



Family Engagement in Systems Toolkit: Assessing & Improving Family Engagement at the Systems Level

Family Voices has received funding from the Lucile Packard Foundation for Children's Health (LPFCH) to develop a Family Engagement in Systems Toolkit to assess and improve family engagement at the systems level. This work is a continuation of initial research, also funded by LPFCH, in which Family Voices created a [framework for assessing family engagement at the systems level](#).

There is an increasing focus on family engagement among health providers, payers, and systems of care as a strategy for improving health care quality; patient safety; patient, family, and provider satisfaction; health care outcomes; and reducing costs. Because children and youth with special health care needs (CYSHCN) utilize more health care services than other children do, their families have expert knowledge of the systemic barriers (e.g. prior approvals, narrow networks, confusing eligibility for community-based services and supports) that result in a fragmented system of care.

Family Voices believes families of CYSHCN can be important drivers of systems change, using their experiences and expert knowledge in partnership with professionals to ensure that all children receive health care in a well-functioning system. Family Voices, in partnership with experienced family leaders and professional partners from community, academic, and public health pediatric settings, is now developing a Family Engagement in Systems Toolkit for assessing and improving patient and family engagement at healthcare systems, using evidence-based development strategies. The Toolkit will include:

- (1) An assessment tool for patient and family engagement at the systems level, and
- (2) A supporting set of resources to improve systems-level patient and family engagement activities.

We anticipate that the users of the tool will be groups who are already involved in patient and family engagement activities, or who want to start conducting these activities. Potential users include family organizations, Title V Programs, Medicaid programs, health insurance programs, hospitals and other healthcare providers, and other health-related programs and settings.

Family Engagement in Systems Expert Workgroup Members

- Lauren Agoratus, *SPAN, NJ*
- Deborah Allen, ScD, *LA County Health*
- Amal Alsamawi, MPH, *Wayne State University, MI*
- Joni Bruce, *Oklahoma Family Network*
- Juno Duenas, *Support for Families, CA*
- Merrill Friedman, *Amerigroup, Wellpoint, Inc., DC*
- Carolyn Gleason, *MCH Regional Consultant*
- Allison Gray, *Lucile Packard Foundation for Children's Health, CA*
- Bev Johnson*, *Institute for Patient & Family Centered Care (IPFCC)*
- Julie Lucero, *School of Community Health Sciences University of Nevada, Reno*
- Karen Kuhlthau, PhD, *Massachusetts General Hospital, MA*
- Carolyn S. Langer, *MassHealth, MA*
- Anne Riley, PhD, *Johns Hopkins University, Bloomberg School of Public Health*
- Yolanda Sandoval-Nez, *Native American Disability Law Center, NM*
- Joan Scott, MS, CGC, *MCHB, HRSA*
- Renee Turchi, *Drexel University, PA*
- Deborah Klein Walker*, *Cambridge, MA*

*Also *Consultants to the Project*

CONSULTANTS:

- Christina Bethell, PhD, MPH, MBA, *Johns Hopkins School of Public Health, MA*
- Paul Cleary, PhD, *Yale School of Public Health*