

Fact Sheet

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Engaging Families in Improving the Health Care System for Children with Special Health Care Needs

by Priscilla Marbell, MD, MPH

The evidence is clear that patient outcomes improve, and family and provider satisfaction rises, when health providers who care for children with special health care needs (CSHCN) actively partner with parents and caregivers in what is known as family-centered care.

Yet offering family-centered care is only part of the story. To create a high-quality system of care, the family perspective must be actively pursued and incorporated at all levels of the health care system -- direct care, organizational design and governance, and policymaking.¹

A review of relevant literature on patient and family engagement finds that at present most family engagement activities occur in physicians' offices, hospitals, and clinics. There is both need and opportunity for families also to be engaged within the broader health care system and as contributors to public policy decision-making.¹ Involving families in program and policy planning makes it more likely that the services provided will be appropriate and utilized.

Evidence shows that family engagement:

- Leads to better quality of care^{2,3}
- Improves quality of life^{4,5}
- Lessens parental anxieties and fears⁶
- Reduces health care costs^{3,4}
- Improves families' communication and relationship with health professionals⁵
- Increases patient and family satisfaction^{4,5}
- Increases family investment in care⁷
- Leads to more efficient use of services^{5,6}

Barriers to family engagement that providers, agencies, health plans and policymakers can address include:

- Lack of knowledge about the value of family engagement
- Lack of consideration for families' schedules when setting meeting times and locations
- Lack of compensation for families' contributions and incurred costs

- Lack of orientation, mentoring and ongoing support to enable families to participate meaningfully
- Lack of opportunities for families to participate in program and policy planning
- Lack of guidance and protocols for engaging families
- Changes required in organizational culture and behaviors to engage with families

Strategies for Improving California's Health Care Systems

Systemic changes will be necessary to establish family engagement as standard operating procedure for public and private programs and agencies that serve children and their families. These improvements can be implemented at the local and state levels.

Local Health Care Organizations and Systems can:

- Promote the establishment of family advisory committees/roles in agencies, organizations, and practices^{3, 8, 9, 10}
- Involve families as co-leaders in planning and decision-making^{3, 7}
- Provide training and mentoring to parents and family members to enable leadership roles⁸
- Provide supports such as childcare and stipends for travel and time spent at meetings^{8, 9, 11}
- Employ family members as peer navigators or mentors for other families¹²
- Include family engagement measures in organizational performance measurement²
- Identify and support networks for engaged families – for example Family Resource Centers Network of California¹³
- Promote and strengthen cross-sector collaboration of engaged families^{8, 13}
- Establish family-friendly workplace policies⁷

State Health Care Organizations and Systems can:

- Include families' perspectives in developing health care policies and legislation³
- Require an audit of family participation by all state agencies that serve CSHCN¹⁴
- Develop effective materials to educate families and agency staff on the importance of family engagement¹⁵
- Require each state agency that serves families to include family members in an advisory role
- Develop mechanisms to enforce the family engagement requirements¹⁴
- Develop and use a standard measure to assess family engagement in the health care system
- Reward agencies and organizations that perform well on pre-determined family engagement measures¹⁶
- Convene informational legislative hearings for families of CSHCN to inform elected officials of their needs in terms of policy changes¹⁴
- Establish a cross-sector, state-level Family Advisory Committee that will be responsible for developing a standardized protocol for improving the quality of services¹⁴

- Assure adequate funding to support the practice of family engagement by government agencies that serve children ¹⁴

Foundation Support:

The Lucile Packard Foundation for Children's Health has made family engagement a priority, and has provided support for a range of activities to improve the process:

- [Surveyed State Title V programs](#) across the country and California Children's Services programs in California counties to identify the current status of family engagement
- Commissioned a [report on families' involvement](#) in policymaking in public programs serving CSHCN in California
- Supported the Lucile Packard Children's Hospital Stanford in establishing a [statewide network](#) of Family Advisory Councils, the California Patient & Family Centered Care Network, comprising pediatric hospitals and clinics
- Partnered with Family Voices of California to [develop a standardized curriculum](#) that has been used in its Project Leadership to train families to better participate in public policy advocacy
- Sponsored a workshop on family engagement for five managed care health plans that will be serving children currently enrolled in the state's California Children's Services program
- Publishes a [bi-weekly newsletter](#) to keep family and child advocates informed about programs and policies
- Provided funding to allow Support for Families/Family Voices of California to expand its communications capacity
- Provided grant support to national Family Voices to develop a Family Engagement Framework
- Supported a [public hearing on family engagement](#), organized by Children Now, for the California State Senate Select Committee on Children with Special Needs

The Foundation will continue to support activities that train families to become strong advocates and empower them to serve in policymaking roles, and will encourage local and state systems that serve children and families to actively engage consumer perspectives in their decision-making.

Priscilla Marbell, MD, MPH, is a community health researcher with practical expertise working with non-profit organizations to promote maternal and child health and support underserved communities.

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