VIEWS FROM THE FIELD
OCTOBER 22, 2012
GRANTMAKERS IN HEALTH

Improving Systems of Care for Children with Special Health Care Needs

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The tremendous advances in pediatric health care over the past several decades have created a new challenge for those who care for children. While a growing number of children survive previously fatal illnesses, many of them now live permanently with complex chronic conditions. Unfortunately, our health care systems currently are not organized to provide optimal long-term care and services for these children and their families.

> ***Transforming a system of care is, of course, a formidable task for a grantmaker. It requires an understanding of the current system, a vision of a better system, and a plan for promoting change.***

When children with chronic conditions are acutely ill, they generally receive high-quality, comprehensive medical care. Once the acute stage has passed, however, families typically find that ongoing care for a child with complex needs involves a series of discontinuous, uncoordinated, and costly services and programs. Lack of communication among providers, limited access to pediatric subspecialists, care that is disease-specific rather than holistic, and multiple sources of provider reimbursement all contribute to this fragmented care. The result often is adverse health outcomes for children, tremendous strain on families, and increased costs for families and the health care system.

The Lucile Packard Foundation for Children's Health, based in Palo Alto, California, has begun to address these issues as part of our mission to increase the quality and accessibility of health care for children. Since 1997 our foundation has been the fundraiser for Lucile Packard Children's Hospital and the child health programs at the Stanford University School of Medicine. In this role, we support medical care for acutely ill children in our hospital and outpatient clinics. Recognizing the need for better care and services beyond the clinical setting, in 2009 we inaugurated a grantmaking and advocacy program aimed at enhancing the health care system to meet the broader needs of children and families. Our goal with this program is a system that provides high-quality, family-centered care that is coordinated through a medical home and funded by a unified, comprehensive payment system.

Transforming a system of care is, of course, a formidable task for a grantmaker. It requires an understanding of the current system, a vision of a better system, and a plan for promoting change. We began by convening national and state experts, and commissioning a number of studies. Through this work we documented the performance shortcomings of the system of care for children with special health care needs (CSHCN) in California, and identified promising system improvement efforts in other states. Of special value was an ethnographic study of families with CSHCN that identified a number of patterns of experience around which future projects could be developed.[1] The experts we convened also produced an idealized model of an enhanced system.

All of the information we obtained, as well as ongoing solicitation of advice from key stakeholders, has helped identify a number of leverage points that have the potential to shift policy and practice. The foundation now supports advocacy and research that target specific areas we believe have that potential.

To develop our advocacy agenda, we have organized a statewide network composed of parents, youth, health care professionals, public and private agency staff, insurers, and other

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[1] Lucile Packard Foundation for Children's Health, *Six Models for Understanding How Families Experience the System of Care for Children with Special Health Care Needs: An Ethnographic Approach* (Palo Alto, CA: 2012).

stakeholders. Our goal for advocacy is to find unifying themes that transcend the specific goals of various stakeholders and apply to all children with special health care needs. In a statewide survey, network members identified care coordination as a top priority and opportunity. Other priorities that we believe have the potential to improve the system include care planning for CSHCN, improving the experience of families interacting with the health care delivery system, strengthening family advocacy, and enhancing self-management in child health care.

> *Family-centered, comprehensive, and high-quality care is a joint responsibility of health care providers, patients, and families.*

CURRENT ACTIVITIES

- ***Care Planning*** – Ideally, health care should be planned and predictable, allowing patients and providers to anticipate what will occur, coordinate efforts, and assume responsibility appropriately. Family-centered care proponents long have advocated for the creation of care plans, written or electronic, jointly created by providers and families or patients. Unfortunately, the use of care plans is not yet common even in the care of CSHCN. The foundation recently awarded a grant to the Center for Medical Home Improvement to develop national consensus on a care plan template and a care planning process.

- ***Improving Families' Experiences*** – Family-centered, comprehensive, and high-quality care is a joint responsibility of health care providers, patients, and families. The foundation currently supports two related projects. One details the opportunities for applying a life-course approach to the care of CSHCN; the second will identify approaches in helping families cope by exploring the implications of the ethnographic models of family experience, which were documented in the study cited above.

> *Families' capacity to advocate for their child, themselves, and for other children and families varies greatly. Yet families are potentially the most effective advocates for better health care systems and better individual care.*

- ***Strengthening Family Advocacy*** – Families' capacity to advocate for their child, themselves, and for other children and families varies greatly. Yet families are potentially the most effective advocates for better health care systems and better individual care. The foundation has a number of projects newly under way that will provide more and better information for families about the performance of the current health care system, and also will offer training opportunities that will allow families to apply their experiences and knowledge to improve the system of care.

- ***Enhancing Self-Management in Child Health Care*** – Better quality and efficiency in health care can be achieved in part by supporting children, youth, and families to improve their skills in monitoring and managing health problems. Through decades of experience in the care of adults with chronic health problems, experts have identified effective approaches to help patients obtain better self-management skills. The foundation is beginning work that will translate that experience into systemic improvements supporting better self-management skills for children and youth.

- ***Public Policy*** – The foundation is in the early stages of formulating its strategies to respond to the needs of CSHCN and their families, and to take advantage of the opportunities created by the Patient Protection and Affordable Care Act. We are well aware that our work must include some focus on innovations in health care financing that control costs while improving health and patient experiences. We also must identify financing models that reimburse providers for maximizing the health outcomes of CSHCN rather than for episodic care.

GOING FORWARD

Though our work is focused on the system of care for children in California, we have designed our programs so that the advances made with our support will be applicable elsewhere. The child population in our state is large and diverse. Children with at least one foreign-born parent make up half of the 0-18 population, and the childhood poverty rate approaches 20 percent. The issues California children with special needs encounter reflect the circumstances faced by CSHCN and their families, service providers, and policymakers across the country. We look forward to partnering with others in the public and private sector to improve the system of care for CSHCN, and to sharing the results of the work we support.

VIEWS FROM THE FIELD *is offered by GIH as a forum for health grantmakers to share insights and experiences. If you are interested in participating, please contact Faith Mitchell at 202.452.8331 or fmitchell@gih.org.*