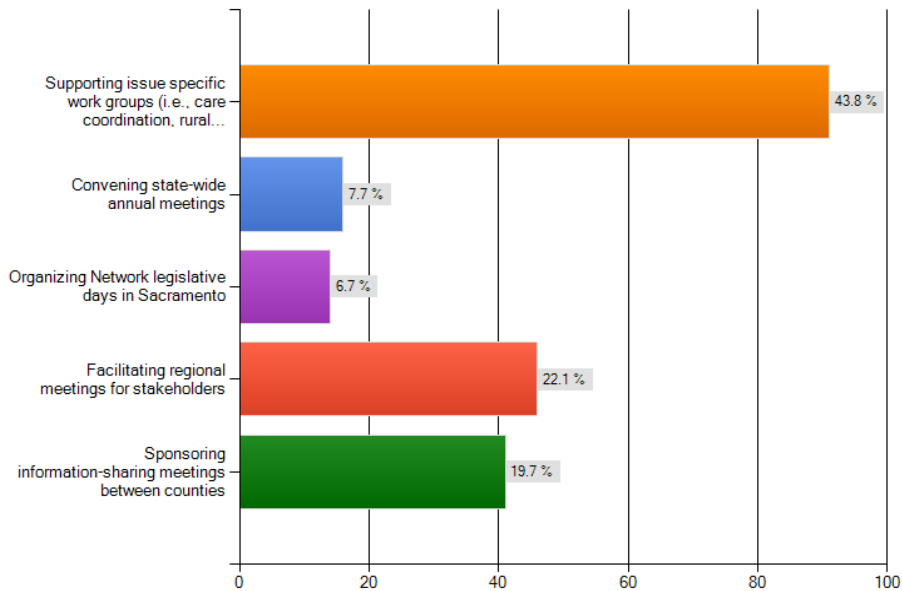


Figure 4.

### ***Strengthening Advocacy for Children with Special Health Care Needs***

The Foundation recognizes that "on the ground" work by family members and other advocates is likely to be the most effective approach to changing programs and policy. Consequently, a variety of Foundation resources will be made available to strengthening the capacity of advocates, including forming and supporting the Network. Network members were asked to provide guidance to the Foundation as to how its resources could facilitate "on the ground" activities. The responses encouraged the Foundation to support issue-specific work groups (44%) and local meetings rather than statewide convenings (Figure 5). Network members from non-profit organizations valued issue specific working groups and facilitating regional stakeholder meetings equally (Figure 6).

**Considering the issue you selected in question 2, which strategy would be most effective? (Choose one)**

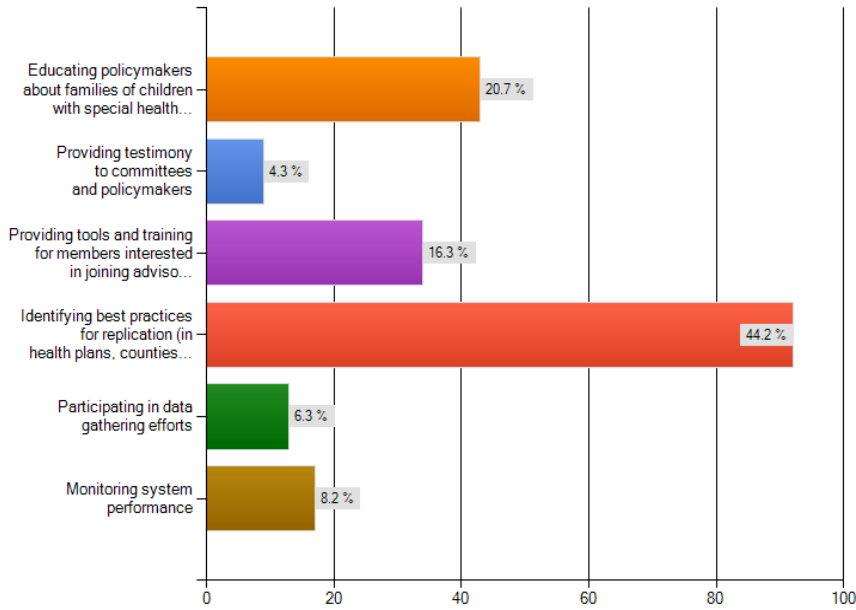


Figure 5.

**The Lucile Packard Foundation for Children's Health wants to support health care advocacy efforts for children and their families. Which Foundation activity would be most helpful? (Choose one)**

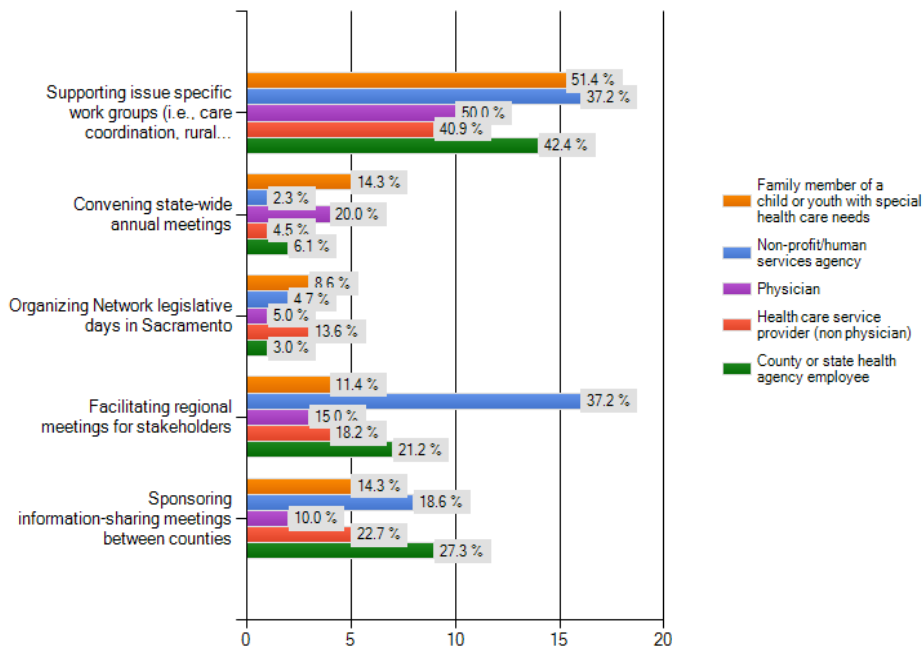


Figure 6.

### Other Foundation Activities

The Foundation has strategies at its disposal other than directly supporting advocacy to improve care for children with special health care needs primarily through its grant making capabilities. The survey asked Network members to help prioritize among ten options for these other strategies. Results for the highest ranking choices are shown in Figure 7. Developing and promoting new financial models for caring for these children was the most frequently selected option (32%) while training families (25%) and health professions (22%) to advance family-centered care were next.

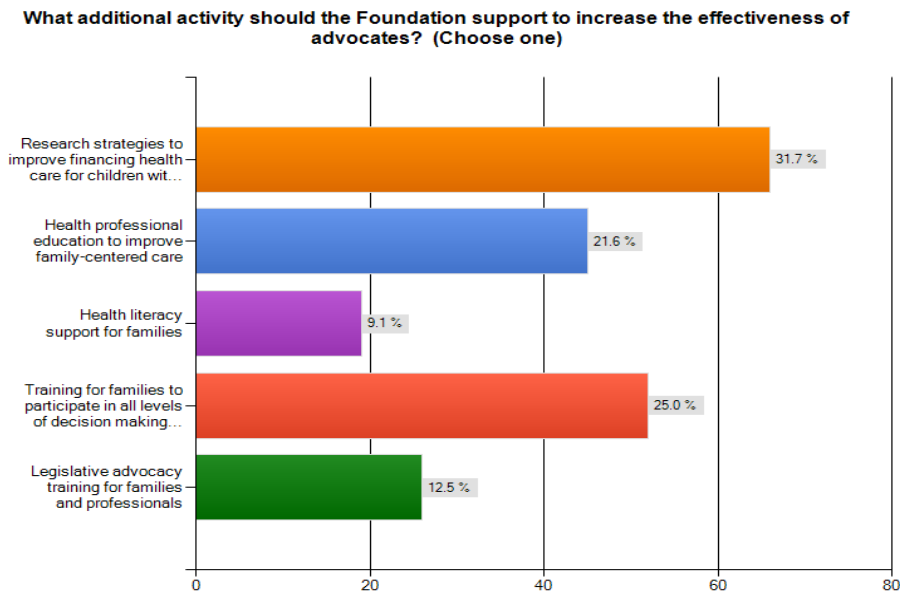


Figure 7.

### Enhancing Communication with Advocates

Advocates for children with special health care needs have a large number of information sources available to them, so much so that some redundancy already exists. The Foundation has communication capacity that could be used to further inform members of the Network and other interested parties, but wishes to target those resources to best serve the advocacy community. The survey presented a number of communication modalities that could be used for that purpose. Respondents preferred to receive monthly topic-specific information above all other approaches. Blogs, tweets and other social media were ranked low, and a substantial proportion of respondents (9%) felt they already had enough information (Figure 8).

**Network members already receive information about children with special health care needs.  
What type of additional communication would be most useful to you? (Choose one)**

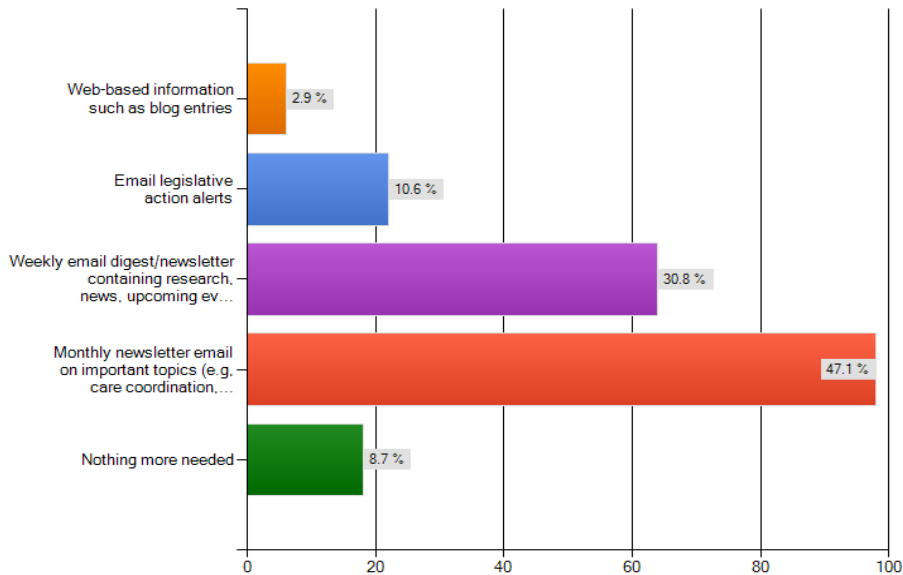


Figure 8.

## DISCUSSION

California’s system of care for children with special health care needs is complex, fragmented and expensive. It will require redesigning if it is to provide the access to services and quality of care required to adequately meet the needs of many children and families. As more children with complex and chronic health problems survive and live for much longer durations, the demands on the health care system will grow, and without change it will continue to underperform. Informed advocacy is important to stimulate and guide change and has the potential to create informed policy and effective programs. The results of this survey offer insights into the issues that are important to a wide range of stakeholders in the care of these children.

The survey was designed to engage stakeholders in the care of children with special health care needs in prioritizing activities that they, in concert with the Lucile Packard Foundation for Children's Health, could take to improve the health care system. Overall the priorities reflected in the survey results demonstrate a pragmatism on the part of the respondents. The topics that were most commonly selected were cross cutting issues, e.g., care coordination, comprehensive services, family-centered care, and the recommended strategies focused on meaningful work opportunities at the local or regional level, as opposed to large convenings to inform and rally the stakeholders. Even suggestions for communication between the Foundation and the Network encouraged meaningful content over frequent contact. More ambitious endeavors such as trying to influence state policy, while of acknowledged importance, seemed less pressing than getting on with system improvement.

This survey identified commonalities among a group of divergent stakeholders and provided a roadmap for the Foundation alone and in concert with the Network and other advocates. These can be summarized as:



- 1) Improving care coordination by identifying best practices;
- 2) Advocating for improvements in policy and practice for the California Children's Services program; perhaps by expanding CCS services to cover the whole child not just specialty care;
- 3) Pursuing workgroups of Network members to address broad issues such as care coordination and rural health and improving financing;
- 4) Holding regional and local meetings to tackle local-level problems;
- 5) Commissioning research regarding financing and provider reimbursement; as well as sponsoring family advocacy training, health professional education; and communicating regularly with Network Members through a monthly newsletter and perhaps a weekly news digest as well.