



## Developing Goals and Strategies to Improve the Care of Children with Chronic and Complex Health Conditions

Letters of Intent due August 12, 2016

Request for Proposals

### Initiative Overview

The Lucile Packard Foundation for Children's Health seeks applications for grants to develop single-topic issue briefs that describe goals and processes to improve aspects of the systems of care for children with chronic and complex health conditions in the US. Developed by multi-disciplinary work groups, the briefs will provide specific, scalable recommendations for action related to practice, research, programs and policy. Letters of Intent are due **August 12, 2016**. Proposals are due **September 15, 2016**, and selected projects will begin **December 1, 2016**.

### Background

Children with special health care needs (CSHCN)<sup>1</sup>, especially children with medical complexity (CMC)<sup>2</sup>, are served by an array of providers and programs that tend to work independently, with little communication or coordination among them. This fragmentation heightens the risk of adverse short- and long-term outcomes, increases health care costs, and creates financial

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<sup>1</sup> Children with special health care needs (CSHCN) are defined as those who have 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." Adapted from: McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland B. A new definition of children with special health care needs. *Pediatrics*, 102(1):137–140, 1998.

<sup>2</sup> Children with medical complexity are a subgroup of CSHCN characterized by having chronic, severe health conditions; substantial health service needs; major functional limitations; and high health resource utilization. Berry JG, Agrawal RK, Cohen E, Kuo DZ. The Landscape of Medical Care for Children with Medical Complexity. Children's Hospital Association, June 2013.

and emotional burdens for families. Shortcomings in the care provided by the systems upon which these children and families depend have been documented but generally remain unaddressed. In addition to the fragmentation of services, a chief barrier to improving care systemically for these children is the combination of an overall low prevalence of lifelong chronic conditions and their diversity of diagnoses. The low prevalence fails to gain attention from policymakers and payers, and the diversity of diagnoses hampers comprehensive care and health care system planning .

A national symposium held on December 7-8<sup>th</sup>, 2015, sponsored by the Lucile Packard Foundation for Children's Health, invited national experts to identify and discuss cross-cutting issues that affect the care of children with more complex health conditions. Discussion of those topics is available on a webcast of that symposium and in its Proceedings, available at [www.lpfch.org/symposium](http://www.lpfch.org/symposium). However, specific recommendations on how to remedy the identified systemic issues through changes in practice, programs, payment and policy remain to be identified, tested and implemented.

## **The Project**

The Foundation seeks proposals to prepare targeted issue briefs, each addressing a single topic from the list below, that provide feasible, specific and scalable recommendations for action to improve the system of care for children with chronic and complex health care needs.

Recommendations will describe pathways to make changes in existing systems by identifying key participants, sequential activities, venues and necessary policy changes. Each applicant will select one topic from this list that they propose to address in their brief:

- Differentiating groups of children by personal health conditions and social factors, and allocating and financing services based on that process
- Ensuring and enhancing the role and participation of families in all aspects of the systems on which children with special health care needs depend
- Providing life course health care for children with medical complexity
- Using state Medicaid quality measurement and data to drive program improvements to meet the needs of children with medical complexity
- Providing care coordination to address medical and social complexity
- Ensuring integration of home health care, palliative care and other long-term care services with other medical services for children with complex health care needs

Proposals will be accepted from individuals and organizations with established expertise in the topic they propose to address and a documented history of making substantial contributions to

the field of child health care services. Preference will be given to applicants who are well-positioned to act on the recommendations that result from their work. Only one proposal will be accepted from an individual or organization. Each proposal will identify a small, multidisciplinary workgroup (e.g., 5-8 individuals) of national experts on the topic, e.g., clinicians, researchers, family representatives, payers, health plan administrators, and policymakers, with whom they will collaborate to prepare their brief. Multiple proposals on the same topic will compete, but applicants proposing the same topic may be encouraged to collaborate on a joint project. Up to four successful applicants will receive funding to develop briefs. A national advisory committee will review submitted proposals.

Each project will be expected to develop a specific vision of how the child health care system of the future should be structured and operate in order to address the chosen topic. Based on this vision, grant recipients are expected to create an issue brief that provides specific actionable recommendations for research, practice, programs and policies which, if implemented, would achieve the goals inherent in the vision. The issue brief might include (1) justification, preferably evidence-based, for innovative infrastructure change, (e.g., structural, information and other technology, venue, organizational and operational characteristics of an evolved system); (2) identification of leadership issues, including key actors and the actions they might take; (3) a timeline and intermediate outcomes; (4) how to employ various tools of change including strategic partnerships, manpower, data, financing, policy and information and education; and (5) recommendations on sustainability and spread. The brief must include an executive summary highlighting the recommendations and a diagram of the recommended activities that depicts their sequence, venue and key implementers.

The Foundation will facilitate several opportunities for project directors to communicate with one another to share ideas, while keeping individual projects and issue briefs distinct. These opportunities are intended to enhance the efficiency of the projects and avoid duplication of efforts while generating products that are structurally similar.

**Proposals must:**

- Include an executive summary;
- Succinctly address the opportunities for change in the care system for children with special health care needs and children with medical complexity;
- Provide a rationale for the choice of their selected topic;
- Document capacity and expertise to lead a workgroup and develop recommendations and an issue brief;

- Provide a work plan, describing the proposed methodology, timeline and interim products;
- Provide a project budget and budget justification;
- Include the forms listed on our website under *Materials for Invited Applicants*, including the Organization and Project Information Form and the Budget Proposal Form; and
- Identify and provide letters of intent to participate from a multi-disciplinary workgroup which **at a minimum** includes a pediatrician with experience in the care of children with complex health care needs, a family member of a child or youth with special health care needs or the youth themselves, a health plan administrator, and a public health/Medicaid representative. Additional members should be selected based on the topic selected. Proposals must include a justification of the selection of each work group member.

Proposals will be evaluated on their potential to yield evidence-based guidance toward changes that will improve the system of care serving children with chronic and complex health conditions and their families and to achieve the aims of better health, better care and better value. The “system of services”<sup>3</sup> upon which these children and families depend can be exceptionally broad and complex, and medical and other health care services may be only one component. Applicants should consider changes in health care access, structure, organization and processes, insurance benefits, financing and payment, quality measurement, monitoring and assurance, education, and public policy. Specific recommendations for linkages between the health care system and other systems may be included.

Budgets for each approved project will be up to \$50,000 for a grant period of 6-9 months, and are intended to cover the time and administrative costs of the applicant, honoraria, especially for family representatives, travel expenses and indirect costs, which the Foundation caps at 10 percent. Applicants are encouraged to identify additional sources of funding for this work including the provision of in-kind services and co-funding from other public or private funders.

Grantees are expected to meet the Foundation’s requirements for the submission of narrative and financial reports, as well as deliverables. Selected applicants will commit to working with the Foundation staff and one another to ensure the success of their individual projects. Funded applicants are expected to collaborate with the Foundation in disseminating project results.

## Eligibility Criteria

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<sup>3</sup> Perrin, J.M., Romm, D., Bloom, S.R., Homer, C.J., Kuhlthau, K.A., Cooley, C., Duncan, P., Roberts, R., Sloyer, P., Wells, N. and Newacheck, P., 2007. A family-centered, community-based system of services for children and youth with special health care needs. *Archives of pediatrics & adolescent medicine*, 161(10), pp.933-936.

Non-profit organizations, public agencies, academic and other health care research institutions and stakeholder coalitions are eligible to submit proposals. Individuals, private foundations 509(a), and religious organizations for religious purposes are not eligible to apply.

### How to Apply

Applicants should submit the Letter of Intent form which can be downloaded at [http://www.lpfch.org/sites/default/files/letter\\_of\\_intent.doc](http://www.lpfch.org/sites/default/files/letter_of_intent.doc) by **August 12, 2016**.

Applicants should download and complete the proposal [forms](#) posted as *Materials for Invited Applicants* on the Foundation’s website. The proposal narrative is limited to a maximum of 15 pages. All documents should be submitted electronically to [grants@lpfch.org](mailto:grants@lpfch.org) by **September 15, 2016**. For more information, contact Tiauna George, Grants Manager, at (650) 736-0675 or [grants@lpfch.org](mailto:grants@lpfch.org).

### Key Dates for Applicants

RFP Release	May 3, 2016
Webinar for Prospective Applicants Recording: <a href="http://www.lpfch.org/cshcn/blog/2016/07/13/pre-application-webinar-review-request-proposals-complex-care">www.lpfch.org/cshcn/blog/2016/07/13/pre-application-webinar-review-request-proposals-complex-care</a>	July 12, 2016
Letters of Intent Due	August 12, 2016
Proposals Due	September 15, 2016
Projects Selected and Approved	November 1, 2016
Award Letter Emailed	November 4, 2016
Award Letter Due Back to the Foundation	November 25, 2016
Project Start Date	December 1, 2016
Project End Date	May 30 - August 31, 2017