

# **Family ♥Voices From Data to Action**

## **What is the overall purpose of the project?**

The overall purpose is to build on – and put to use - the extensive information and analysis collected in the Family Partners Project to improve care and services for children with special health care needs and their families.

## **Why is this project important?**

During the Family Partners Project - a national survey of 2220 families' experiences with health care for their children with special needs was carried out and interviews with 17 managed care organizations were completed. A considerable amount of data was collected and analyzed; a variety of reports and articles were published. This information provides a basis for action.

Family♥Voices knows that national information needs to be considered with local and state information, resources and opportunities. Further, intentional efforts are often needed to take the next steps to translate knowledge to improved care and services for children with special needs and their families. Basic to Family♥Voices' beliefs is that families need to be actively involved in the discussions and deliberations that impact children's and families' lives.

## **Who is conducting the From Data to Action Project?**

Family Voices, a national grassroots network of families of children with special needs is conducting this project.

## **Who is funding this project?**

This project is funded by the David and Lucile Packard Foundation of California, who also significantly supported the Family Partners project.

## **What are the activities of this project?**

### **Managed Care Interviews**

Family♥Voices is committed to ensuring that families have direct input into the systems of care that can improve children's health. We want to learn about the policies and practices managed care organizations have developed to address a range of issues of special importance for children with special health care needs and their families. We also want to learn about innovative programs and policies plans have developed.

Managed care interviews will be completed in states around the country; in some states a number of interviews will be carried out. Participating Family♥Voices State Coordinators will identify key managed care organizations in their states and invite these managed care plans to participate. Each interview will be carried out by a two-person parent team.

## **Forums**

Family♥Voices is committed to working in partnership with professionals to improve the health of children with special health needs.

In three areas of the country, California, Massachusetts and Tennessee Family♥Voices family leaders will plan forums with state Title V and Medicaid staff, managed care officials, families and others important to children's health.

The forums will be an opportunity for family leaders, staff of managed care plans, providers, state agency staff and advocates to come together to learn about the findings of the "*Your Voice Counts*" survey of the health care experiences of families of children with special health care needs, and of the managed care interviews and to discuss key issues for children with special needs in their area. Forum participants will consider local opportunities and develop plans and strategies for improving the quality of care for children with special health care needs in their area.

## **Data Analysis**

During the previous project extensive data was collected from interviews with 2,220 families about their experiences with health care for their children with special health care needs. While significant analyses were carried out, there are still many questions to explore.

Family♥Voices, in collaboration with the Center for Child and Adolescent Health at Massachusetts General Hospital will conduct additional analyses of the survey data

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