

# Families in Program and Policy FiPPs CSHCN Report

**Interviews on Family Participation  
with State Title V  
Children with Special Health Care Needs  
Programs**





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## **Interviews on Family Participation with State Title V Children with Special Health Care Needs Programs**

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Support for this project was obtained from the Division of Services for Children with Special Health Care Needs (6U40 MC 00149-06-02), Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration, Health and Human Services.



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# Families in Program and Policy

## FiPPs CSHCN Report

**A Report of Interviews with CSHCN Programs about the  
Participation of Families in Title V CSHCN Programs, 2002**

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# ACKNOWLEDGMENTS

Program and policy level family participation in programs for Children with Special Health Care Needs has been a goal long envisioned by both parents and professionals. The great progress that has been made in the development of such partnerships between families and professionals has been the result of the inspiration, co-operation and the hard work of many caring individuals.

Staff of the *Family Voices* Family-to-Family Health Information Center Project, funded by the Division of Services to Children with Special Health Care Needs (6U40 MC 00149-06-02), Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration, Health and Human Services, worked closely with staff of the *Family Voices* Partners in Information and Communication Project, funded by the Division of Child, Adolescent and Family Health (6U93 MC 00121), to collect the information summarized in this report.

The project would not have been possible without the vision and inspiration of Diana Denboba and Merle McPherson, MD at the Maternal and Child Health Bureau, Division of Services for Children with Special Health Care Needs and David Heppel, MD at the Maternal and Child Health Bureau, Division of Child, Adolescent and Family Health.

*Family Voices* network members and other family leaders provided wisdom, vision and expertise in the development of the interview tools and process.

An Advisory Committee of Directors of Children with Special Health Care Needs Programs and Maternal and Child Health Programs, AMCHP staff, providers and family members provided expert guidance.

Experienced parent leaders assisted in piloting the interview tool and carried out the interviews: Becky Adelman, Lauren Agoratus, Kathy Bachmann, Molly Cole, Donene Feist, Beth MacDonald, Norma Lopez, Loraine Lucinski, Maureen Mitchell, Melody Oldenberg, Missy Ringgenberg and Melissa Vickers.

Staff of Children with Special Health Care Needs Programs in every state and two territories generously took the time to participate in the telephone interviews and provided thoughtful responses.

Lois Wainstock, a consultant to the study, provided expert guidance and insight in the development of the interview protocols and the analysis of the findings. *Family Voices* technical staff designed the Title V Toolbox website and provided invaluable hard work and insight on all aspects of the project. Thanks also to Polly Arango and Jennifer Cernoch for their review and comments.

Peggy Curran, Katherine Cruz Fernandez, Lindsey Pope and Conni Sun provided careful and creative technical assistance throughout the project and with the report.

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# FAMILY VOICES

*Family Voices* is a national organization of families and friends speaking on behalf of children and youth with special health care needs.<sup>1</sup> Our mission is to advocate for health care services that are family-centered, community-based, comprehensive, coordinated and culturally competent for all children and youth with special health care needs; promote the inclusion of all families as decision makers at all levels of health care; and support essential partnerships between families and professionals.

*Family Voices* operates many projects to improve the health and well being of children and families. The *Family Voices* organization consists of family leaders in every state, supported by staff in Arizona, California, Illinois, Iowa, Massachusetts, New Mexico, North Carolina and Texas.

Many groups focus on particular childhood illnesses or populations. Others represent children and adults or concentrate on specific reform proposals. Until *Family Voices* formed, there was no national organization that spoke for all children and youth with special health needs regardless of diagnosis - a population estimated at over 9 million children under the age of eighteen.

Catalyzed by the 1992 presidential campaign and its focus on health care reform, families from across the nation came together to create *Family Voices* in December, 1992. With a common goal of improving systems of care for children with special health care needs, the organization was established as a national grassroots network with representatives in every state. It was soon evident that this national network filled an enormous need for information, expertise, partnership and support, not just for families and family leaders, but also for professionals who care for children and youth with special health care needs.

Early funding from the Robert Wood Johnson Foundation, Maternal and Child Health Bureau and later the Annie E. Casey and the David and Lucile Packard Foundations, among others, helped *Family Voices* to provide assistance and resources to state *Family Voices* leaders. National and regional *Family Voices* conferences provided crucial opportunities for building family leadership and promoting family knowledge and involvement in many child health initiatives.

*Family Voices* has become a vibrant organization with active members in every state whose knowledge, perspectives, and influence are respected and continually solicited in the shaping of programs and policies for children and youth with special health care needs. Findings from *Family Voices* research projects have been published in professional journals. *Family Voices* has produced numerous reports and materials to help families in caring for their children. *Family Voices* provides technical assistance to 35 funded Family-to-Family Health Information Centers, as well as to family leader volunteers throughout the country. The *Family Voices* network provides assistance to individual families in states and communities as well as partnership with professionals at all levels of care. *Family Voices* supports the empowerment of youth with special health care needs through Kids as Self Advocates (KASA). Looking forward to the future, *Family Voices* remains strongly committed to partnership with professionals and support for families in the quest for quality health care for all this nation's children.

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<sup>1</sup> Children who have or are at increased risk for a chronic, physical, developmental, behavioral, or emotional condition and who also require health related services of a type or amount beyond that required by children generally. — Division of Services for Children with Special Health Care Needs, Maternal and Child Health Bureau.



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# INTRODUCTION

The world of services for children with special health care needs has changed in dramatic ways in the decade 1992 – 2002. Increasing acknowledgment of the role of families as critical partners with professionals in program and policy activities has been one of the important areas of change. Under the visionary leadership of the Maternal and Child Health Bureau (MCHB), Division of Services for Children with Special Health Care Needs (CSHCN), Title V Programs for CSHCN around the country have expanded initiatives with families to firmly establish the philosophy that family roles in the design and implementation of programs are essential if these systems are to be truly responsive to families' needs. A widely accepted language and understanding of the importance of such family involvement is now evident in many arenas, including other MCH programs as well as other service systems such as mental health and foster care. The purpose of gathering the information reported here has been to add to the knowledge about the evolving roles of families and family organizations at the program and policy level in Title V State Programs.

In 2001 – 2002, *Family Voices*, funded by the MCHB Division of Services for CSHCN, conducted a study of 53 CSHCN programs in order to document progress in family participation within these programs. The study was undertaken jointly with the *Family Voices* Partners in Information and Communication Project, funded by the MCHB Division of Child, Adolescent and Family Health. This initiative built on several earlier initiatives. A 1992 study collected baseline information on the participation of parents and other family members from the staff of Title V CSHCN programs.<sup>2</sup> In 1993 a further investigation of the numbers and roles of family members employed by CSHCN programs was undertaken.<sup>3</sup> In turn, these investigations had been preceded by an inquiry in 1987 about parent participation on advisory committees in MCH and CSHCN programs.<sup>4</sup>

This report summarizes information collected in telephone interviews with Title V CSHCN programs in 2001 – 2002 and compares it where possible with information collected through the similar study from 1992. The information is also briefly compared to information collected in 2001 – 2002 from MCH Programs about these same topics. A companion report of the MCH information, [Families in Program and Policy FiPPs MCH Report](#), as well as further information comparing findings from CSHCN and MCH interviews, is available at [www.familyvoices.org/fipps/home.htm](http://www.familyvoices.org/fipps/home.htm). This report also compiles results from a questionnaire completed by *Family Voices* family leaders, comparing their perspective on family involvement to the information reported by the CSHCN programs. Finally, this report describes the *Family Voices* Title V Toolbox, a web repository developed from resources provided by CSHCN and MCH programs and family leaders ([www.familyvoices.org/toolbox](http://www.familyvoices.org/toolbox)).

The information reported provides a rich picture of Title V CSHCN program activities with families and family groups and substantial growth in family involvement activities in many states in the decade 1992-2002. This report will be useful to those involved in national, state and local planning and policy activities for children with special needs, particularly to the state and family leaders who continue daily to create the partnerships that provide critical roles in improving maternal and child health and assuring quality of care for children and their families.

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<sup>2</sup> This earlier project was carried out by the CAPP (Collaboration Among Parents and Professionals) National Parent Resource Center Project at the Federation for Children with Special Needs. Findings are summarized in a publication, [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](#), Wells, N., Anderson, B., Popper, B., 1993.

<sup>3</sup> CAPP Project, Federation for Children with Special Needs, [Family Employment in State Title V Programs: Conference Proceedings and Survey Report](#), Anderson, B., Popper B., and Wells N., 1995.

<sup>4</sup> [CAPP Report, Survey of Parent/Consumer Participation on Advisory Committees to State Health Departments and Private Hospitals](#), 1987, Popper, B.

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## Background: Title V Maternal and Child Health

Created in 1935 through the Social Security Act, Title V is administered through the Maternal and Child Health Bureau. The original purpose, “to improve the health of all mothers and children, including children with special health care needs,” underlies all Title V programs, with activities evolving to meet the changing social and health needs of families and children.

While State MCH and CSHCN Programs have always involved families in some aspects of their work, it was in the 1980’s that the role of families in Title V Programs began to receive a stronger focus. At that time, the MCHB Division of Services for CSHCN articulated and emphasized a central role for families in participating in the care of their own children as well as in providing guidance at the program and policy level. Support for family participation had been reinforced through many Division activities including: family participation in meetings, documents that articulated the value of family involvement, and funded projects that emphasized roles for family members. In 1989, the Omnibus Budget Reconciliation Act (OBRA) mandated that CSHCN programs supported by MCHB work toward providing “family-centered care” that is community based, coordinated, and culturally competent. OBRA provided guidelines requiring states to indicate their commitment to family-centered care. Effective partnerships with families have been considered central to realizing this goal.

In the 1990s, MCHB added questions to States’ Title V Block Grant reporting requirements asking them to rate their state on involvement of families in Title V CSHCN programs and policies (Performance Measure 14, now Form 13: Characteristics Documenting Family Participation in CSHCN Programs). In 2000, several Healthy People 2010 goals specifically targeted this population, including one about the development of systems of care for children with special needs. MCHB articulated a framework of six measurable outcomes that would lead to a quality system of care for children with special health care needs. These objectives emphasize the central role of families as partners at every level of care and service delivery. The President’s New Freedom Initiative, announced by George W. Bush in February, 2001, incorporates these six objectives and provides a wide forum for recognizing the importance of family participation across all agencies of the federal government.

The establishment of a strong national network of families and family leaders working to improve the health care of children with special health care needs through *Family Voices* has added momentum to MCHB efforts. By creating a highly effective method of communication, training, and support among parent leaders around the country and by strengthening collaborative relationships among families, public and private providers, and policy makers, *Family Voices* has fueled the growth of family leadership and family involvement with many partners and systems, significantly with Title V MCH and CSHCN Programs.

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# METHODOLOGY

The concept and approach to obtaining information and establishing a baseline about family participation within Title V Programs has evolved over time. Over the last 10 years (since the 1992 interviews with CSHCN Programs), family participation has become evident in MCH Programs. As a result, this study's methodology targeted both CSHCN and MCH Programs for evidence of family participation and was carried out jointly as part of the *Family Voices* Family to Family Health Information Center (F2FHIC) and the Partners In Communication (PIC) projects.

Interview questions were based on the 1992 interview tool and further expanded through review by project staff, discussions with CSHCN staff and *Family Voices* Network Members, and the advice of an advisory committee of parents and professionals. Questions for the CSHCN and MCH interviews were nearly identical, with only a few differences to reflect the specific programs and requirements. The interview tool was piloted in four states and revised based on this field experience. The CSHCN Questionnaire is included in Appendix D of this report.

CSHCN Directors were prepared for the interviews through an initial postcard announcement, a display at the annual Association of Maternal and Child Health Programs (AMCHP) conference, and a direct mailing that included a copy of the interview tool and a letter of introduction with guidance information. Guidance information included such terms as "families" - defined as relatives, guardians and foster families as well as parents and siblings, and "family/family organization involvement in program and policy activities" - defined as family members or groups who advise or assist the Title V program in understanding needs and providing quality care and services for children and families. Guidance information also asked respondents to focus their responses on the preceding 12 months and to specifically consider efforts their programs make to include family members from a diverse range of socio-economic, racial, cultural and ethnic backgrounds. Participants were told that similar questions were asked of staff in their MCH programs. They were encouraged to include other staff in the phone interview, if they wished. Interview materials were also posted on the *Family Voices* website.

Telephone interviews, lasting approximately one hour, were carried out by 12 parent leaders who had been recruited nationally. Each interviewer was trained and prepared through group conference calls and individual technical assistance and provided with follow up support from project staff. The strategy of telephone interviews was chosen in order to facilitate discussion and expand upon the information reported. Parent interviewers completed the phone interviews and submitted written summaries which were sent back to the CSHCN staff for clarification and approval.

Fifty-three CSHCN programs completed the interview protocol. In 41 states, the interview was completed with the CSHCN Director, while the remaining 12 were conducted with program staff designated by the Director.

This report primarily provides a snapshot of family participation as it was reported by the CSHCN Director or designee at the time of the interview in 2002. Responses are dependent on the extent of the knowledge of the person interviewed and may also be dependent on an individual's interpretation of certain questions. Additionally, some activities have certainly changed since the information was collected. More than a dozen questions had open-ended components. Since this was a discussion interview, additional comments of a qualitative nature were obtained, although in a few cases, this information contradicted information provided in quantitative questions.

Quantitative results are compared to information collected from the 1992 CSHCN study and with the parallel 2002 MCH study, where applicable. Narrative discussions and quotations are noted (italicized text within boxes) along with quantitative results to provide a fuller picture. State-specific tables of responses are included in Appendix C of this report. Qualitative information is provided without reference to specific programs. Suggested strategies for family involvement noted by CSHCN programs in response to open-ended questions is provided in Appendix B of this report.

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In addition to the interviews with CSHCN Programs, this study also requested input from *Family Voices* leaders in the states on topics similar to those in the CSHCN Program interviews. Quantitative results obtained from family leaders are compared to those reported by CSHCN Programs, where applicable, and open-ended responses are noted to provide a greater understanding of topics covered. The Family Leader Questionnaire is included in Appendix E of this report.

Finally, this study sought to proactively increase and provide support for family participation through the sharing of resources. As part of the interview process, CSHCN Programs were asked to contribute (by e-mail) materials, tools, or publications which promote the involvement of families, such as job descriptions, contracts, policies, etc. These resources have been categorized and stored in a web repository on the *Family Voices* website, [www.familyvoices.org/toolbox](http://www.familyvoices.org/toolbox). The repository is accessible to the public and allows for existing resources to be downloaded and new resources to be submitted and stored. A description of the Family Voices Title V Toolbox is included in Appendix A of this report.

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# EXECUTIVE SUMMARY

All state Title V CSHCN programs reported in 2002 that families are involved in program activities and over 80% of these programs reported family participation in each of the following areas:

- on advisory committees,
- in in-service trainings,
- in the Block Grant process,
- in addressing state performance measures,
- with initiatives to improve MCH,
- in 2010 CSHCN priorities, and
- as paid staff / consultants.

When asked about the extent of family involvement in program and policy activities, all CSHCN programs reported that families are involved at some level. Over half (57%) indicated that families are involved in most activities, 43% indicated families are occasionally involved in such activities, and none indicated that families were not really yet involved.

Since the previous 1992 study of family participation in CSHCN programs, there has been considerable growth in family involvement. Most programs (56%) reported in 2002 that the length of time that families have been involved in their programs is 10 years or less. Coinciding with this growth, family participation in in-service trainings and family members serving as paid staff or consultants has increased considerably from the 1992 study.

CSHCN programs indicated a variety of benefits to their program from family involvement. At least 72% of programs rated the following benefits as high or medium:

- increased awareness and understanding of family issues and needs,
- increased parent/professional communication and understanding,
- improved planning and policies resulting in more responsive services,
- increased availability of families able to participate with programs,
- increased responsiveness to federal requirements,
- establishing a base of a strong coalition for change within the program, and
- improved understanding of programs by legislature, state officials, public

Throughout the survey, CSHCN programs elaborated on the ways in which families contribute to and strengthen the program. Programs reported that participating families bring a wealth of information and experiences to their partnership roles and often serve as intermediaries in sharing information between CSHCN staff and families. Family members bring a needed family perspective to program and policy planning and provide critical information regarding communication with families and outreach strategies to underserved populations. Through connections in their communities, participating families often serve as a direct link to consumer groups. Participating families provide information about program outcomes and effectiveness through feedback from other families. By participating at the program and policy level in CSHCN programs, families are in a strategic position to learn about how programs are administered and how to navigate state and private agencies. They share this information with other families, serving as mentors and helping to build parent-professional partnerships.

For a long time, there has been a lack of sensitivity about what we ask parents to do in the care of their children. The more we are involved with family-centered care, our ability to recognize a family's needs is much higher than it used to be.

Families have been instrumental in showing us areas (where) we needed to expand our covered services list (services we provide under the CSHCN program), and it has been a win-win situation.

- Services are better for everybody – our providers feel better...our families feel better...
- The commitment is strong...all the way to the MCH director.

- (We) Always learn more from communication with families.
- Greatest benefits to program and staff.
- Fortunately, (program) has very invested, involved parents in the programs
- They have opened my eyes out of the bureaucratic policy and into the real world of what families face every day.

Supporting families is an essential component in successful family involvement. CSHCN programs reported on a variety of ways in which they help families participate. Almost all CSHCN programs (94%) provided travel expenses; financial support/payment of services was provided by 75% of programs. Other supports include child care/respice (68%), mentoring (68%), office space (60%) and clerical support (60%). When compared to the 1992 study, there has been much growth in the number of programs providing these supports, particularly in the number of CSHCN programs providing payment and child care.

Nonetheless, involvement of families can be a challenge to programs. Obstacles to family participation reported by most programs were constraints of time and location of meetings and having an ongoing source of funding to pay families. Involving families from diverse communities was also noted as a challenge. Programs shared successful strategies for increasing the participation of underrepresented families, including the employment of staff from diverse backgrounds, using a variety of communication methods to reach communities, and building relationships with trusted groups.

...after 10 years, we could never imagine our program without family involvement.

*Family Voices* leaders, in a parallel questionnaire, shared their perspective on family participation in CSHCN programs. Many findings follow a similar pattern to findings from CSHCN program interviews. Family respondents indicated that increased awareness of family needs, increased communication, and improved policies were the result of family involvement in CSHCN programs. Most family respondents noted the constraints of time, location, and lack of payment as obstacles to family participation but also acknowledged that many programs are now providing support through payment, child care/respice, and travel reimbursement. Family leaders also emphasized the value of the support and framework that a relationship with a family organization provides to both individual family participants and Title V agencies.

When the feds started talking about family involvement, people listened.

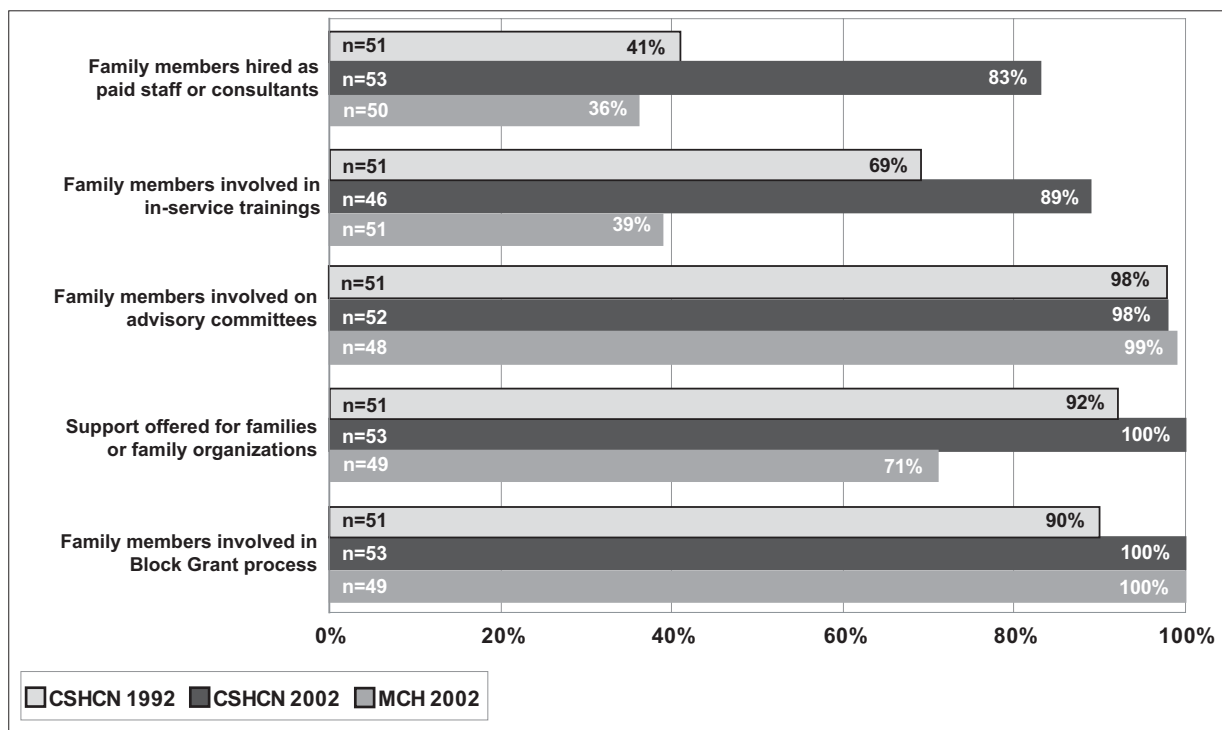
Both programs and *Family Voices* leaders discussed the critical impact of the MCHB accountability requirements in increasing awareness of the importance of family participation in program and policies. Based on comments from program and family respondents, this report recommends that CSHCN programs, MCHB and families work together to develop more detailed guidance on how to measure and report family participation. In addition, this report highlights the importance of sharing successful strategies among programs and family organizations, particularly in such key areas as the involvement of families of diverse cultures and the participation of families in the Block Grant process. A key component to supporting family participation is payment for time/services and this should be a standard in models of family participation.

The information from the interviews with CSHCN programs, the resources on family involvement contributed to the Family Voices Title V Toolbox, and the perspective of *Family Voices* leaders provide a rich picture of family involvement in program and policy activities within CSHCN programs. Enormous progress has been made since the first information on this topic was collected in 1992. Participation by family members has, in many ways, become widely accepted, even standard practice in many areas, leading to programs and policies that will be more family-centered and responsive to family needs. The conversation has moved beyond whether family participation should happen to in-depth exploration and experimentation with how best it can happen.

# FAMILY INVOLVEMENT IN CSHCN AND MCH PROGRAMS, 1992 AND 2002

Chart 1 provides a summary of information on family involvement in key areas for CSHCN 1992, CSHCN 2002 and MCH 2002.

**Chart 1. Comparison of Family Involvement in CSHCN and MCH programs (1992 and 2002)**



Considerable growth can be seen in reported family involvement within CSHCN programs in 2002 as compared with the information gathered about this topic in 1992. All areas of family involvement have increased with the exception of family involvement in advisory committees, which was already reported by 98% (50/51) of CSHCN programs in 1992. The growth in family participation is most obvious in CSHCN programs that were just beginning family involvement activities in 1992. The most dramatic changes reported are in the areas of employment of family members by CSHCN programs. Family involvement in MCH programs was studied for the first time in 2002.

In 1992, 41% (21/51) of CSHCN programs reported hiring family members, but by 2002 this number had doubled, with 83% (44/53) of CSHCN programs reporting that they had employed family members. In addition, another three programs reported paying family members for time or services. Only six CSHCN programs in 2002 did not indicate that they paid family members in any of these ways. Family members were hired by 17 MCH programs in 2002, a number similar to the reported level of family members hired by CSHCN programs in 1992.

(Families) are becoming more and more involved. We ask them to review policy, forms, participate on task forces, work groups, etc. (Our state CSHCN) program is operated primarily by counties. To the extent we can, we give counties authority to hire parents within the county programs...

The reported participation of family members in in-service trainings also increased from 1992 to 2002; the percentage of programs responding that they involve families in such trainings increased from 69% (35/51) in 1992 to 89% (41/46) in

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2002. Thirty-nine percent of MCH programs reported family participation in in-service trainings. These “involved families” may or may not be employed by the Title V programs.

In 2002, as compared to 1992, CSHCN programs indicating that they involved family members in the Block Grant process increased from 90% (46/51) to 100% (53/53). These CSHCN programs described a variety of ways in which family members participated in their Block Grant process, particularly in needs assessments and focus groups. In the open-ended comments, CSHCN programs indicated that although the Block Grant is difficult to understand, they find substantive ways for families to contribute. All MCH programs reported involvement of family members in the Block Grant process in 2002.

In the area of support to families or family organizations (a combined question in 1992), support was offered by 92% (47/51) of CSHCN Programs in 1992 and by 100% (53/53) of such programs in 2002, while 71% of MCH Programs in 2002 reported providing such support.

In the 1992 study, CSHCN programs consistently mentioned two recommendations as important to effective family participation: setting aside funds to support family participation and providing information and support to encourage such participation. The above findings from CSHCN programs in 2002 seem to indicate that most programs have embraced and implemented these recommendations within the last 10 years. Almost all CSHCN programs now provide financial reimbursement to families through several avenues (hiring, payment for time/services), and support/information for family participation in other areas has increased. Clearly there has been much progress within CSHCN programs regarding their commitment to pay families for their contributions, in identifying sources of funds that can support family involvement, and in other methods of financially supporting family roles. As family involvement in MCH programs was asked about for the first time in 2002, it will be interesting to track the progress of various elements of family participation in MCH programs over the next few years.

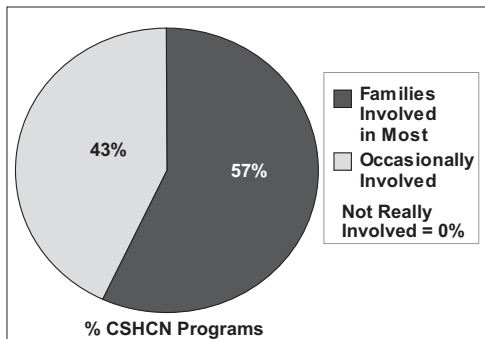
The Family Voices companion report on the findings for the MCH interviews and more information on a comparison between CSHCN and MCH findings is available at [www.familyvoices.org/fipps/home.htm](http://www.familyvoices.org/fipps/home.htm).



# OVERALL FAMILY INVOLVEMENT IN CSHCN PROGRAMS

An initial interview question asked state CSHCN programs to indicate the extent to which families are part of program and policy activities in their program.

**Chart 2. Extent of Family Involvement in CSHCN Program & Policy (n=53)**



All CSHCN programs responded that families were involved to some extent in program and policy activities. Over half (57%) of all CSHCN programs indicated that families were involved in most program and policy activities in their program, while 43% indicated that families were occasionally involved in these activities, as can be seen in Chart 2.

Much value is placed on families as true partners and they play key roles in advocacy and policy making. Families are represented on categorical work groups and many informal relationships exist with parents and parent organizations. (Our state) is a small community where we know each other well and are able to partner in many informal ways....

## Key Ways that Families are Involved

To an open-ended question about key ways that families are involved in their CSHCN programs, respondents reported numerous kinds of family involvement at the community, county and/or state levels. Family participation in committees at all levels was most frequently mentioned. Families serve on Governors’ Councils, Steering Committees, Advisory Boards and other statewide leadership committees, including councils established by state legislation. Families also serve on program-specific committees such as a Universal Hearing Screening Committee.

In addition, programs reported parents participating in many other activities, including staff training, parent focus groups, family conferences and activities at health centers. Programs reported that families assist with state policy development, quality assurance, community assessment, strategic planning, outreach activities, hiring staff, partnership development with other agencies, development and review of resource materials and other publications, mentoring of new parents, identification of resources, supporting parents, writing grants, helping with surveys, and disseminating materials. Several programs reported that involving families in special projects and grants had led to more participation in ongoing activities.

Employment was reported as a key mechanism for supporting family participation. Many programs employ one or two parents to interact with the state CSHCN office. Programs also reported that employed parents are assigned to regional offices to more effectively work with local families and staff. Contracts with family organizations appear to be an important method for providing family involvement in some programs, often in addition to other family participation activities. In several programs, the CSHCN program reported specifically looking to fill staff and managerial positions within their agency with family members that

have children with special needs as an added opportunity to facilitate family perspective.

(Our) involvement with (statewide family organization) has been increasing steadily. . . . (state CSHCN staff) go to their annual meetings and present about the different programs in (our state). When our eligibility workers send out applications for the CSHCN program, they also send applications for the (statewide parent organization).

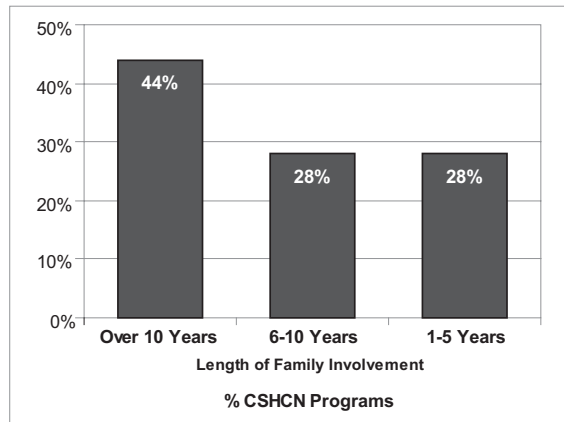
A major family initiative that we undertake on an ongoing basis is the parent leadership component of Early Intervention. . . . This. has a regional structure with EI Parent Consultants in every region.

The EI system is contracted through grantees who must agree to involve families in the hiring process, program evaluation and policy making.

## History of Family Involvement

CSHCN programs were asked to approximate how long families have been involved in their programs.

**Chart 3. History of Family Involvement in CSHCN Programs (n=53)**

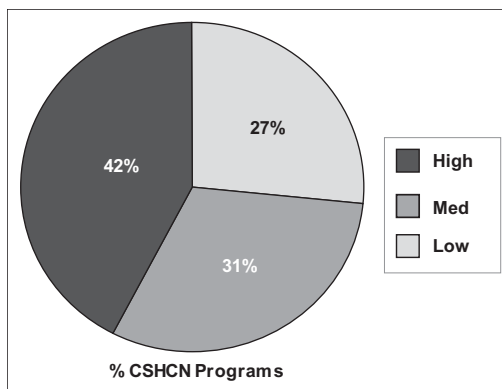


As shown in Chart 3, 44% of programs reported that families have been involved with their program for over 10 years, 28% reported this involvement for 6-10 years and 28% for less than six years. There appears to be a substantive increase in both the quantity and the quality of family involvement with Title V CSHCN programs in the past 10 years, which will be discussed in more detail throughout this report.

## Early Intervention as an Influence

CSHCN interviewees were asked to rate the degree to which family involvement in CSHCN activities has been influenced by Early Intervention (EI) activities in their state. We asked this question because in approximately two-thirds of the states, EI is organizationally located in the same department as the Title V Program, and family involvement is significantly included in the language of EI legislation, policy and practice.

**Chart 4. Influence of EI on Family Involvement in CSHCN Activities (n=52)**



As indicated in Chart 4, most CSHCN programs (73%) reported a high (42%) or medium (31%) degree to which family involvement in CSHCN programs has been influenced by EI activities, while just over one quarter (27%) rated EI influence as low. Examples of influences noted include funding provided through EI for the development of parent networks and for scholarships for families to attend workshops and conferences.

The required family involvement in EI programs appears to have favorably influenced family involvement in other program and policy activities.

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## Relationships to Family Organizations

Relationships with family organizations provide many advantages for CSHCN programs, including access to experienced parent leaders, a source of ongoing parent participation, and important communication mechanisms to reach constituencies through mechanisms such as listservs and mailing lists.

Most CSHCN programs (96%) reported having a relationship with *Family Voices*, and almost 40 % of these programs characterize the relationship as “formal.” Most programs (89%) also reported having a relationship with other types of family organizations. The most frequently mentioned other such organizations were Parent Training and Information (Special Education) Centers, Parent-to-Parent Programs, Early Intervention Parent Leadership Groups, Developmental Disability Councils, and specific disability support groups for such disabilities as Sickle Cell Anemia, Deafness, Spina Bifida, Brain Injury, Cystic Fibrosis, and Metabolic Disorders.

We've had an established relationship with the family groups...I think they feel like we are looking for information but we are not always listening to what they say...

Now that we have an active Family Voices group...they were very helpful in getting a rate increase for our providers.

The contracts with other agencies...do require family involvement...some include family partnership training...some include family teaching.

## Contract Requirements

When asked if family member involvement was required in contracts developed for the provision of services, the responses from CSHCN respondents were split, with 53% indicating family involvement was required in some of their contracts and 47% indicating that such involvement was not specified. Of the contracts specifying the hiring of family members, examples of family roles included outreach, advocacy, program evaluation, policy making, and participation on hiring committees. Other examples noted were contracts stipulating the provision of family training and contracts developed for family organizations to provide services to the program and to families.

(Our state CSHCN) program contracts with (statewide family organization) and through that contract families are involved in state level policy development, quality assurance activities and support is provided to a network of resource parents across the state...

Twenty percent of responding CSHCN programs specifically mentioned contracts they had with family organizations which provided a range of services for them, from parent to parent services, to specific services such as care coordination or wrap around services, to a comprehensive contract to provide all family involvement in the program.

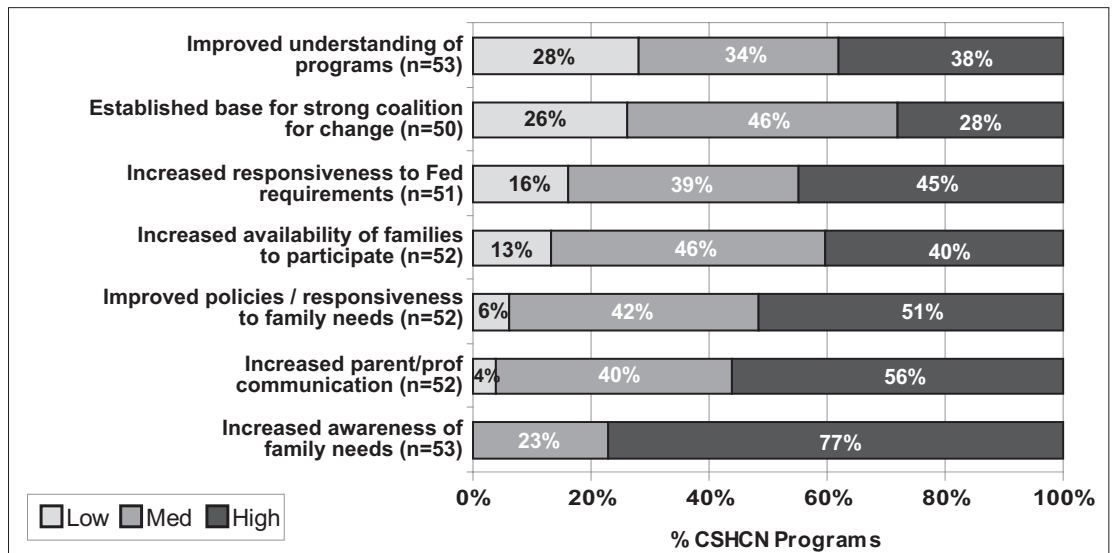
If there are policy questions, it is wonderful to pull in a family to ask “what do you think about this?”

Examples of contracts, which include job titles, responsibilities, compensation ranges, etc. can be found in the *Family Voices Title V Toolbox*, [www.familyvoices/toolbox.org](http://www.familyvoices/toolbox.org).

## Benefits of Family Involvement to CSHCN Programs

CSHCN programs were asked to rate (Low/Medium/High) the level of benefit from family participation in seven areas. (The areas were derived from responses to open-ended questions in the 1992 interviews).

**Chart 5. Benefits of Family Involvement to CSHCN Program**



Your policies change based on the voices you are hearing.

As we work with communities... we specifically work with CSHCN parents to develop their skills to effect community change. They may effect this change in a variety of things such as working with schools to make them more accessible. One community developed a children's resource center so it would be easy for families to find information about services and programs and resources for children... not only health issues, but also a variety of social service programs...

...We work with a (program) that boosts family involvement by providing a chat room for parents of CSHCN as well as articles about medicines and conditions, which are reviewed by providers. We are also starting a chat room for adolescent CSHCN.

The majority of programs rated all seven categories of benefits at the High or Medium level. As Chart 5 shows, the benefit most strongly rated by CSHCN Directors and staff is increased awareness and understanding of family issues and needs. Programs reported that families provide a 'real world' perspective of health care policies and procedures, enabling CSHCN staff to better assess the effectiveness of their system.

Other benefits of involving families rated Med/High by at least 80% of CSHCN programs are 1) increased parent/professional communication and understanding, 2) improved planning and policies resulting in services more directly responsive to family needs, 3) increased responsiveness to Federal requirements, and 4) increased availability of families to participate. Open-ended comments indicated that programs which contracted with a family organization may have an easier time finding parents to participate in program and policy activities. Programs indicated throughout the interviews that the MCHB Division of CSHCN requirements and encouragement to involve families have had a major influence on their thinking about the value of such involvement and their efforts to ensure such involvement.

Some programs (38%) felt strongly that family involvement aids in improving the understanding of programs by legislature, state officials, and the public. Just over one quarter of the programs felt strongly that a benefit of family involvement is in establishing a base for a strong coalition of change within the program. Comments noted that since CSHCN staff are restricted in the roles that they can take with legislatures, it is particularly valuable to have knowledgeable family advocates to speak out when programs and services are threatened.

# FAMILY INVOLVEMENT IN ADVISORY COMMITTEES/TASK FORCES/GROUPS

*98% of CSHCN programs (51/52) in 2002 and 98% of CSHCN programs (50/51) in 1992 reported family involvement in advisory committees/task forces/groups.*

## Number of Committees

CSHCN programs see family involvement in advisory committees, task forces, and groups as providing many benefits to CSHCN programs. It is a time-honored method used by programs to address tasks in public health, so it is not surprising that these groups offered familiar opportunities to involve families. Programs were asked to provide the percentage of committees/task forces/groups in which families participated in their state.

Another capacity in which parents participate is through the local Parent Advisory Committees. These committees meet regularly to provide support for families... (families in our state) are also supported to attend AMCHP, and (parent organization) meetings....

**Chart 6. Advisory Committees/Task Forces/ Groups in Which Families Participate (n=52)**

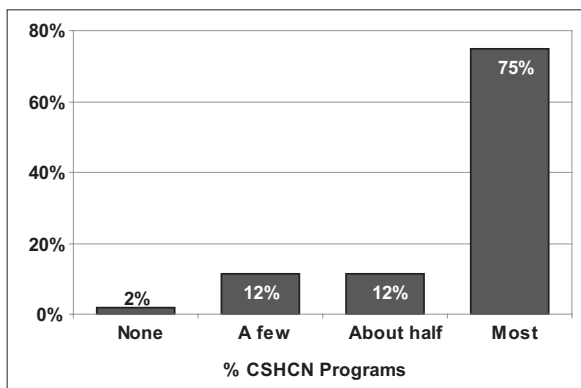


Chart 6 indicates the extent of reported family involvement in advisory committees, task forces, and groups. Of the responses from 52 states/territories, 75% indicated that families were involved in most of the committees, task forces, and advisory groups in their CSHCN program. Twelve percent of responding CSHCN programs indicated that

- We have a diverse advisory group made up of CSHCN parents that represent children of all ages, families that use all levels of services.
- We have a Parents Action Council (PAC) that has been established by state legislation. This is the group that works with our (CSHCN) program and participates in both the Medical Directors and Administrators meetings.

families were involved in about half of all their committees, task forces and advisory groups; another 12% indicated that families were involved in a few such committees. Only one CSHCN program reported no involvement of families in their committees, task forces, and advisory groups. These results are similar to findings in 1992; participation of families in committees was reported by all but one state in the question asked 10 years earlier.

## Types of Committees

CSHCN programs reported family participation in a wide variety of advisory committees, task forces and groups related to many topic areas. Respondents were asked to indicate all the categories that applied. Twenty-four programs reported family participation in joint MCH/CSHCN Advisory and CSHCN Advisory Committees. Examples of many other types of committees in which families participate were provided by 38 CSHCN programs. These included committees around specific initiatives, such as: Newborn Hearing/Screening, Genetics/Birth Defects, SCHIP, Health Disparities, Medical Home, Care Coordination, Early Intervention, Oral Health Care, Mental Health Care or specific conditions such as Hemophilia, Asthma or Brain Injury. Other listed committees related to broader goals such as leadership development, standards development, needs assessment

Frequently you hear that parents of adolescents with disabilities are overprotective and that a barrier to transition is that the families are controlling... families talking to other families about the question of transition really revealed to us the extent to which what appears to be overprotectiveness is often a very sharp recognition of the limits of the adult care system... this flipped our way of thinking about "where does the problem lie" in a very subtle but very important way.

They (families) are the leadership in some of the committees, particularly at the local level - they direct the action.

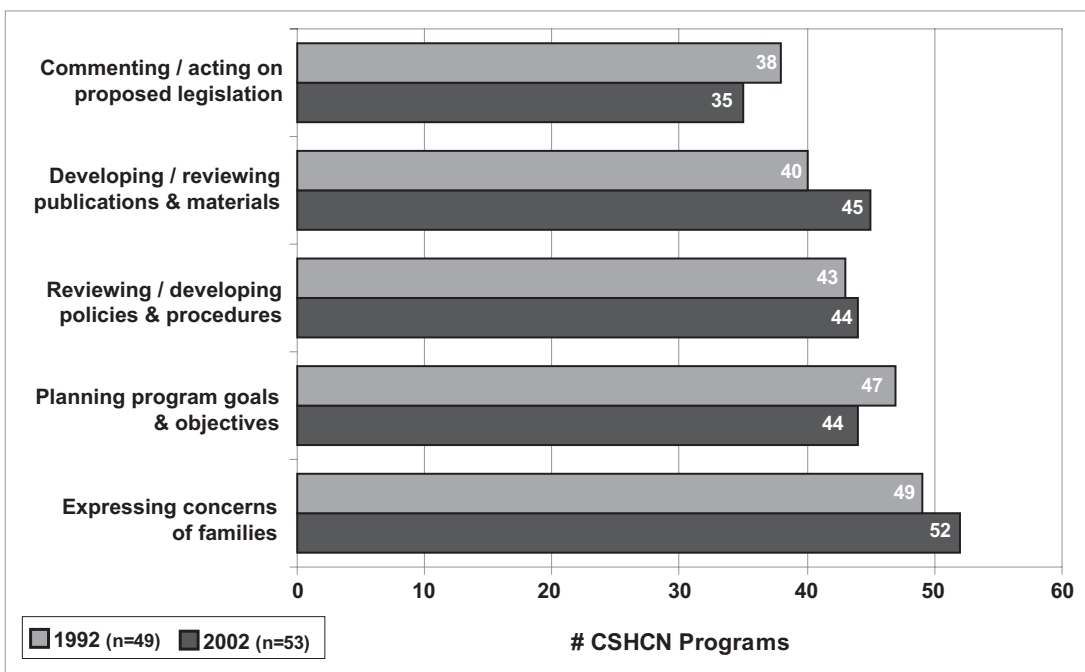
and parent-to-parent support. Some committees operate on a statewide basis while others are regionally or locally based.

The wide range of focus of these committees is evidence that family participation in committees is universally accepted and practiced. The strong and consistent support and encouragement for this kind of family participation indicates that this practice is clearly providing benefit to both families and state programs.

## Ways in which Families Contribute

Programs were asked to rate the ‘measures of contribution’ of these committees in five areas. A comparison to 1992 is provided in Chart 7.

**Chart 7. Contributions of Families in Advisory Committees, Task Forces, and Groups, 1992 & 2002**



In both 1992 and 2002, responses from at least 35 CSHCN programs indicated family contribution in all five pre-defined areas of inquiry. In addition, there is much similarity in the number of programs reporting on each measure of contribution in 1992 and 2002. The ability of families to “express concerns of other families” was rated as a contribution by more programs than any other measure in both 1992 and 2002. In addition to these pre-defined measures of contribution, 19 CSHCN respondents noted other ways in which families contribute, including:

We have several groups. We ...have (a project) which is a group of parents of children participating in our (CSHCN) program and they do a lot of work helping to make the clinics family-friendly and to provide support and assistance to other families and to provide training to providers on assorted issues related to providing family-friendly, culturally competent services...

- Strengthening relationships with other family groups,
- Participating in hiring committees and in contract and grant monitoring and reviews,
- Presenting at conferences and meetings, and
- Conducting qualitative research in the community

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## Recruitment of Families

The ability of CSHCN programs to identify families for participation in advisory committees/task forces/groups is the first step in realizing the benefits of such participation. Overall 41% (22/53) of CSHCN respondents indicated that identification of family participants was a difficulty or obstacle to involving family members. CSHCN programs were asked to share the ways in which they recruit families and insure outreach to special or diverse populations, including fathers and grandparents. Of the 14 CSHCN respondents, most indicated that families were often recruited by other families, including through family staff members and through family organizations. Other ways in which families are recruited include:

- those who use the program’s services,
- newsletters,
- schools,
- faith-based community organizations,
- nonprofit agencies,
- other committees,
- workshops, and
- health fairs

Many respondents indicated that they have established specific goals to ensure representation from culturally diverse populations which they target through such strategies as working with community groups, specific one-to-one outreach and translated materials. See page 33 for a more detailed discussion of these strategies.

(We) recruit families every way possible. They may have been a family we worked with, may have been a critic of services, may have worked with a partnering agency, or may have sat on the Governor’s Council.

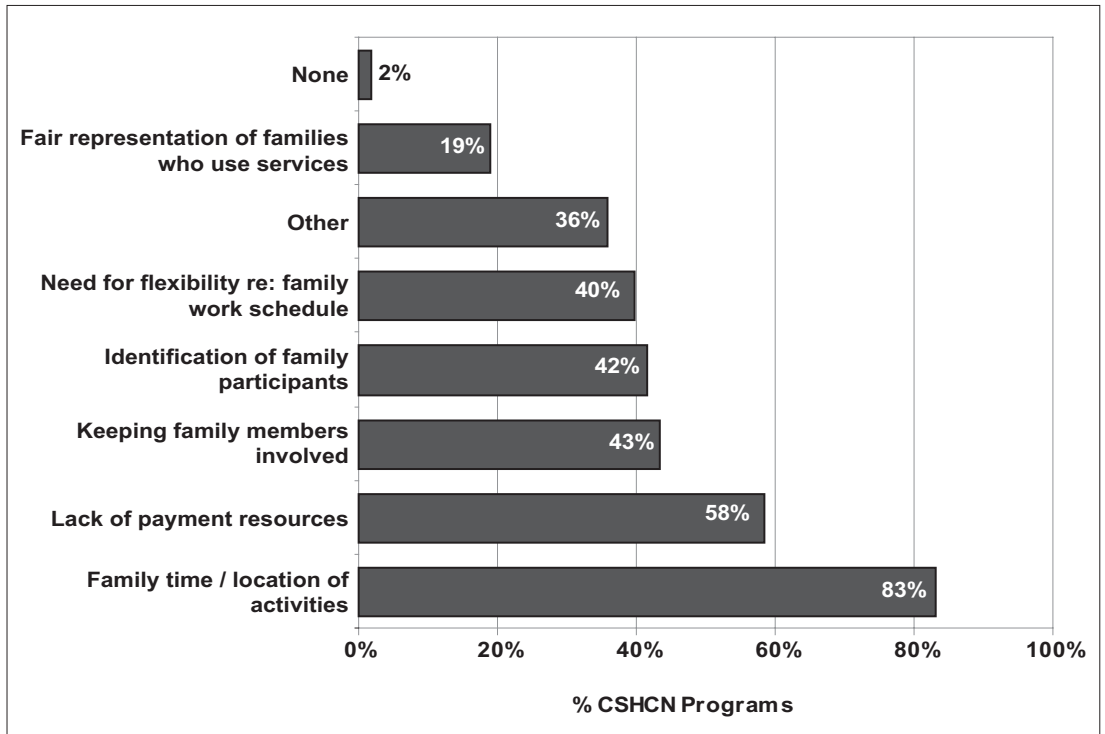
It is very hard to get the families to participate on the committees and not having the money to pay them. Also, the language barrier is challenging.

We struggle with recruitment. We have a core group of families to call upon, but we haven’t seen the benefit of an expanded network of families.

## Obstacles to Involving Families

In addition to the difficulty of identifying families for participation on advisory committees/task forces/groups, CSHCN programs indicated other obstacles.

**Chart 8. Obstacles to Involving Families in Advisory Committees, Task Forces, and Groups (n=53)**



(There is a) gap between what we are asking families to do and the input they can provide. We need to provide more education so they can provide good and meaningful input.

We need to do a better job at cultivating families at the local level and bringing them up for more intensive participation.

The Title V program is very complex and hard to articulate...Families may or may not know that the service they are getting is a Title V service – they may see it as a community based service.

As indicated in Chart 8, families' time constraints or the location of meetings were the most frequently rated obstacle to involving families (83%). More than half of the CSHCN programs (58%) indicated that lack of resources/methods for paying family members for time and expenses was an obstacle to involving families. Keeping family members involved in an ongoing way was indicated as an obstacle by 43% of CSHCN respondents, although this may be related to a family's constraints for time and travel as well as payment for time and expenses. One program indicated that no obstacles or difficulties precluded family involvement. Beyond these identified obstacles, 19 CSHCN programs noted other difficulties to involving families, including language barriers, effective mentoring, finding childcare and transportation.



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# FAMILY INVOLVEMENT IN ADDRESSING STATE PERFORMANCE MEASURES AND SPECIAL INITIATIVES

## State Performance Measures

*91% of CSHCN programs (48/53) reported that families are involved with state performance measures.*

In addition to the National Performance Measures that states are asked to report on in their Title V Block Grant Reports, programs also identify and collect data on seven to ten measures of their own choosing – State Performance Measures (previously called State Negotiated Measures). These measures address state needs, and at least one should address children with special health care needs. The Maternal and Child Health Bureau defines criteria and must approve the measures, which largely remain the same for several years unless a state requests a change. Forty-six of 53 CSHCN programs rated the family involvement in these negotiated measures and the average rating was 2.2 in a scale of 1-3 (1=low, 2=med, 3=high). The range of topics of the measures included access to health care, service coordination, preventive care and screening. Some of the more common methods that programs reported for involving families in these performance measures were through advisory committees, surveys, focus groups, home visits, community health fairs, and needs assessments.

In general (I hate stereotypes), people who rise to levels of program leadership tend to have a high need for control, and parents are potentially a wild card. They make us uneasy-and that's why we have them!

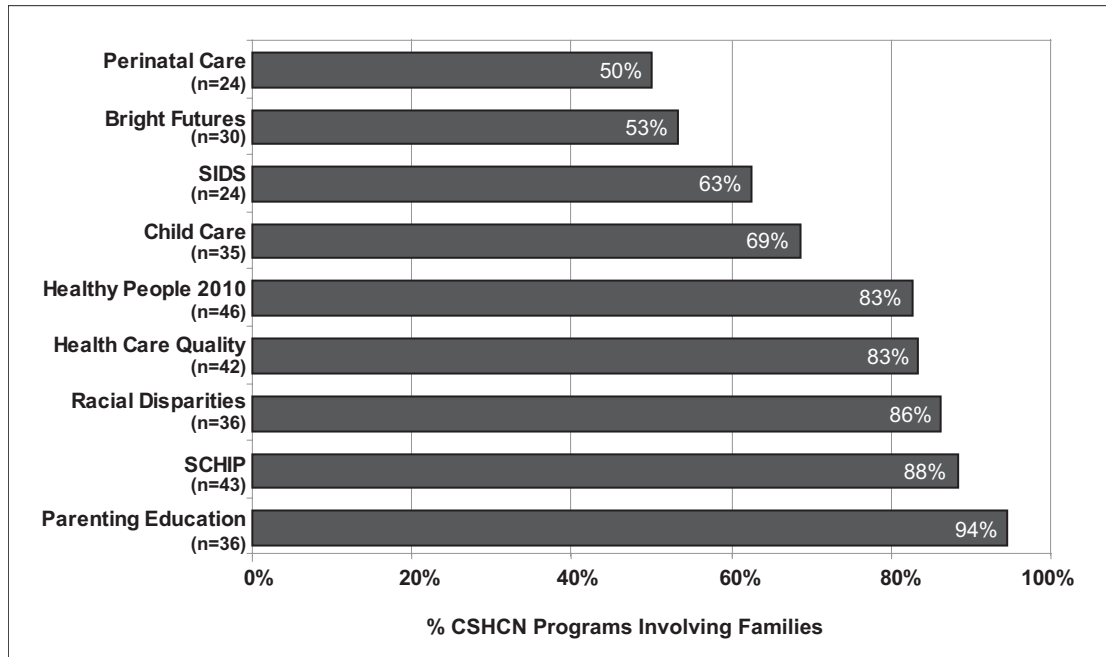
## Special Initiatives

*98% of CSHCN programs (52/53) reported involving families in at least one of their special initiatives to improve maternal and child health.*

As encouraged by HRSA and the Maternal and Child Health Bureau, CSHCN programs address a number of special initiatives that focus on “improving maternal and child health”. In this study all programs reported that they undertake special initiatives and all programs but one noted that they involve families in addressing at least one of their special initiatives. As shown in Chart 9 CSHCN programs vary in their involvement of families in these special initiatives.

Other programs within the (state health bureau) have become more aware of how important it is to have families involved in their decision making and policy making...

**Chart 9. Family Involvement in Special Initiatives (n=53)**



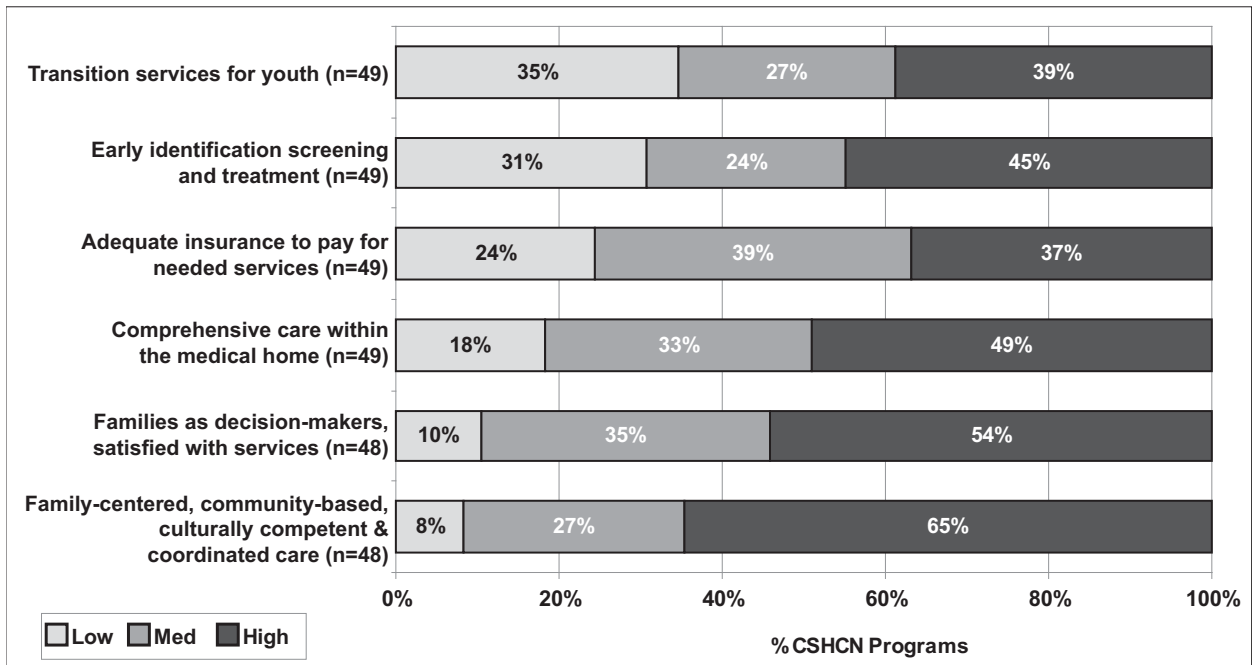
Not all programs address every special initiative, but of the programs that do, Chart 9 shows that at least half of all programs involve families in each of the above initiatives. Parenting Education is the initiative that almost always (94%) involves families. Over 75% of CSHCN programs that address Healthy People 2010, Health Care Quality, Racial Disparities, and SCHIP provide for participation of families. Additional Special Initiatives involving families noted by state respondents included Mental Health, Transition, Medical Homes, Ryan White (HIV Families), Hearing Screening, Early Head Start, and Respite.

## Healthy People 2010

96% of CSHCN programs (51/53) reported involving families in at least one of the six Healthy People 2010 priorities.

CSHCN Directors were also asked to rate the level of family involvement in each of the six 2010 CSHCN priorities.

**Chart 10. Rating of Family Involvement in 2010 Outcomes**



As Chart 10 indicates, CSHCN programs reported the highest level of family involvement in the goals of 1) assuring family-centered, community-based, culturally competent, coordinated care and 2) families as decision-makers, satisfied with services. Programs rated most of the family involvement in these initiatives as Medium or High. The areas that programs ranked as having the lowest family involvement were in 1) pursuing the goals of assuring transition services for youth and 2) early identification screening and treatment.

The 2010 objectives are the framework I use for thinking about where we are going....I think our own experience with families pushes us in the direction of recognizing those objectives.

# FAMILY INVOLVEMENT IN THE BLOCK GRANT PROCESS

100% of CSHCN programs (53/53) reported in 2002 that families are involved in the Block Grant process, up from 90% (46/51) reported in 1992.

We do better work and are more on target in reaching the needs of families. We have more accountability and more thoughtful planning. Having parents of children with special health care needs involved has helped others in MCH recognize the need for parent/consumer involvement in their programs.

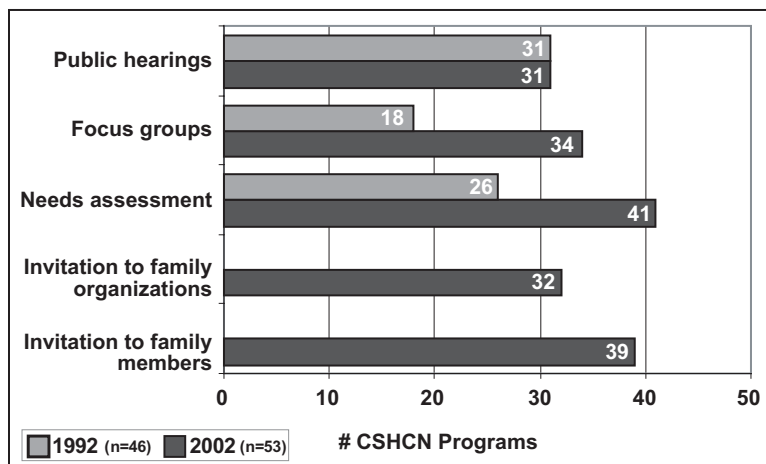
MCHB requires programs to file yearly Block Grant applications to indicate how MCHB funds have been and will be spent, and these applications must be made publicly available for comment from any person within the state. Title V Block Grant Reports and Applications are due in mid-July each year, though programs are engaged in the efforts and accounting throughout the year. The MCH Block Grant application is a complex process. CSHCN programs contribute to this process, along with many others. Programs use varying methods to develop the application and a variety of methods to solicit family input to the process. Responses to questions about the Block Grant process asked in 2002 indicate progress from 1992, both in comfort with soliciting family input and in appreciation of the benefits of family input, while still recognizing the complexity of this goal. Increasing comfort and involvement from both programs and family members with family involvement in the Block Grant process has most likely been influenced both by the federal expectations inherent in a philosophy of family-centered care, and by the specific federal requirements for accountability around family involvement.

The families have an increased understanding of what the purpose of the program is, as well as giving them a sense of having input into developing policies that work for them. This has been a big benefit.

## Methods of Involvement

Interview questions asked CSHCN staff about what specific methods they used to solicit family input for the Block Grant. Where possible, the findings for 2002 are compared to 1992 in Chart 11.

**Chart 11. Family Participation in Block Grant Process, 1992 & 2002**



In 2002, all programs reported utilizing at least one method in seeking Block Grant input from families as indicated in Chart 11. Each of the above methods was utilized by over half of the 53 states/territories responding to the questions.

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The method indicated by the most CSHCN programs (41/53) is a needs assessment. Another method frequently used by programs to involve families is through invitations to individual families to review the Block Grant (39/53). In comparison to findings from 1992, the use of focus groups showed the largest increase (from 18 programs to 34 programs), while involvement in needs assessment increased from 26 to 41 programs. Public hearings was reported by the same number of programs (31) in both 1992 and 2002. Specific examples of methods for involving families noted by programs include having Family Advisory Committee members involved in the development and review of drafts of the Block Grant, involved in developing and disseminating needs assessment tools and assisting in analyzing findings. Fifty-nine percent of CSHCN programs indicated that they had invited a parent or family member to attend their regional Block Grant Review.

## **Rating Family Participation (Form 13: Constructs of a Service System)**

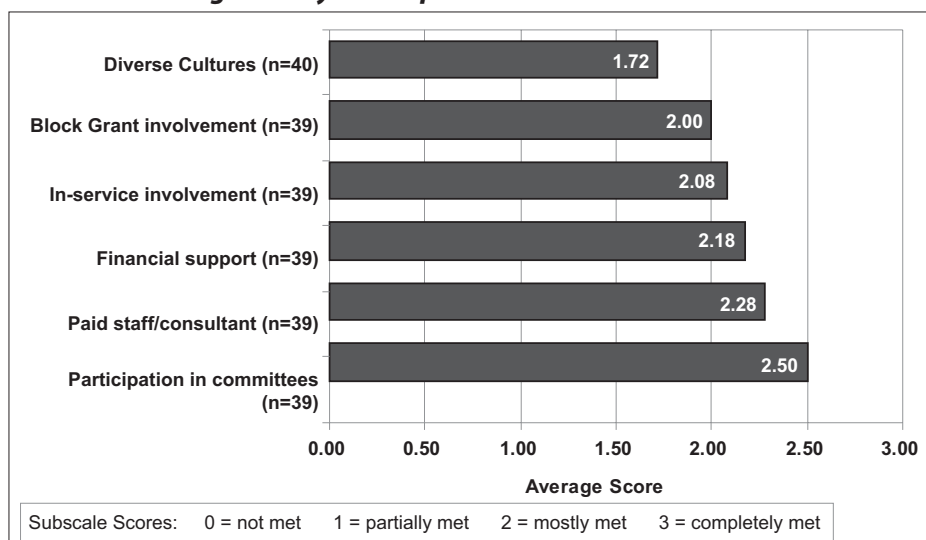
Performance Measure 14 (Form 13: Constructs of a Service System) requires programs to rate themselves in the Block Grant along six aspects of family participation. The 2002 study asked the CSHCN respondents to indicate how they determine their scores. Of the 45 programs that responded, 22 (49%) indicated the score was determined internally by staff within the program, one program (2%) indicated the score was determined by staff or consultants from other programs, and 22 (49%) indicated the score was determined by a combination of both methods. Programs described a variety of methods used for determining various sub scores. These included surveys, data collection & analysis, discussions with parent advisory committees and regional staff, focus groups, telephone interviews, meetings, or as part of a state contract with an external family organization.

After a review of what we had done for the whole year, I gave it (Performance Measure 14: Form 13) to the FAC (Family Advisory Committee) and asked them to discuss it, fill it out. Our scores varied by 3 points, mine being higher.

There was no specific method used except review of scores and discussions from previous years .

CSHCN programs provided subscale scores ranking their family participation as shown in Chart 12.

**Chart 12. Average Family Participation Subscale Scores**



In the past scoring felt like guessing as it was very subjective. This year felt more objective as (our parent consultant) had input from some parents around the state. (She) is now working on ways to measure each of these more objectively.

In general, CSHCN programs reported high marks on these elements. On average, the highest ranked subscale score was for family participation in committees (2.50) and the lowest ranked subscale score was for family participation from diverse cultures (1.72).

Although the federal requirement of states to specifically report on family involvement in their programs has clearly raised awareness of the importance of these activities, programs noted that they do not have specific guidance as to how to arrive at their scores.

In response to more directives from the federal level, our state is now able to address family involvement.

## Benefits & Difficulties of Involving Families in the Block Grant Process

CSHCN staff were asked to identify benefits to their program from having families involved in the Block Grant process. Programs indicated a number of benefits, summarized in the following categories:

- Families identify programs' strengths and weaknesses,
- Families help set priorities in planning programs,
- Families provide feedback on program family-centeredness,
- Families help programs comply with Performance Measure 14 (Form 13),
- Families provide 'real-life' measures, and
- Families help develop parent-professional communication and relationships within Title V.

Many CSHCN programs also mentioned benefits that they believe family members receive from being involved in the Block Grant Process. They noted that through participation, families are better able to understand the department,

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services and supports and also learn about program constraints. Participation broadens parents' understanding of Title V and what changes are needed in programs, resulting in families who are empowered to be more effective in working with legislators.

CSHCN respondents were also given the opportunity to discuss their perceptions of the difficulties or obstacles of involving families in the Block Grant process. The overwhelming comment was that the Block Grant is very long and difficult to understand, rigid in its format and bureaucratic in its language. Some programs mentioned that it should be worked on consistently for at least a year but that such a prolonged time frame makes it difficult to find families who can commit time to such a lengthy process. Families of CSHCN are constrained by time, travel, and child-care. Some families may also be reluctant to participate because it can be hard to identify how the lengthy Block Grant process relates to the needs and services of their child. Identifying parents of diverse background to participate may be difficult because of complexity, language and cultural barriers.

Despite these obstacles and programs' comments about room for improvement in the process, many programs seemed confident that they were involving families in the Block Grant in beneficial ways. They appreciated the guidance that MCHB has provided to programs to encourage the inclusion of families and to recognize the benefits of doing so. Many programs acknowledged that they are improving in their capabilities to do this effectively, and look forward to further improvement in the future.

- We train families to be reviewers of the grant. There is increased respect for families.
- ...next year we will gather comments on the block grant via a web page.
- The biggest obstacle is getting the document to families in a form they can understand. The document is overwhelming.

# FAMILY MEMBERS EMPLOYED BY CSHCN PROGRAMS

It is really beneficial. The family advocates at the centers are involved in a lot of activities that we don't necessarily hear about. They've made the program more community based. They bring us "sanity" to the way in which we think...

83% of CSHCN programs (44/53) reported employing family members as staff or consultants in 2002, up from 41% (21/51) in 1992.

One method to assure family involvement in CSHCN programs is to hire family members as staff or consultants.

**Chart 13. CSHCN Programs that Employ Family Members**

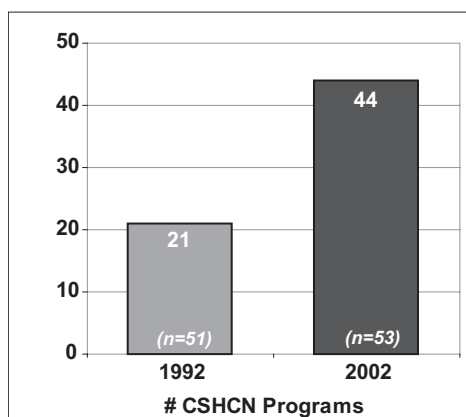


Chart 13 indicates that the number of CSHCN programs who employ parents has more than doubled from 21 in 1992 to 44 in 2002. These 44 CSHCN programs indicated employing parents in a variety of positions (some programs reported employing in more than one way): 23 employ parents as staff, 25 employ parents as consultants, 9 employ family members through a contracting parent organization or agency. The difference between the terms "staff" or "consultants" appeared somewhat artificial. Programs sometimes involved

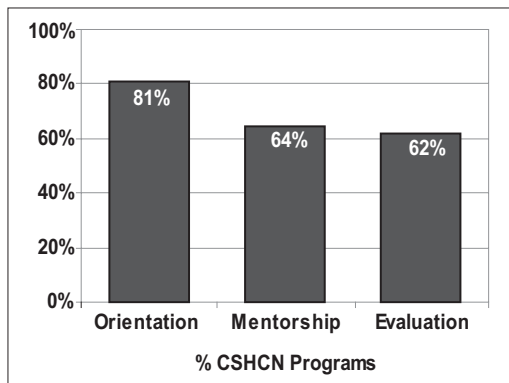
It was difficult hiring the first one. The culture here was very opposed to the idea, worrying that they wouldn't be able to talk freely.

families as consultants for ease of hiring or to circumvent state requirements that families might be unable to meet. In other cases families were hired through another agency, often a parent organization, to ensure that the family employee had ready access to a "family rich" environment with information about current family issues and resources. Position titles and responsibilities were similar, regardless of the "contracted" or "staff" designation. Twenty-eight CSHCN programs reported on the number of parents that they employ which ranged from 1 to 45.



CSHCN staff also reported on assistance provided to employed family members in order to help families succeed in their roles.

**Chart 14. Assistance Provided to Family Members Employed as Staff or Consultants (n=42)**

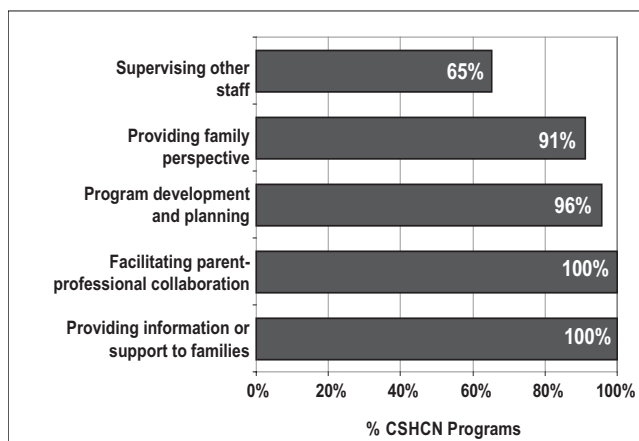


Staff from 42 CSHCN programs reported on assistance provided to employed family members. More than half of all responding programs indicated that they provide orientation, mentorship and evaluation.

We have a kind of Affirmative Action policy of hiring...when we have positions open for anything...we consider personal experience with disability as part of the whole package...even for positions that aren't specifically focused on the hiring of the parent with special health care needs...From the top there's an intent to include a parent perspective in everything we do.

The 23 CSHCN programs that employ family members as staff rated components of these positions.

**Chart 15. Responsibilities of Family Members as Staff (n=23)**



As indicated in Chart 15, in the CSHCN Programs who employ parents as staff, most or all consider the role of the family member to provide information and support to families, to facilitate collaboration between families/family organizations and state Title V programs, to assist in program development and planning for families,

and to provide a parent/family perspective to Title V. Sixty-five percent of CSHCN programs employing parents as staff reported having a parent in a supervisory role. Other important components of a Family Staff position were specified as:

- Recruiting, training, and expanding the network of families serving in advisory capacities for various initiatives, such as focus groups, Block Grant review, conference participants and presenters, and
- Representing the CSHCN Division on other committees (such as a Safety Committee), and providing consumer input for the agency Strategic Plan.

We train (parent consultants) to be able to feel comfortable in bringing in information from the community...and many times this is taken into consideration.

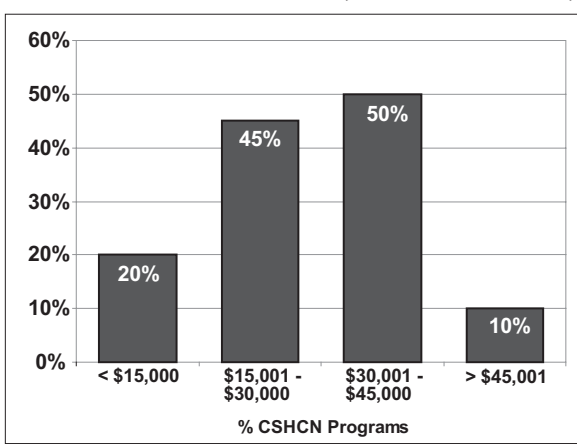
We employ them through (a statewide parent organization)... and that has turned out to be an enormous strategic boon for us – that has given these parents a little breathing room between themselves and the department.... And strengthened the family organization by expanding its scope within health care.

(Our state) has a paid parent consultant who works with (a number of) Parent Consultants throughout the state.... This type of contract allows the state to write the job description to include only parents of children with special health care needs.

Using an outside contract with a parent organization is an efficient and effective method of addressing our own policy needs and ensuring parent participation at all levels.

Some of the more common job titles for families employed as staff are Parent Consultant, Family Consultant, Family Advocate, Family Advisor, Family Liaison Specialist, and Parent Resource Specialist.

**Chart 16. Salaries of Family Members Employed as Staff (n=20)**

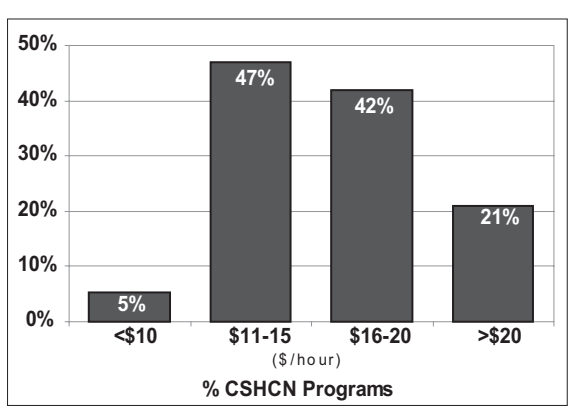


Of the 23 CSHCN programs that employ family members as staff, 22 provided information on employee status: 8 employ parents full-time, 7 employ parents part-time, and 7 employ parents in both part-time and full-time positions. Of programs that employ parents as staff, 20 provided information about full time equivalent salaries for employed parents in various positions. These are shown in

Chart 16. Programs were asked to check all categories that applied. The vast majority of salaries ranged between \$15,000 and \$45,000.

### Family Members Employed as Consultants

**Chart 17. Hourly Wages for Family Members Employed as Consultants (n=19)**



Twenty five CSHCN programs reported employing family members as consultants, either directly or through an agency. Of these 25, 19 CSHCN programs provided hourly rate information for parents hired as consultants. This information is shown in Chart 17. Similar to parents hired as staff, parents hired as consultants typically have such job titles as Parent Consultant, Resource Parent, Family Advocate, Family Consultant, Parent Peer Consultant, and Parent Network Specialist.

Family Advocate, Family Consultant, Parent Peer Consultant, and Parent Network Specialist.

There has been much growth in the past ten years in hiring families for their expertise as family members and in paying family members for their contributions. However, programs are definitely still working on the best ways to hire family members within state systems and how to best use the talents and resources of families and family organizations to meet their program goals. As described above, the way the family member is hired - as a consultant, staff or through a family organization - may reflect a convenience for the state program or be the only way a family member can be paid within the state government

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hierarchy. The responsibilities assigned or hours worked by the family member seemed to be similar regardless of the manner in which they were reimbursed (as a permanent employee or contractor). Contracting through another agency might give the state flexibility in the kinds of qualifications needed for the position or in the type of activities that can be undertaken by a family member. In addition to the 44 programs that indicated they have hired family members as staff or consultants or through contracts with parent organizations, three more programs indicated that they pay families for time or services, assumingly on a more periodic basis. For further information about hiring families, check the examples of job descriptions and job titles and reports on this subject posted on the *Family Voices* website at [www.familyvoices.org/toolbox](http://www.familyvoices.org/toolbox).

## **Suggestions for Hiring Family Members**

CSHCN programs were asked what suggestions they would make to other programs that are considering hiring family members, based on the obstacles or benefits their program has encountered. The most frequently mentioned suggestion for hiring and keeping family members is for the state programs to be flexible. Parents of CSHCN often have time constraints due to caring for their children. Programs are more able to retain parents as staff if they can adjust to a parent's time constraints. Other recommendations from experienced CSHCN respondents included:

- Look for parents of diverse culture by utilizing non-traditional methods – develop relationships with specific non-profits, special education directors, and faith-based community organizations,
- Work with a parent organization to provide a broader family perspective,
- Provide specific job descriptions and responsibilities,
- Provide training and on-going professional development, and
- Hire consultants rather than staff as this helps with flexibility.

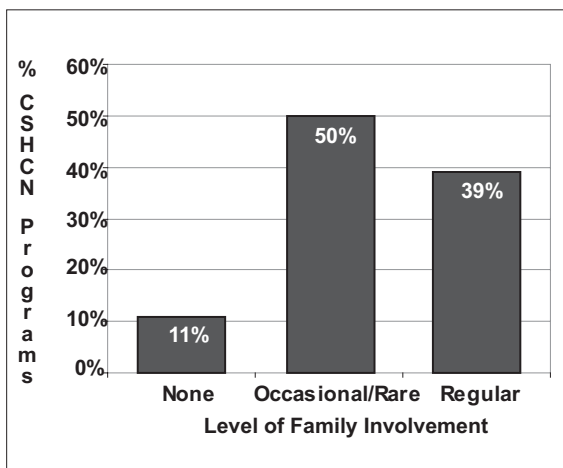
# FAMILY INVOLVEMENT IN IN-SERVICE TRAININGS

89% of CSHCN programs (41/46) reported involving families in in-service trainings in 2002, up from 69% (35/51) in 1992.

CSHCN programs were asked to rate the level of family involvement in in-service trainings and these results are shown in Chart 18.

**Chart 18. CSHCN Programs Involving Families in In-Service Training (n=46)**

Parents develop materials, participate in strategic planning, community assessment and training of lay and professional groups.



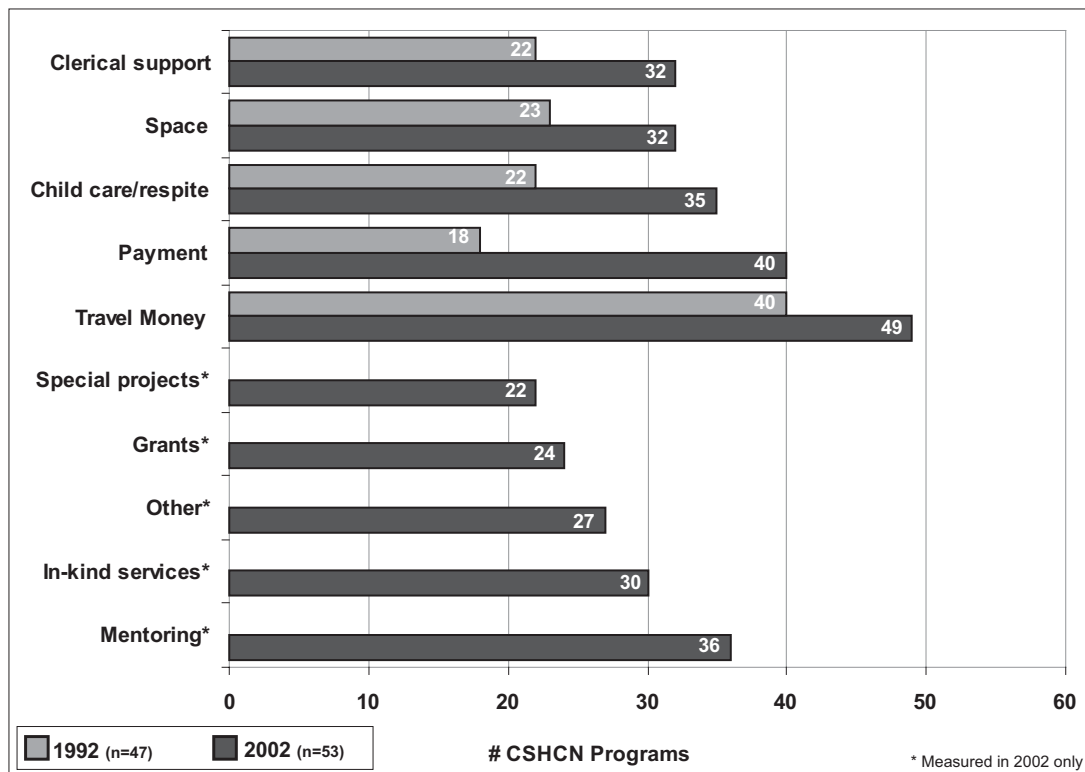
Involvement of family members in in-service training is reported by 89% of CSHCN programs in 2002, an increase of 20% (6 programs) from 1992. Thirty-nine percent of programs in 2002 reported that this involvement occurred regularly while 50% noted that it was occasional or rare. Families were reported to have no involvement in these trainings by 11% (5) CSHCN programs in 2002.

# SUPPORT PROVIDED TO FAMILIES AND FAMILY ORGANIZATIONS

100% of CSHCN programs (53/53) reported that they offer support to families who participate in Title V program and policy activities and 98% (52/53) reported that they offer support to family organizations in 2002, up from 92% (47/51) in 1992.

The types of support provided to facilitate family participation are shown below, comparing findings from 1992 and 2002 where applicable.

**Chart 19. CSHCN Programs Providing Support**



As illustrated in Chart 19, findings in 2002 indicate an increase in all areas of supports provided to families or family organizations since 1992, the most significant being an increase in the number of CSHCN programs providing payment to families for time and services rendered, from 18 programs to 40 programs. The most frequent area of support provided was travel money for meetings, conferences, etc. as indicated by 49 (92%) of CSHCN programs. Recognizing the importance of mentoring to assure effective family participation, 36 (68%) of programs reported providing this form of support. Child care and respite support, indicated as an important tool for supporting the participation of families of CSHCN, was reported by 35 (66%) of CSHCN programs.

In 2002, all but one state indicated that they provide support to family organizations. More than half the CSHCN programs (32) indicated providing office space and clerical support to participating family organizations. Many CSHCN respondents also indicated that other supports, such as Special Projects (22), Grants (24), and In-kind Services (30) are provided. CSHCN staff also

(We) recommend their (family members) inclusion in the development of policy and program so that when we are working with our sister agencies who don't normally include family organizations, we try to do things to ensure that family organizations are included in their activities.

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We have meetings at different times of the day—early morning, during the day, and evening meetings. Families have so many demands on their time; families with really compromised children have really full plates. We often offer care for the children during the meetings—something for them to do, and there are trained people available. We pay for people to attend meetings, give them mileage, and per diem expenses for long travel. When families can not attend meetings we go to them and conduct key informant interviews. As we are sincere about wanting family participation we have to do what we can to remove the barriers.

frequently mentioned other supports that they provide including lodging and meals when necessary, helping parents find jobs, writing support letters for family organizations, acting as a fiscal agent for grants, assisting with conference planning, sending family members to national conferences and providing training in grant writing.

The amount and kind of funding and other supports that CSHCN programs are providing to families and family organizations and the number of programs providing such support has grown exponentially in the past 10 years. This is certainly now an important factor in ensuring family participation to CSHCN programs.

(We provide) recognition of their (family members) contributions. . . . We have bi-annual meetings and five people awards. As groups are reporting and as we introduce people, we talk about the contributions of the individuals and the groups. We do things to honor people. It is important. Sometimes we get so caught up in the “battle” that we forget to recognize that we’ve done something. People need to have time to really let it sink in all that they’ve accomplished. They need to feel like they have group approval and thanks for all the hard work they’ve done.

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# STRATEGIES FOR OBTAINING INPUT OF UNDER-REPRESENTED AND UNDERSERVED POPULATIONS

CSHCN programs were asked to provide examples of particular strategies they used to obtain the input of underrepresented and underserved populations. Although CSHCN staff indicated that it was difficult to obtain such input, they were well aware of the essential need to do so. They provided a variety of outreach strategies, beginning with establishing a trusting relationship with groups that represent diverse constituents. Without building such relationships, underserved groups will most likely be reluctant to communicate their concerns and needs. This priority of developing a trusting relationship is often incorporated into the strategies used by the CSHCN Program. These strategies include:

- Recruiting of families from different ethnic backgrounds as family advisors, often identified in the process of using services,
- Working with contracted facilitators and other individuals, including people from schools, advocacy groups and faith-based organizations, who have a relationship with particular groups,
- Employing staff from various ethnic backgrounds and bilingual abilities, and
- Working with other state programs who have established a relationship with a minority community.

Put the need for outreach in a contract whenever possible.

We work on ongoing trust-building, especially with the Native American population. It's a process that does not occur overnight.

We have used facilitators with focus groups who have worked with underserved populations.

CSHCN programs also employ a variety of strategies that focus on communication with underrepresented and underserved populations. These include:

- Translating materials and providing interpreters,
- Running focus groups targeting specific underserved groups in their own community, and
- Using a variety of mediums for outreach: media, radio, TV, print, schools, hospitals, clinics, agencies, phone surveys, health fairs, etc in appropriate languages.

• This is a challenge. There is no really good way to know if you are getting the kind of penetration into these communities that you really want to have. We have a very diverse group of parent consultants, but this is subjective!

• Recognize this as an issue. Very difficult to identify parents. Also, reimbursement system prohibits involvement of underserved parents.

Some CSHCN programs address the issues of outreach through their programs' infrastructure. Mechanisms built into their program which focus on funding and training to improve outreach to underserved and underrepresented communities include:

- Providing training and conference opportunities about outreach strategies for parent consultants, including learning about successful strategies from other programs,
- Providing transportation for families of underserved communities to attend meetings and assuring that translation and interpreter services are available,
- Making calls to underserved communities to request specific feedback,
- Providing incentives such as pay, coupons, food, etc. to participants providing input, and
- Specifying outreach activities in contracts.

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# FROM THE VIEWPOINT OF FAMILY MEMBERS

... We have learned what a tribute each of us can give to the other. ....there are (number of employed parents in the state) so we each know our territories and their cultural differences. For the most part we work very well together with the (staff) of the CSHCN program. As with any new program, there is the "growing" period of time. It is a wonderful feeling when the Directors of (names of several state agencies and programs) all have given parents and families the chance to be recognized as valuable team members.

The information presented in the prior sections of this report summarizes how state CSHCN programs characterize family involvement in their programs. It is also helpful to look at family involvement with CSHCN programs from the perspective of family leaders in the states. In order to do that, a brief questionnaire (see Appendix E) was sent to *Family Voices* leaders in each state, covering many of the same topics as covered in the CSHCN program questionnaire. Family leaders from 38 states provided responses.

Overall, *Family Voices* leaders indicated that they were knowledgeable about family participation in their CSHCN program. Respondents were asked about their working relationship with the CSHCN program. About one third said they had a close working relationship with the CSHCN program and that they rely on each others' expertise and support. This group also noted that families and family organizations were involved in most CSHCN program activities. Half indicated that they sometimes work together and are familiar with each others' programs. Approximately one sixth said that they did not have a close working relationship with their CSHCN program, rarely consulted with each other, were not knowledgeable about each other's activities, and that families and family organizations were not really involved at the program and policy level with their state CSHCN program.

Lack of (families employed) means (program staff) have to work hard to meet with family folks at all levels. This can be good, but having someone on the inside as a paid person would be the BEST answer to including families.

All *Family Voices* leaders who indicated a close, working relationship with the program rated family involvement as medium to high in increasing awareness and understanding of family issues/needs and establishing a base for a strong coalition for change within the program. Ninety percent of those that indicated a close working relationships with the program said that family involvement led to a medium to high degree of benefit in improving planning and policies resulting in services more directly responsive to family needs. Correspondingly, of the family respondents that noted their relationship to the program was distant, 100% said that the program had a low degree of benefit from family involvement in the areas of increased awareness and understanding of family issues/needs, establishing a base for a strong coalition for change within the program, and improving planning and policies resulting in services more directly responsive to family needs. On the whole, family respondents felt that a more integrated relationship between programs and families resulted in a higher degree of benefit to the program.

It is important to clearly define roles. In (our state), staff want family members' opinions, but the planning process is NOT where parent employees are involved.

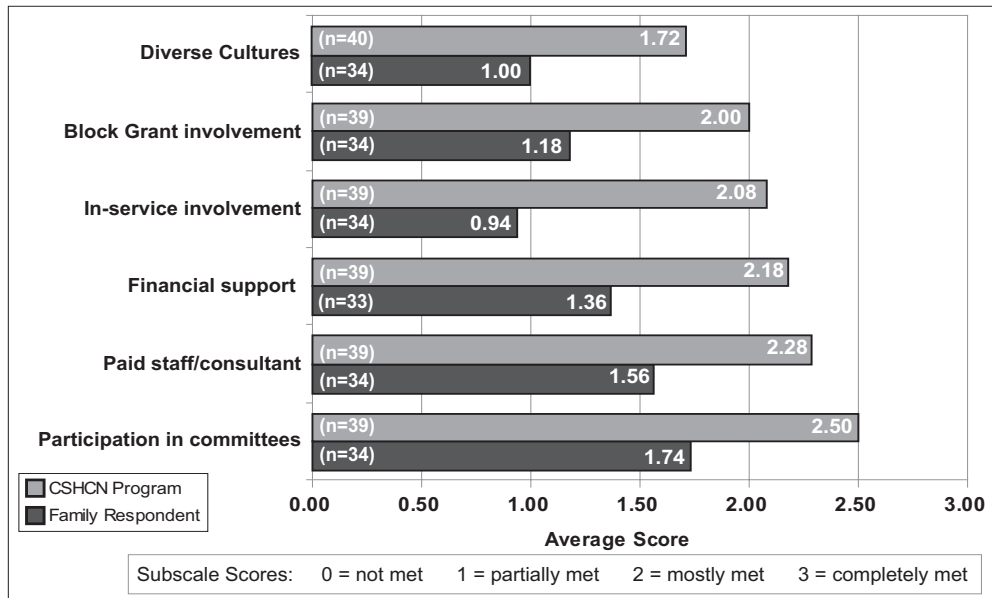
## Rating Family Participation

Parallel to the responses from CSHCN programs, family respondents were asked to rank their state CSHCN program on each of the elements of the MCHB performance measure related to family participation (Form 13). Rankings from family leaders were similar to rankings from CSHCN programs as shown in Chart 20, although family respondents consistently rated the Form 13 elements lower than did the programs. Both groups gave the highest rating to involving family members on advisory committees/task forces, closely followed by financial support for parent activities or parent groups and hiring paid staff or consultants to the state CSHCN program (for their expertise as family members). Family respondents ranked involvement in in-service trainings as the lowest, with an average score of .94, indicating that this element was rated slightly less than partially met.

The ability (of employed families) to express their true opinions without the fear of being fired could be accomplished by hiring parents for Title V through parent organizations therefore buffering their positions.



**Chart 20. Family Scoring of Family Participation (Form 13)**

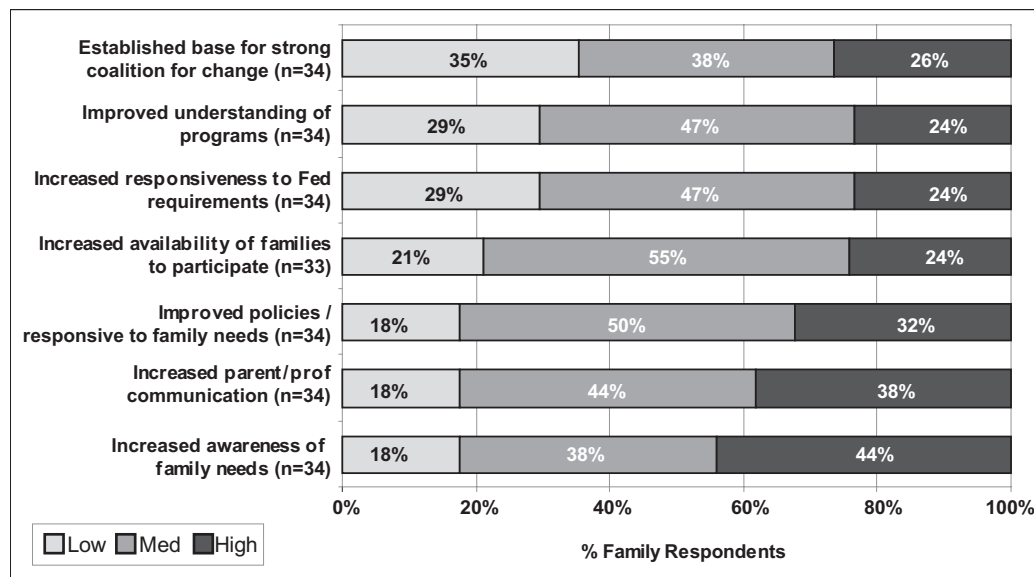


### Family Viewpoint on Benefits of Family Involvement to CSHCN Programs

Family respondents were also asked to rate the degree to which family involvement had benefited their state CSHCN program.

Families carry a strong voice in policy formation . . . .by employing families you are demonstrating an equal partnership and compensating people for their expertise.

**Chart 21. Family Ratings of Benefits of Family Involvement**



Parent ratings, although lower than program ratings (see Chart 5), follow a similar general pattern, with some exceptions. Parallel to state responses, family respondents rated family involvement as having the most impact on increased awareness and understanding of family issues and needs and increased parent/professional communication and services more responsive to family needs. Families, like programs, indicated that family involvement had less of an impact in establishing a strong coalition for change.

Employing families has the impact of . . . providing a constant presence, opportunities for informal discussion, assistance with resources and thinking of families' perspectives.

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Additional benefits of family involvement noted by families paralleled sentiments expressed by professionals in CSHCN programs: increasing awareness, increasing program responsiveness to real issues, and increasing relevance of program activities.

A regular consistent funding stream to support Family Voices or an organization employing families to sit at policy tables would give us the stability to train and mentor others, as well as develop families from diverse cultures to understand policy, learn and become involved.

States should receive directives from MCHB DSCSHCN regarding mandated family involvement components. MCHB should assign professional "mentors" to Title V directors (for parent involvement). Instead of a checklist on the Block Grant application, states should be mandated to provide documentation to support their self-ranking.

Have a defined career path, job descriptions, and roles for parents with and without formal academic preparation. Include CEUs for parents in training opportunities. Publicize pay scales, and develop mechanisms for equitable compensation. Provide equal access to employee benefits. Allow flexible working arrangements...such as hardware and software for home office set ups.

The impact of families has diminished as their role has become more defined by representing their hospitals and state agency (rather than by representing families). The paid parent positions have ceased to be a catalyst, and the parents are no longer truly challenging and moving systems development. It's an ongoing problem when hiring parents within an agency. For whom do they really work????

## Family Viewpoint on Support Provided to Families and Family Organizations

Roughly parallel to CSHCN staff responses, *Family Voices* respondents indicated that many CSHCN programs are providing support through payment for time/services, travel money to meetings, mentoring and child care/respite money. However, the family respondents also identified many difficulties and obstacles to involving families effectively, primarily time constraints on families, location of activities, lack of resources for paying family members, difficulty in keeping family members involved and assuring fair representation of families who use services. They worried that involved families are looked upon as the exception and that the potential for broader family participation is not yet fully recognized.

## Ideas for Improvement

*Family Voices* respondents offered a number of ideas for increasing and improving family involvement with CSHCN programs including:

- Providing further mandates and guidance from MCHB on family involvement,
- Making family involvement a priority, a commitment in each state,
- Encouraging all CSHCN programs to believe in and respect the benefits of family participation,
- Committing more resources to support family involvement and outlining effective mechanisms to use resources to support this involvement,
- Making concentrated efforts on outreach/awareness,
- Providing more training for both family members and professionals,
- Providing flexibility/variation in meeting times/locations to accommodate working families,
- Encouraging partnerships with family organizations, and
- Developing models of effective mentorship.

## Impact of Family Employment on CSHCN Programs

*Family Voices* respondents were well acquainted with how their programs employ family members; in a few cases, they were the employed parent. Respondents noted a number of positive effects that employed family members have contributed, including

- being effective at changing policies,
- becoming an integral part of policy and procedure committees,
- helping programs understand the family perspective on needs and delivery of services,

- providing assistance to other families,
- helping to make materials more family-friendly,
- increasing information sharing within programs and to other families,
- improving communication and trust,
- assisting with team building within programs,
- increasing referrals to CSHCN programs, and
- assuring more common sense approaches and efficacy in problem solving.

Family leader respondents warned that a danger of the increased employment of family members is that programs may feel that their obligations for parent involvement are complete when improvements still need to be made.

We pushed for them to contract (employed parents) through (parent organizations) so the (employed parents) could hold on to their identity and get input from their (parent organization), have better access to matching families with community based support and family services. We believe it has kept the (employed parents) honest and able to really speak on behalf of the families, enabled them to bring more resources to the table, improved relations through cross training.

## What is Needed to Support Family Members as Employees

Several family respondents felt strongly that families should be employed by an outside agency. They noted that this type of relationship provides distinct differences and potential benefits as compared to families employed directly by CSHCN programs. Families employed in this way are in frequent contact with other parent leaders in similar positions and benefit from the mentorship, support, knowledge, and ongoing activities provided by the family organization. Similarly, CSHCN programs benefit from the relationship with a family organization that can provide a continual and diverse source of consultants. Parents employed by family organizations may also feel better able to express family perspectives and opinions.

(I) feel strongly that families should be employed by an outside agency. It allows more flexibility.

Further suggestions from family respondents include:

- involve parents in the planning process for hiring families,
- provide more resources to hire family members,
- provide more training and support for family members in paid positions,
- allow flexible work arrangements,
- ensure competitive pay and benefits,
- have clearly defined job expectations and roles,
- provide room for parents with and without formal academic preparation,
- assure provision of satisfactory, productive work by helping with space/equipment/supplies,
- build a network of families from which to recruit, utilize the *Family Voices* network, and
- care about the employed families.

I truly think it is easier for the family person to work to their capacity if they are provided the job of "parent". It was difficult for one of our parents to maintain perspective when asked to also be, "the systems, and state agency." Family's have a unique insight and perspective. The (employed families) needs security with flexibility in a job, but have an ability to impact systems change without repercussions. Tricky, but not impossible!

Family respondents clearly recognized the enormous progress that has been made in involving families in program and policy activities of CSHCN programs while at the same time offering ideas for how to improve such involvement.

Work more closely with Parent Centers on parent mentoring and leadership opportunities. Provide stipends and childcare for Parent Center trainings and activities.

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# INSIGHTS AND RECOMMENDATIONS

The following insights and recommendations are drawn from the comments and data supplied by both state and family leaders. They are intended to provide guidance to state CSHCN programs, MCHB and family leaders on ways to continue to improve family-centered services and programs through enhancing family/professional partnerships.

1. The leadership provided by the MCHB Division of Children with Special Health Care Needs is recognized by both state programs and family leaders as critically important in fostering the growth of family/professional partnerships and family-centered care. Such encouragement should be continued and expanded in a variety of ways through MCHB priorities, publications, grant funding activities and guidance.
2. CSHCN Programs and families clearly report considerable growth in the participation of family members in the Block Grant process, despite its complexity. Additional guidance from MCHB about involving family members within this overall process is needed to continue to build on this progress.
3. There is an evident gap between ratings given by families and programs regarding the Block Grant questions on family participation. Both program and family respondents requested that MCHB provide more explicit direction on how to measure and substantiate family participation, including guidance about how to include family perspective in completing Form 13.
4. Training and opportunities provided by MCHB for families to participate in Block Grant review teams has demonstrated the value of and provided impetus for including the family perspective in Title V programs. This kind of family participation should be widely acknowledged and advertised, continued and expanded.
5. CSHCN programs, families and family organizations have benefited from the sharing of information, strategies, and tools at meetings and through publications, special initiatives and the *Family Voices* Title V Toolbox. Ongoing support for this kind of exchange should be continued and expanded.
6. Both programs and family leaders noted that progress in family/professional partnerships within CSHCN programs have influenced other programs and services within their states. Successes, models and best practices in this work should be advertised and shared widely with other divisions within the MCHB, with other bureaus of the department and with other federal agencies.
7. State Title V CSHCN Programs and family leaders recognize that the inclusion of families of diverse cultures is essential in building responsive programs. Dissemination of ideas about effective strategies for ensuring the inclusion of families of diverse cultures should be widely shared.

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8. Both State Title V CSHCN Programs and family leaders noted the importance of regularly recruiting, educating and mentoring new families to participate in program and policy level activities. Programs should be encouraged to build relationships with established family organizations within states, and to enlist their help in recruiting and mentoring new families in order to continually renew the pool of family members available for involvement.
  9. Partnership through shared grant writing, joint sponsorship of conferences, and materials development were mentioned by both programs and family respondents as valuable opportunities for enhancing family-centered care. Incentives to encourage the joint undertaking of these kinds of activities within states should be promoted.
  10. Recognition of the value of family participation through providing payment for parent time has become widely accepted as an essential element in building effective programs. However, programs and family members also expressed some cautions about families in paid positions, such as the potential that having a position within the CSHCN program sometimes compromises a family member's ability to express divergent views. Ongoing dialogue and opportunities to exchange information about the experiences of these family members in employed positions will support continued improvement of these models.
  11. A number of state and family respondents commented on the value of strong relationships between family organizations, such as *Family Voices*, and CSHCN programs. Family organizations provide access to a large number of families for participation, help recruit and mentor family members, and provide outreach into communities. Family organizations are often networked with other family organizations and agencies to facilitate communication of important information. Relationships with family organizations should be fostered and promoted by CSHCN programs.
  12. Family-to-Family Health Information Centers (F2F HICs) provide assistance to families and professionals and are specifically chartered to promote partnerships between families, Title V programs, and other key stakeholders. Family Voices has engaged in a number of activities to link and support the current F2F HICs. As the number of F2F HICs increases, they need to continue to be connected with each other and supported through a national family-run technical assistance center.
  13. State Title V CSHCN Programs and family leaders both noted the value of providing recognition and celebration of the important contributions of family members and professionals to this collaborative work. Respondents noted public recognition at meetings and awards focused on such partnerships are methods that help to provide support for these initiatives.



# TITLE V TOOLBOX FOR FAMILY PARTICIPATION:

## A Web-Based Repository of State Resources to Support Family/Title V Collaboration

The *Title V Toolbox for Family Participation* provides a central forum for states and families to learn about existing models and methods for involving families in Title V programs. It is also a place where states that have been successful in developing working partnerships with parents can share their expertise to support fledgling efforts in other states. As one family coordinator in a state health department said of this project, "I wish this [resource] had been available to me three years ago when I started."

### Types of Toolbox Resources

The *Title V Toolbox* shares resources for supporting family participation, such as:

- Mission statements and policies of individual state MCH and CSHCN programs
- Family advisory committee development tools
- Tools for employing parents as consultants or staff
- Information on contracts or examples of contract language

Resources on measuring state performance such as:

- Needs assessments and focus group tools
- Block Grant review materials
- Materials to help family members understand Performance Measure 14 (Form 13)

The Toolbox also contains examples of family friendly information developed by states and others such as:

- Resources to educate families about Title V
- Samples of family friendly information to offer guidance to families

General information and useful links are also provided to help families learn more about Title V and ensuring cultural competency. The *Toolbox* also provides an easy to use mechanism for submitting materials for posting, allowing a continually renewable source of valuable resources.

### Finding the Toolbox

The *Title V Toolbox* is located on the *Family Voices* website at <http://www.familyvoices.org/toolbox>. The *Toolbox* is also linked from the *Family Voices* homepage.

### Use of the Toolbox to Date

The *Toolbox* was launched in Spring, 2003 and has averaged over 1,200 web hits per month.

<http://www.familyvoices.org/toolbox>

The screenshot shows the homepage of the Title V Toolbox. At the top, there is a navigation bar with 'Family Voices | Home | Contact Us'. Below that is the title 'Title V Toolbox for family participation'. A welcome message follows, stating the purpose of the toolbox. The main content is organized into several sections: 'Find Materials by Category' with a search link, 'Supporting Family Participation' (listing mission statements, advisory committees, employment tools, and contract information), 'Measuring State Performance' (listing needs assessments, block grant materials, and performance measure 14), and 'Providing Family Friendly Information' (listing title v information and examples of resources). There is also a 'More About Title V' section with sub-sections for 'What is Title V?', 'Performance Measure 14 and State Negotiated Measures', and 'Families in Program and Policy: A Survey of State MCH and CSHCN Programs'. The footer features the 'FAMILY VOICES' logo and the text 'Feedback | About Family Voices | MCH'.

## SUGGESTIONS FOR INVOLVING FAMILIES

The following strategies and tips were shared by CSHCN Programs as successful examples of involving families in committees and other activities.

### Identifying and recruiting families

- Involve field staff who have direct interaction with families
- Recruit directly through clinics
- Partner with community, faith based and advocacy groups and organizations
- Ask other agencies within your building or sphere such as Early Intervention, mental health, etc. for their ideas
- Partner with any outreach staff from other programs within your state such as Medicaid or SCHIP
- Recruit at local and state conferences, health fairs, other meetings
- Approach families directly from other groups and ask for their involvement; explain opportunities
- Use family organizations, local parent groups from schools and community groups
- Actively call families and others to recruit a diverse population representing urban, rural, remote areas, fathers, grandparents, culturally diverse populations
- Use newsletters, direct mailed letters, flyers, fact sheets, and other printed materials – printed in multiple languages - that explain services and include information about involvement opportunities
- Use electronic communication – e-mail, e-newsletters, etc.
- Distribute information widely to reach families early, including through hospitals, birth defects registry, newborn screening, Early Intervention
- Gather ideas from other states at national and regional conferences
- Use others from the cultures you are trying to reach such as community organizations that are language or culture based
- Do presentations for community groups, church groups, advocacy groups on a variety of topics and include information about family involvement opportunities
- Send out letters to everyone in the program advertising openings
- Send out letters or materials through other organizations such as parent groups
- Call families for feedback on services, and include recruiting
- Use focus groups for feedback and recruitment
- Include recruitment questions in satisfaction questionnaires, or in questionnaires about special initiatives such as Medical Home
- Send out a “Request for Application” to every group in the state and individuals that have been involved in the program.
- Recruit constantly and in every way possible



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## Supporting families

- Provide incentives such as stipends, travel expenses, child care – either through payment or by providing trained child care workers and space for children at the meeting. Include meals and overnight accommodations, if needed
- Use different methods of reimbursement
- Drive to homes and bring parents to meetings if needed
- Build supports through contracts – to maximize flexibility
- Include specific information about what is needed, what is expected, the time commitment and payment
- Partner with family groups to provide training programs that prepare families for participation
- Build in mentoring for parents at early stages of participation
- Look for funding sources through administration, block grant dollars, other grants

## Being Creative and Flexible

- Always be sensitive to the needs of families and don't equate lack of participation with lack of interest
- Reflect parent ideas in meeting agendas and include families in ongoing planning; keep families involved in substantive matters so they feel they are making a difference and are not just window decoration
- Do a survey to receive input on how to better involve families
- Utilize teleconferencing or video conferencing to include families in alternate ways at in-person meetings
- Share written information about meetings with those who can not attend
- Contact families in advance of scheduling meetings to identify what times work for them
- Have meetings at different times of the day – early morning, during the day, evening, weekends
- Go out and conduct key informant interviews to insure diverse input
- Experiment with different strategies to see what works - try local meetings/groups, statewide or regional; rotate locations
- Try meetings by conference call
- Piggy back on other meetings to be most efficient
- Don't get demoralized or angry when someone doesn't show up, but build alternative representation
- Involve more than one family/family member
- Recognize in advance that there will be some unpredictable constraints

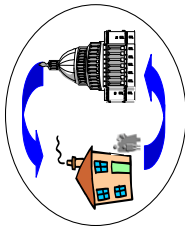
# STATE BY STATE TABLES

**Table 1. Family Involvement in CSHCN Programs: Overall, Benefits to Program, Contribution to 2010 Goals**

	Family Involvement in Program Activities	Length of Family Involvement in Program	Family Involvement Required in Contracts	Benefit to Program H=High, M=Medium, L=Low							Family Contribution to 2010 Goals H=High, M=Medium, L=Low						
				Awareness of family issues	Planning for more responsive services	Program Understanding by legislature, public & state	Parent Professional Communication	Availability of Family Members	Coalition for Change	Responsive to Federal Requirements	1	2	3	4	5	6	
AK	Most	6-10	Y	H	H	H	H	M	M	M	M	M	M	H	M	M	L
AL	Most	6-10	N	H	H	H	H	H	M	H	H	L	M	M	H	H	L
AR	Most	>10	N	H	H	M	M	M	H	H	H	M	H	M	M	M	H
AZ	Most	6-10	Y	H	M	M	M	M	M	L	L	L	L	M	H	H	L
CA	Most	>10	Y	H	M	H	H	H	H	H	H	H	H	H	H	H	M
CO	Most	1-5	Y	H	H	H	M	M	H	H	H	H	H	H	H	H	M
CT	Occasional	6-10	Y	M	M	L	M	L	L	L	L	M	M	L	M	M	L
DC	Occasional	1-5	N	H	H	H	H	H	H	H	H	M	M	H	H	M	H
DE	Most	6-10	Y	H		M	H	M		H		H	H	H	H	H	H
FL	Most	>10	Y	H	H	M	H	H	H	H	H	H	H	H	H	H	M
GA	Occasional	1-5	Y	M	L	L	M	L	L	L	L	M	L	L	M	L	M
HI	Occasional	6-10	N	M	M	M	M	L	L	M	M	M	M	M	M	M	M
IA	Occasional	>10	N	H	M	H	M	M	M	L	L	L	M	M	M	M	M
ID	Occasional	6-10	N	H	M	M	H	M	L	M	M	M	H	H	L	L	L
IL	Occasional	1-5	N	H	M	L	L	M	M	L	L	H	M	L	H	H	M
IN	Occasional	6-10	N	M	M	L	H	L	M	M	M	H	M				M
KS	Occasional	6-10	N	M	M	L	M	M	M	L	L	M	M	M	H	M	H
KY	Occasional	>10	Y	H	H	M	H	H	M	H	H	H	M	H	H	M	H
LA	Most	>10	Y	H	H	H	H	H	M	H	H	H	M	H	H	H	M
MA	Most	>10	Y	H	H	M	M	H	H	H	H	H	H	H	M	H	H
MD	Most	1-5	Y	M	H	H	H	H	H	H	H	H	L	H	H	M	H
ME	Most	>10	N	H	H	L	H	H	M	H	H	M	M	L	H	H	M
MI	Most	>10	Y	H	H	M	H										
MN	Occasional	1-5	N	H	H	L	M	M	M	M	M	H	H	H		H	H
MO	Occasional	1-5	N	M	L	M	M	M	M	M	M	L	L	L	L	L	L
MS	Most	>10	Y	M	H	H	H	M	M	M	H	H	M	H	H	H	H
MT	Occasional	1-5	N	H	H	L	M	M	M	M	M	M	L	L	H	L	L
NC	Occasional	>10	N	H	M	M	H	M	H	H	H	H	H	H	H	M	L
ND	Occasional	1-5	Y	H	M	L	M	M	L	M	M	L	M	M	M	M	L
NE	Most	>10	N	H	H	H	H	H	H	H	H	M	H	H	H	H	H
NH	Most	>10	N	H	H	L	M	M	L	M	M						
NJ	Most	>10	Y	H	M	M	H	H	L	L	L			H	H		H
NM	Most	>10	Y	H	H	H	H	H	H	H	H	H	H	H	H	H	H
NV	Occasional	>10	N	H	M	H	M	H	M	H	H	H	H		H	H	L
NY	Most	>10	N	H	H	H	H	H	M	H	H	H	H	M	H	H	H
OH	Most	6-10	N	H	M	H	L	M		H	H	M	L	M			M
OK	Most	6-10	Y	M	M	M	H	M	L	M	M	M	M	H	M	H	H
OR	Occasional	6-10	N	H	M	M	H	M	L	M	M	H	M	L	H	H	L
PA	Most	1-5	Y	H	L	L	M	L	L	M	M	H	L	L	L	H	H
PR	Most	1-5	Y	M	M	H	M	M	M	M	M	L	M	L	M		L
RI	Occasional	6-10	N	H	H	M	M	M	L	H	H	L	L	L	L	L	L
SC	Occasional	1-5	Y	H	M	H	H	H	M	M	M	H	L	L	H	H	M
SD	Occasional	C	N	M	M	L	M	H	M	M	M	H	M	L	H	M	L
TN	Occasional	>10	N	M	M	M	H	H	M	M	M	H	M	H	H	H	H
TX	Most	>10	Y	H	H	H	H	H	H	H	H	M	H	H	H	H	M
UT	Most	>10	Y	H	M	H	M	M	M	M	H	H	H	H	M	M	M
VA	Most	>10	Y	H	H	L	H	L	M	M	M	L	H	L	H	H	L
VI	Most	>10	N	H	M	L	H	M	M	M	M	L	L	M	M	M	L
VT	Most	>10	Y	H	H	H	H	H	H	H	H	H	H	M	H	M	L
WA	Most	6-10	Y	H	H	M	H	H	H	H	H	H	H	M	H	H	
WI	Most	C	Y	H	H	L	M	M	L	H	H	H	L	L	H	M	H
WV	Most	C	N	H	H	M	H	L	L	M	M	M	L	M	H	H	H
WY	Occasional	6-10	Y	H	H	H	H	H	H	L	L	M	H	H	M	H	H

**Table 2. Family Involvement in CSHCN Programs: Meeting Contributions, Supports, Block Grant Participation, Performance Measure 14 (Form 13), In-Service, Employment**

	Family Involvement in Committees M=Most H=Half F=Few	A=Expressing concerns of families B=Planning program goals & objectives C=Reviewing/developing policies & procedures D=Developing/reviewing publications & materials E=Commenting/acting on proposed legislation	Block Grant Participation A=Public Hearing B=Focus Groups / meetings C=Invited family members D=Invited family organizations E=Needs assessments	Supports to Families A=Child care/respite B=Mentoring C=Payment for time/services D=Travel Money E=Other	Supports to Family Organizations F=In-kind services G=Space H=Clerical support I=Special Projects J=Grants K=Other	Average Performance Measure 14 Subscale Score	Family Involvement in Staff In-Service Trainings	Employment C=consultant S=staff CPO=contracting parent organization
AK	M	ABCDE	ABCDE	BDEFGHJ		2.50	Occasional	
AL	M	ABCDE	BCDE	ABCDEFGHIJ		2.83	Regularly	C,S
AR	M	ABCDE	ACE	ABDFGHI		2.83	Occasional	S
AZ	M	ABCDE	BCD	ABCDEK		2.17	Regularly	C
CA	H	ABCD	ADE	CDIJK		2.33		C,CPO
CO	M	ABCDE	D	DEFGH		3.00	Regularly	S
CT	M	ACDE	ABCDE	CE		2.17	Rarely	S
DC	M	ABCDE	BCE	ABCDEHJ		1.83	Occasional	C
DE	M	ABCDE	ABCDE	BDEGHJK			Regularly	
FL	M	ABCDE	ABCDE	ABCDEFGHIK		1.50	Occasional	C,CPO
GA	F	A	BCDE	ABDI		1.83	None	
HI	M	ABCDE	DE	ACDK		2.00	Occasional	C
IA	H	ABE	ABCE	BCDFGHIJ			Regularly	S
ID	F	ACD	AD	ABDFGHK		3.00	Regularly	
IL	F	ABCDE	ABCDE	ABCDFGHI		2.50	Rarely	S
IN	F	A	DE	CDJ			Occasional	CPO
KS	M	ABCD	E	DJ		1.50	Occasional	C
KY	M	ABCDE	ABCDE	ABCDEFGHIK		2.00	Regularly	C,S
LA	M	ABCDE	ABCDE	ABCDGK		2.83	Regularly	S
MA	M	ABCD	ABCDE	ABCDGHK		2.17		S,CPO
MD	M	ABCDE	ABC	ABDFGHIJ			Occasional	S,CPO
ME	M	ABCD	BCDE	ACDFGHJK		2.67	None	C
MI	M	ABCDE	C	ABCDGHI			Regularly	C,S
MN	M	ACD	BC	BCDFGI		1.33	Rarely	C
MO	M	ABDE	AB	ABCDFGH		2.40	Rarely	S
MS	M	ABCE	BCDE	ACDGIH		1.50	Regularly	
MT	M	ABCD	A	ACDI		1.50	None	C
NC	M	ABCDE	BCD	ACDEG		1.67	Occasional	C
ND	F	ABCDE	ABCDE	BCDFHJ			Regularly	C
NE	M	ABCDE	CDE	ABCDHJ		2.00	Regularly	C
NH	M	ABCDE	E	EGHJ			Occasional	C
NJ	M	ABD	D	CFGJ			Regularly	S,CPO
NM	M	ABCDE	ABCDE	ABCDFGIJ		2.17	Occasional	C,
NV	M	ABCDE	ABCDE	ABCDGIJ		2.00	Rarely	S
NY	M	ABCDE	ABCDE	ABCDEF		1.00	Regularly	S
OH	H	ABCDE	ABC	DHJ				S
OK	M	ABCD	ABCD	ABCDFI		1.83	Occasional	SC
OR	H	ABD	CE	ACDFGHK		1.67	Regularly	C,S
PA	M	ABC	CE	ADEFGH		3.00		
PR	F	ADE	BE	ABCDFGHIJ			Rarely	
RI	M	ABCDE	ABCDE	ABCDEHJK		3.00		C,CPO
SC	M	ABCDE	ABCE	ABCDFHI		2.67	Regularly	S
SD	None		CDE	ABCDFGHK		2.00	Occasional	CPO
TN	H	ABCDE	ADE	BCDFGIJ		3.00		S
TX	M	ABCD	ABE	BCDI		1.83	Rarely	C
UT	M	ABCDE	ABCDE	ABCDFGHIJK		2.00	Regularly	C
VA	H	ABCD	BCE	DEK			None	
VI	M	ABC	E	DFGH		1.83	None	S
VT	M	ABCDE	ABCDE	BCDEGHJ		2.50	Occasional	CPO
WA	M	ABCDE	ABCE	ABCEFGJ			Rarely	C,S
WI	M	ABCDE	E	ABCDEHJ		2.33		C,S
WV	M	ACDE	ACDE	ABCDHI		1.67	Regularly	C
WY	M	A	ABCDE	ABCDFI		2.50	Occasional	



**Families in Programs and Policy:  
Interviews with State MCH and CSHCN Programs**

**FAMILY VOICES CSHCN Interview Tool**

Family Voices, a national grassroots network of families of children with special health care needs, is collecting information on family participation in program and policy activities using a telephone survey. Family Voices' parent leaders will call to interview a staff person from both state Maternal and Child Health (MCH) and Children with Special Health Care Needs (CSHCN) programs in each state.

As you answer these questions, please think about:

- Involvement of families/family organizations in program and policy activities – By this we mean family members or groups who advise or assist the Title V program to understand needs and to provide quality care and services for children and families.
- Our broad definition of what constitutes a family or family organization: one that includes, for example, relatives, guardians, and foster families as well as parents and siblings.
- The particular efforts your program has made to include family members from a diverse range of socio-economic, racial, cultural and ethnic backgrounds.
- Family involvement within your program *during the past 12 months*.
- Your CSHCN program. Keep in mind that an almost identical set of questions is being asked of the MCH program. We are very aware that CSHCN programs have typically had many more years of work with families. A similar set of questions will explore and collect baseline information on MCH program activities with families. Please don't base your answers to this survey on Early Intervention (EI) activities. Information on parent involvement in EI is being collected by another project. Question 1-E asks how family involvement in CSHCN programs has been influenced by EI.
- Family Voices is also collecting information for a web-based repository of materials that illustrate and support family-involvement. As you respond to questions in this survey, please identify materials, policies, procedures, and mission statements your program has developed, including focus group tools, explicit policies and procedures to encourage family input, job descriptions, etc. During this interview we will ask for the name of a person we can contact later to gather materials. For more information about the web-based repository, see description at Family Voices web site ([www.familyvoices.org](http://www.familyvoices.org)).

**Information collected by:**  
State: \_\_\_\_\_

**Date of Interview:** \_\_\_\_\_

**Name of person responding to questionnaire:** \_\_\_\_\_

**Title:** \_\_\_\_\_

**Telephone #:** \_\_\_\_\_

**Fax#:** \_\_\_\_\_

**Email address:** \_\_\_\_\_



- I. **Family involvement in your CSHCN program**  
To what extent are families part of program and policy activities in your program? Families and family organizations are...

\_\_\_\_\_ involved in most of the things we do  
\_\_\_\_\_ occasionally involved in what we do  
\_\_\_\_\_ not really yet involved in what we do.

Please tell us more about the key ways families and family organizations are involved in your CSHCN program.

- B. **Approximately how long have families been involved in your program?**  
\_\_\_\_\_ 1-5 years \_\_\_\_\_ 6-10 years \_\_\_\_\_ over 10 years
- C. **Does your program specify or require family member involvement in any of the contracts you develop for the provision of services?**  
yes \_\_\_\_\_ no \_\_\_\_\_  
If yes, please offer examples.

- D. **Considering all your CSHCN activities, please tell us the degree to which family involvement benefited your program.**

Benefit to program	Degree			Comments
	Low	Med	High	
Increased awareness and understanding of family issues and needs				
Improved planning and policies resulting in services more directly responsive to family needs				
Improved understanding of programs by legislature, state officials, and the public				
Increased parent/professional communication and understanding				

