



Families in Program and Policy: Interview with State Maternal and Child Health (MCH) and Children with Special Health Care Needs (CSHCN) Programs

What is the overall purpose of the project?

The overall purpose is to collect and report information on family participation in state MCH and CSHCN programs. The information collected will provide baseline information on MCH programs and will update information on CSHCN programs. The interview will build upon and refine information originally collected in 1992, published as *Families in Program and Policy: Report of a 1992 Survey of Family Participation in State Title V Programs for Children with Special Health Care Needs* (1993, Wells, Anderson, Popper) and information collected yearly through the MCH Block Grant reporting requirements.

Why is this project important?

Most states recognize the importance of including families in program and policy activities with health care systems and many are eager to highlight ways they include family opinion and input in the design and delivery of services, programs, and policies. Basic to Family♥Voices' principles is the belief that families should be actively and substantively involved in the discussions and deliberations that impact children's and families' lives. The 1993 report, above, gave baseline information about activities of families with Children with Special Health Care Needs Programs and should be updated to reflect current activities and priorities.

Additionally, and based on the 1993 report, state CSHCN Title V programs are now required to report yearly on family involvement, using a common set of measures - through the MCH Block Grant, Performance Measure 14. This interview will delve more deeply into the program and policy activities with families and suggest next steps and recommendations to strengthen the partnership. States will also be asked how they presently calculate the scores Performance Measure 14 calls for. Information will be shared with states, families, and family organizations to enable state programs and families to learn from each other.

Who is conducting the Families in Program and Policy: Family Participation in State MCH and Children with Special Health Care Needs Programs Interview?

Family♥Voices, a national grassroots network of families of children with special needs, including an extensive network of experienced family leaders, is conducting this project. Family♥Voices is committed to working in partnership with families and professionals to improve the health of children with special health needs. Family♥Voices will invite an expert advisory panel to work with us to determine important areas for information collection and report.

Who is funding this interview?

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This project is supported by the Maternal and Child Health Bureau, Department of Health and Human Services, HRSA, through two grants to Family Voices funded by:

- 1) The Division of Child, Adolescent, and Family Health
- 2) The Division of Services for Children with Special Health Care Needs

What information will be collected from states?

Interview questions will ask about the roles and input of family members and consumer organizations with both CSHCN and MCH programs in each state. Questions will include:

- The kinds and extent of family input to programs and policies, both formal and informal. Special attention will be given to important initiatives such as SCHIP, Healthy People 2010, Bright Futures, etc.
- The ways MCH and CSHCN programs involve families in addressing state negotiated measures such as Medicaid, managed care organizations, Early Intervention, etc.
- The involvement of family perspectives in in-service training for staff
- The kinds and extent of family involvement with the MCH Block Grant process.
- Information will also be collected about how family members are recruited, mentored, supported and compensated for these activities, whether as volunteers, staff, or consultants.
- How MCH and CSHCN programs assure the inclusion of family members representing cultural and socio-economic diversity.
- The kinds of support MCH and CHSCN programs provide to encourage parent-organized activities in their states.

How will this information be collected?

Family Voices parent leaders, assisted by Family Voices national staff, will hold telephone interviews with staff of CSHCN and MCH programs in each state, using a telephone questionnaire developed by the project with the assistance of the Advisory Panel. The information collected will be reviewed by families and family organizations in each state.

What information will be collected from Family Voices leaders and how will it be collected?

A brief set of questions, drawn and adapted from the interview tool used with the state programs will be sent out over Family Voices Talk, a closed List Serve that reaches Family Voices staff and coordinators. The purpose will be to solicit from these family leaders information on innovative family participation and ideas for fostering further family participation in Title V programs.

What will be done with the information collected?

The information collected will be compiled in a report that will be posted on the Family Voices website and widely disseminated through Family Voices' channels and the MCH state and federal network.

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