

# Fact Sheet

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## It Takes a Family:

### An Analysis of Family Participation in Policymaking for Public Programs Serving Children with Special Health Care Needs in California

By Maryann O'Sullivan with Frances Tompkins

Families and patient advocates long have said, “Nothing about me without me,” meaning that they need to be active participants in decisions that affect their health care and well-being. But how well is their request being honored by public health programs? This fact sheet summarizes the findings of a new report that considers the role of family participation—i.e., by parents or guardians or youth—in government entities such as boards, advisory committees, and task forces that make policy and implementation decisions regarding

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services for California's children/youth with special health care needs.

The report's authors interviewed parents, advocates and

administrators; reviewed literature regarding family participation, particularly regarding policy decisions; and conducted preliminary research regarding family participation on more than 60 California government policy entities that have roles in programs that serve children with special health care needs.

A key finding is that while some state and local government entities incorporate and support robust family participation, overall involvement of families is very inconsistent and often fairly anemic in policymaking and implementation of decisions. There are substantial differences in the amount of family participation, the role families play in decision-making, and the support offered to families who do participate.

## Policy Recommendations

The report suggests that the State Legislature take the following actions to ensure appropriate family representation on state and local policy entities.

- **An audit of family participation:** The Legislature—or, alternatively, the California State Auditor—should require each state agency that includes programs that serve CSHCN to report whether those programs include family participation on their policy entities; whether there is an adequate number of family representatives; the process for choosing family representatives; the level of authority/responsibility/participation regarding decision-making; the clarity of roles and the support and training offered to family representatives; the diversity of members and the availability of translation services; and the availability of financial support for transportation and childcare.
- **Informational field hearings:** The Legislature should conduct a series of informational field hearings around the state to engage families of CSHCN in informing the Legislature regarding the level of need for family participation on government policy entities that serve CSHCN, and to hear from government agencies regarding their commitment to family participation on these entities.

- **A cross-agency advisory committee:** As long as the system of care for CSHCN remains fragmented among numerous and uncoordinated government agencies, so too will be the experience of families, adding to the burden on the very people it is intended to serve. Family participation on one entity might dramatically improve/advance care for the individuals served in that program. However, since many CSHCN and their families must interact with numerous

*In the report, one respondent noted that ‘when money problems happen, family participation is the first thing to go.’*

systems, it is critical to devise solutions that take into consideration the numerous touch points these families have with government organizations. A state-

level permanent Family Advisory Committee should be established to adopt a common definition and standards for family-centered care and to improve quality, family-centeredness and coordination of care. This Family Advisory Committee should include representation from families, family groups, all government agencies that serve CSHCN, and others.

- **Establishment of family representation:** The Legislature should require state and local government agencies that serve CSHCN to:
  - Establish formal opportunities at each level of government to include significant family participation in decision-making regarding planning and implementation of service systems;
  - Establish family advisory committees with formal relationships—including shared membership—with decision-making entities to bring further family input to decision-making;
  - Establish and support structured ways for committee members who represent families

to be informed by the experiences of other families of CSHCN and to serve as ambassadors to traditionally harder-to-reach communities;

- Establish mechanisms to support ongoing information, education, training and support for leadership development among families to improve their capacity to participate fully in decision-making at the state and local levels;
  - Provide necessary supports to cover family costs including child care and travel; and
  - Create, adopt and regularly evaluate shared criteria among agencies and provide for training for agencies regarding best practices for maximizing the effectiveness of family participation and assuring cultural competency in decision-making.
- **Mechanisms for enforcement:** Mechanisms should be created to periodically audit and enforce requirements for family participation.
  - **Adequate resources:** Adequate funding should be provided to make the necessary institutional changes to support family participation on government policy entities serving CSHCN.

See the full report at: <http://www.lpfch.org/publication/it-takes-family-analysis-family-participation-policymaking-public-programs-serving>

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