

# AMCHP Issue Brief

## State Profiles in Comprehensive Family Participation

### EXECUTIVE SUMMARY

Family participation (FP) plays an essential role in state Title V Maternal and Child Health (MCH) programs. Family members volunteer, advise and/or are employed by state Title V MCH, and/or Children and Youth with Special Health Care Needs (CYSHCN) programs and bring unique insight and experience and are prepared to advocate on behalf of MCH. Family participation refers to individuals who are involved in a range of activities that engage families in the planning, development, and evaluation of programs and policies at the community, organizational and policy level. This issue brief highlights six states with differing levels of FP and what methods they employ to involve families.

State Title V MCH programs provide resources, deliver critical screening services and support preventive, primary and specialty care. If there are gaps in health care services, Title V MCH programs support or provide those services to special populations, such as CYSHCN. With the addition of a 2003 CYSHCN performance measure focusing on FP, and the requirement within the Title V Maternal and Child Health Services Block Grant (Title V MCH Block Grant) to describe how families are involved in their programs, Title V MCH programs have more incentive than ever before to comprehensively involve families.

The purpose of this issue brief is to provide a summary of how six states [Colorado (CO), Missouri (MO), New Hampshire (NH), New York (NY), Oregon (OR) and Washington (WA)] approach FP, including their insights, successes and challenges. Members of AMCHP's Family & Youth Leadership Committee (FYLC) recommended the states for inclusion in this report. Information was gathered during a 90-minute phone interview with each state. AMCHP asked that a Title V MCH and/or CYSHCN director, and a family member involved with the program, participate on the call. Interviewees were asked to discuss the history of FP in their state, methods they currently use to involve families, partnerships with other family organizations, training and technical assistance, barriers to FP within their agency and profiles of family-involvement activities.

The issue brief emphasizes qualitative, rather than quantitative, information. The following issues are addressed:

- Barriers to family participation

- Current pressures on Title V MCH programs
- Data and measurement: the CYSHCN performance measure
- Family participation in MCH
- Future plans
- History of family participation
- Lessons learned
- Partnerships
- Strategies to involve families
- Training and technical assistance

The states highlighted in the brief have made strides in developing comprehensive approaches to FP. They are also working to achieve thorough and comprehensive FP throughout their Title V MCH and CYSHCN programs. Throughout the interviews, states made the following key suggestions:

- Continue to share with colleagues the value of family participation, especially during state budget cuts
- Invest time in the family-professional partnership
- Operationalize family participation so that it's understood, expected, and supported by the state leadership and infrastructure

### STATE PROFILES IN COMPREHENSIVE FAMILY PARTICIPATION

#### Introduction

Title V MCH programs have been working to develop and strengthen the roles of families in a variety of ways – from planning, implementing and evaluating programs, and providing assistance to other families, to developing policies with family input. While FP began with a focus only on families served by Title V CYSHCN programs, Title V MCH programs are beginning to address the involvement of families more broadly within MCH.

#### What is Title V?

Authorized by Title V of the Social Security Act, the Title V Maternal and Child Health Services Block Grant (Title V MCH Block Grant) supports the infrastructure for Title V MCH services in every state and territory. Consisting of Title V MCH and CYSHCN programs, Title V supports efforts within both the public and private sectors to shape and monitor health-related services for women, children and youth. Title V MCH programs

provide resources, deliver critical screening services, support preventive, primary and specialty care and fill gaps in health care services. All Title V MCH programs are administered by the state health agency; however in seven states the Title V CYSHCN program is located in another state agency or university.

With the development of a CYSHCN performance measure focusing on FP in 2003 and the Title V MCH Block Grant requirement to complete Form 13, Title V MCH programs have tremendous incentive to involve families in a comprehensive manner.<sup>i</sup> However, differences in health care delivery systems, political climates, and state governments affect how Title V MCH programs approach and structure FP. The continued support of Title V MCH leadership is essential to assuring that FP is meaningful and that family leadership development is ongoing.

### **AMCHP's Interest in Family Participation**

AMCHP and the FYLC are deeply committed to understanding and sharing the ways in which states approach FP, and in developing comprehensive family leadership. Membership on the FYLC currently consists of families working with Title V MCH programs, staff at Family Voices (FV; a nonprofit organization that works toward family-centered care for all CYSHCN), Title V MCH directors and federal partners. The FYLC provides board-level support and leadership to develop and implement effective programs, strategies, and policies that advance family and youth involvement in MCH issues at the local, state and national levels. The FYLC envisions all families being empowered as effective leaders and advocates, in partnership with health care. The FYLC was interested in understanding how state Title V MCH and CYSHCN programs involve families throughout the programs, beyond discrete activities and projects.

The issue brief provides a summary of how six states: Colorado (CO), Missouri (MO), New Hampshire (NH), New York (NY), Oregon (OR) and Washington (WA) approach FP. The findings from this report will also inform Title V MCH programs about FP activities, in addition to informing the FYLC as it pursues its FP and leadership development agenda.

### **What is Family Participation?**

Family participation refers to a range of activities that involve families in the planning, development, and evaluation of programs and policies. Family participation can refer to the hiring of an individual to serve as a FP coordinator or parent representative at the state or local level, contracting with a parent group to advise on family issues, or including families as members of advisory groups and boards. The states highlighted represent different levels of FP. Each state configures FP differently, although they share a common view of the importance and value of family input and leadership.

### **Methods**

The selected states were recommended by members of AMCHP's FYLC based on their experience and knowledge of

FP with these states. To collect information, AMCHP asked that a Title V MCH and/or CYSHCN director, and a family member involved with the program, participate on a 90-minute phone interview. Questions were provided to participants in advance, and several questions were taken from a report developed by FV for their 2002 Families in Program and Policy reports for Title V MCH and CYSHCN.<sup>ii</sup> MO, NH, NY, OR and WA all included the Title V MCH and CYSHCN director, or a representative. CO's phone interview did not include the Title V MCH director, and due to a hiring freeze at the time of the interview, WA was unable to include a family member on the call.

Interviewees were asked to discuss the history of FP in their state, mechanisms they use to involve families, partnerships with family organizations, training and technical assistance issues, barriers to FP and profiles of FP activities. This publication emphasizes qualitative, rather than quantitative, information. The difference in state budgets and health delivery structures complicates efforts to compare specific numbers. Length of responses to specific questions and categories varied among states. Lack of information on a certain subject should not be interpreted as a lack of activity. Many other states, not profiled in the brief, are also involving families in innovative ways – in some cases even more extensively than those profiled. The intent is to highlight that there is not one way to engage families and that there are many factors to consider as well as common challenges all Title V programs face. The states that are mentioned in this document may be a resource to programs at different levels of FP.

### **Terms Used Within the Publication**

Families working with Title V MCH programs hold a variety of titles such as family consultant, family participation coordinator, family partner and parent representative. For consistency throughout the brief, the term *family staff* will be used to describe families who are employed by a Title V MCH program, either as a consultant, state employee or under contract with a parent organization to work specifically on FP and family leadership issues. The term *family representative* will be used to describe families that serve on task forces or committees.

## **SUMMARY OF RESPONSES**

### **History of Family Participation**

For five of the six states, FP began in the late 1980's and early 1990's with initiatives in the Title V CYSHCN program. Attitudes toward FP, as well as the role of family staff and representatives, have evolved over the years. Some Title V CYSHCN programs have moved away from providing direct services to infrastructure development, and the overall roles of families have changed.

- For CO, the focus has moved from family participation to family leadership, from families telling their own stories to being leaders in policy development.
- In MO, family participation began in 1999 when the Title V CYSHCN program confronted the need for

- family input. MO formed the Family Partnership Program and employed five family partners, all of whom were parents of CYSHCN. The Title V CYSHCN program also nominated a family member to the AMCHP Family Scholars Program (FSP) who was selected to attend the AMCHP Annual Conference. This family scholar eventually formed a FV chapter and is now employed as a family partner in the Family Partnership Program. The FSP is a leadership program administered by AMCHP with support from HRSA's Maternal and Child Health Bureau, and the Centers for Disease Control and Prevention's National Center on Birth Defects and Developmental Disabilities.
- In NH and WA, a focus on family participation came about when their state Title V CYSHCN program discontinued direct service provision. In NH, the parent role has expanded from working with families in direct services to increased policy planning and goal setting.
  - In NY, family participation evolved from a grant-specific position to a Title V position and has expanded from basic engagement to involving families in policy-making activities, at the local and regional level, as well as involving youth.
  - In OR, the Title V CYSHCN program has collaborated on the development and support of a family-professional partnership with clinical programs at the Child Development and Rehabilitation Center at OR Health & Science University. As a result, family participation is becoming a valued standard of service delivery.
  - WA described how family participation in Title V CYSHCN programs has become institutionalized. There are clear guidelines and expectations, making it easier to maintain family participation.

### **Partnerships**

States were asked to describe the nature and type of partnerships between their Title V MCH and CYSHCN programs, and family organizations. Four of the six state Title V MCH programs provide contracts to family groups such as FV (NH and CO), Parent to Parent (P2P; CO, NH and WA; P2P is a state and local network of programs that promote access and support for parents of CYSHCN), Fathers Network (FN; WA) and Families Together (NY). OR's CYSHCN program hires families as temporary staff to serve on local community-based multidisciplinary teams and is also able to provide family presenters with honoraria at its training conferences and other key meetings. In addition to contracts, states provide in-kind services through staff assistance, meeting spaces, conference support and translation services.

### **Strategies to Involve and Compensate Families**

States were asked to describe specific techniques they use to identify, recruit, involve, and compensate family staff and representatives. All states emphasized the importance of compensating families for their work either by salary or stipend.

- *Roles of Families:* Table 1 describes the different roles that family staff assumes. States generally felt that the following categories provided the best description (although WA indicated that the first category did not apply to their program). Since NH

partners with FV via contract, family members are precluded from supervising state employees, and therefore the last category did not apply to their program.

- *Boards and Committees:* All states interviewed involve families on boards, task forces and committees (e.g. newborn screening, early childhood systems and youth leadership committees). States often look to their partners, such as colleagues in education, early intervention and health providers, to help identify families to serve in these positions. Finding culturally diverse families is a challenge for some states, while other states indicate a challenge in finding families to represent CYSHCN broadly on committees, rather than just on condition-specific committees (e.g. an autism task force).

**Table 1**

<b>ROLE<sup>III</sup></b>	<b>STATES RESPONDING YES</b>
Providing direct, non-medical services, information or support to families (e.g. parent information and referral, P2P information or links, problem solving and resources identification)	CO, MO, NH, NY, OR
Providing a parent/family perspective to Title V MCH programs (e.g. review of materials, attending Title V MCH meetings to offer family input)	CO, MO, NH, NY, OR, WA
Participating in program development and planning for families (e.g. developing materials and curricula for families, organizing family meetings and conferences)	CO, MO, NH, NY, OR, WA
Encouraging or facilitating collaboration between families/family organizations and Title V MCH programs (e.g. encouraging coalition building, increasing communication and collaboration with family groups)	CO, MO, NH, NY, OR, WA
Supervising other family members or staff employed by Title V MCH programs (e.g. recruiting, orienting, training, mentoring and evaluating)	CO, NY, OR, WA

- *Local Level:* CO, MO and OR fund family staff at the local level working in local health departments, county offices or on community-based teams. Local staff in MO and OR are paid an hourly wage. In CO, local family members are paid in the same manner as other contractors – either by salary, hourly wage or contract.
- *State Level:* All states employ at least one family member at the state level, paid by the state (NY, CO and WA), university (OR), local health office (MO), or contract with FV (NH).
- *Contracts:* OR and NH include criteria for family participation (e.g. participating on or facilitating community-based teams) in contract language, in which contract requirements for vendor agencies incorporate expectations that vendors also address the issue of family participation.
- *Stipends:* All states except MO provide stipends for families serving on boards and committees. NY and WA have written policies for stipends, and CO's state-level Family Leadership Task Force provides stipends for families.

### **Training and Technical Assistance**

States are making every effort to train families and promote leadership development. Title V MCH and family staff are often invited to local, state and parent trainings for CYSHCN. In addition, family staff conducts trainings for other parents. In CO, each local office is provided \$2,500 for any staff member to receive family technical assistance, which is often used to attend trainings and conferences. CO also conducts a Family Leadership Training Institute (FLTI), which is a 20-week leadership program focusing on civic engagement and helping parents become advocates for their children and families within their community. In NY, the Early Intervention Program, which works closely with Title V MCH programs, provides training to parents on public speaking and presenting public testimony. States noted the value of the AMCHP Annual Conference in providing networking opportunities for families. All six states have sent a family member as a family scholar to the AMCHP Annual Conference. Both CO and NH highlight the key role of the AMCHP Family Delegate Program in orienting new family staff to MCH and national issues, and in developing state leaders. In 2010 WA sent a nationally accepted family member to the AMCHP Annual Conference. An AMCHP Family Delegate is a parent, relative or adult consumer of the Title V MCH program who has been designated by a state or territorial Title V MCH program director to serve as a voting member of the agency's five-person delegation to AMCHP.

States reported the need for additional training and/or technical assistance in the following areas:

- Cross-agency training for families (e.g. special education, office for children)
- Family participation and family-centered care training for professionals
- Core competency curriculum for family scholars attending AMCHP's Annual Conference
- Cultural competency training to reach diverse families
- Training for states in conducting focus groups of families

- Leadership training for AMCHP Family Delegates
- Coordination with other family advisory groups in WA, e.g., Department of Early Learning, Early Support for Infants and Toddlers, Office of the Education Ombudsman

### **Data and Measurement: CYSHCN Performance Measure**

Currently, evaluation of the effectiveness of FP programs is conducted on a project-by-project basis. Given additional resources, states would like to systematically evaluate FP. All states emphasized the value of the MCHB CYSHCN performance measure for FP. One state reported that the CYSHCN performance measure is a "nice credential for families to see when they are getting involved." For the completion of Form 13, three of the states are moving beyond self assessment to use this requirement as a mechanism to survey families on the state's progress in involving families.<sup>iv</sup> In CO, regional offices report to the state, and the responses are reviewed by the state FP coordinator and an evaluator. In NH, members of FV complete Title V MCH Block Grant Form 13, and in NY, youth and families are involved in completing the form.

### **Family Participation in Maternal and Child Health**

Despite a general receptivity toward involving families within Title V MCH programs, no state indicated that their program has undertaken the same level of comprehensive approach toward FP as the Title V CYSHCN program. Still, Title V MCH staff has gained greater receptiveness and awareness toward FP. Within MCH, some of the greatest interest in expanding FP is coming from child and adolescent health, as it is in WA and CO. CO's Title V MCH program has developed a Youth Partnership for Health program, but is facing challenges in recruiting youth into leadership positions. The following are comments made by states in addressing FP in Title V MCH programs:

- We have not made all-out efforts to involve parents in Title V MCH programs. We have involved parents in various task forces, but we could do better.
- The role of families in Title V MCH programs is much less defined. Our Title V MCH program has problems with limited funds, but awareness is rising.
- There is not a MCH developmental continuum. Family participation is on a project-by-project basis.
- We do not have the same pool of parents as do Title V CYSHCN programs. Most of our Title V MCH program work is community-based – we have very few consumers of direct Title V MCH services.
- It's harder to recruit families when it's less condition specific. It's hard to get someone involved who has a healthy child.

### **Current Pressures on Title V MCH Programs**

For Title V MCH and CYSHCN programs, FP is a familiar term and commitment. However, budget cuts and state hiring freezes are placing unprecedented stress on these programs. All states interviewed reported that state budget cuts were threatening Title V MCH program activities. As a result, states are mainly concerned with preserving existing FP activities rather than undertaking large expansions.

## **Barriers to Family Participation**

Title V MCH programs face a number of barriers in developing and/or expanding FP. The three major challenges noted by states are budget cuts, lack of knowledge about the value of FP and developing family leadership.

- **Budget:** All states have made some level of financial commitment to funding family participation, at least through the Title V CYSHCN program. The concern for states is preserving their financial commitment for family staff and activities during budget cuts. One respondent stated, "You have to have a major commitment not to defund family participation." Another said, "You have to continue to share with the rest of your department information about family participation, to maintain its importance in tough budget times."
- **Lack of Knowledge:** States also noted continual challenges in educating staff in their own departments, and other programs and departments, about the value of family participation. One respondent asked, "How do you continue when some people think this is fluff?" And another, "Some people don't like the term family advocacy. Some approach this kind of family participation with defensiveness."
- **Challenges in Developing Family Leadership:** States are struggling to diversify and expand their pool of family leaders. States repeatedly reported concerns about emphasizing a limited number of active families. One respondent said, "A major challenge is family time. We ask families to do more than they have the capacity." NH cited the need to find younger family leaders "who are experiencing the system as it is now, not as it was when our children were young." While NY and CO felt that they have had success in recruiting diverse families to participate in family participation activities, other states, including NH and WA, are experiencing difficulties.

## **Lessons Learned**

All states reported feeling encouraged by their progress in developing comprehensive approaches to FP, but also report that they would like to do more. Their experiences have provided them with a wealth of knowledge in terms of how to grow and support FP in their Title V MCH programs. Among the key lessons reported are:

- Put time into the family-professional partnership. You cannot simply put people on committees, but need to prepare families and staff. True family participation needs time spent on key relationships, financial commitment and a high level of support.
- Operationalize family participation so that it's understood, expected, and supported by the state leadership and infrastructure. Have a structured routine for family members with all the details and practical tips laid out clearly so that parents know what to expect.
- Continue to share with colleagues the value of family participation, especially during state budget cuts. Family participation is synonymous with consumer input, which is a critical need as Title V MCH programs across the country work to retain their operating budgets.

## **Future Plans**

As states face an uncertain financial landscape, states reported that their primary focus will be to maintain their state's current financial commitment to FP. Nevertheless, they will also continue with plans to strengthen FP.

- CO is continuing to work on expanding family leadership in Title V MCH programs.
- MO plans to offer participation stipends to families.
- NH will work to involve a greater number of younger families who are currently experiencing the system in their network of families.
- NY is working to expand its Family Champions and Youth Leadership programs.
- OR plans to develop a stronger statewide network of families, including families in primary and tertiary clinics, and linkage with family organizations.
- WA involves family members in activities in its federal autism and epilepsy grants to test out new family and youth involvement strategies.

## **COLORADO: FROM FAMILY PARTICIPATION TO FAMILY LEADERSHIP**

CO's Title V MCH and CYSHCN programs are located in the Center for Healthy Families and Communities, part of the CO Department of Public Health and Environment. The CO Title V MCH program has gained access to supplemental funding from foundations and other federal programs, which has offset flat funding from the Title V MCH Block Grant. This funding has been crucial, as the state has strict taxpayer rights that limit spending. As the CO Title V MCH program has moved away from providing direct benefits, it has been a struggle to increase understanding of the importance of public health among state employees. Nonetheless, CO is working to move FP to the level of family leadership. As one respondent noted, "We really need to expand the depth of human capital. It is really more than FP. If we give families the toolkit, then systems do change, but first, families must be given the knowledge and courage to go beyond their own situation."

The CO Title V CYSHCN program has employed parent consultants for more than 20 years. Originally, parent consultants provided direct services to families, but as the Title V CYSHCN program moved away from providing direct services, parent consultants now serve as equal partners with Title V MCH program staff and play key roles in program and policy planning. As one family member explained, "We are trying to move from family participation to family leadership. Family participation is sometimes interpreted as telling your own family's story. Family leadership means having a core set of leadership skills which are applicable at all levels of government." The state currently employs one full-time family consultant at the state level, and 14 family-staff members at the local level (in both full and part-time positions). Family staff serve as official state employees and receive a salary. As one family member noted, "Working for the state requires a delicate balance between the roles of the state and citizenry, but it can be done."

CO's Title V MCH program is working to increase FP, particularly in the area of adolescent health. The Title V MCH program has developed a youth leadership program to develop a core group of young leaders. The CO Title V CYSHCN program involves families on a number of task forces, including but not limited to, medical home, Medicaid, newborn screening and Early Childhood Comprehensive Systems Initiative (ECCS) task force. Local family staff recruits families to participate on local committees and discussion groups. Parent groups such as FV and Family-to-Family Health Information Centers<sup>v</sup> (F2F HICs; funded by the Family Opportunity Act of 2006, are staffed by knowledgeable parents and professionals) also assist with identifying families. In addition, the state supports several nonprofit organizations that specialize in cultural brokering for Spanish-speaking, Asian-Pacific and African-American families. At the state level, families that participate on policy-level committees receive a participation stipend after three meetings, if they are deployed to an actual systems-change activity. The Title V CYSHCN program holds meetings in locations that are convenient for families to attend, such as local libraries, schools, faith communities, parks, coffee shops and even in the homes of hosting families.

CO's Title V CYSHCN program supports several advocacy groups to support their operations: the CO Autism Society (for emergency respite care), F2F HIC, Hands and Voices (for families with children with hearing impairments), the Arc of Colorado (advocacy for individuals with intellectual disabilities), El Grupo Vida (for cultural brokering and outreach to Spanish-speaking families) and Kids in Education Jobs and Inclusion (for outreach to the African-American community for children enrolled in special education). In some cases, the Title V CYSHCN program provides in-kind services such as meeting space and facilitation, printing, conference calling and connection to other state agency personnel.

CO FV collects information on the number of families that testify at the state legislature in one year. CO's Title V CYSHCN program is collecting additional data about family leadership. For the reporting of family information on Form 13 of the Title V MCH Block Grant, regional offices report to the state. CO also conducts family satisfaction surveys for state activities, and local offices conduct family satisfaction surveys for local activities.

Respondents pointed to a range of challenges in expanding FP in the state. A primary challenge is that the very families that Title V aims to involve may be struggling with limited incomes and childcare issues – particularly families with undocumented persons. Additionally, the Title V CYSHCN program is working to have more FP in schools, but with limited resources.

- *ECCS Grant Statewide Team:* The ECCS team originated from the ECCS Grant, but has been elevated to the Office of the Lieutenant Governor. As part of the team the Family Leadership Task Force, dedicated to the family participation and support domain, has been particularly effective.

- *Family Leadership Registry:* CO's Title V CYSHCN program has developed a family leadership registry, which serves as a centralized database of emerging and veteran family leaders. The database includes information on the parent's role as a parent of CYSHCN, and information related to areas of experience and skill sets such as legal, business and marketing.
- *Family Leadership Training Institute (FLTI):* CO contracts with the state of Connecticut to provide an evidence-based curriculum that has been implemented in Connecticut for almost 20 years. This community-based model helps families acquire a core set of competencies in civic involvement that will better equip them for policy leadership. By the summer of 2010, CO has graduated approximately 125 family leaders as a result of offering this curriculum in local communities across the state. The curriculum is supported by local partnerships, and is free to participants. The curriculum is intended for a diverse class of participants and is not exclusive to parents who have CYSHCN.
- *Training Funds:* Each local office that employs family staff has \$2,500 allocated for family activities. Decisions as to how to use the money are made locally, but funds are often directed to help family staff attend regional and national conferences, and trainings.

## MISSOURI: FROM FAMILY SCHOLAR TO FAMILY PARTNER

The MO Title V MCH and CYSHCN programs are located in the Division of Community and Public Health, part of the State Department of Health and Senior Services. State budget cuts are placing additional pressure on an already stressed staff. The state also faces unique challenges due to its diverse geographic landscape, which has caused Title V MCH programs to regionalize state programs to meet local needs. MO continues to pay for direct services for CYSHCN by contracting with local public health agencies for service coordination.

Serious investment in FP began in 1999, when the state funded 10 families to attend the AMCHP Annual Conference. In 2001, the statewide Family Partnership Program (FPP) was established. The MO Title V CYSHCN program currently funds the FPP and employs five family members – a state coordinator and four regional partners – on a part-time basis. For ease of budgeting and hiring, family staff is compensated through local public health agencies. In addition to an hourly wage, family staff receives a respite stipend, and are reimbursed for mileage and supplies.

Within state Title V MCH programs, there is awareness and receptivity to FP, but an all-out effort to involve families has not yet been made beyond some involvement in task forces. As one respondent stated, "We do see similar barriers [within MCH]: child care, transportation, the need for flexibility on the hours of meeting. Still, there has definitely been a change. We

talk about families more and we know we need family input." Although MO recognizes that it has come a long way in the past decade, educating other state programs about the value of FP remains a challenge, particularly in the area of mental health. State Title V MCH and CYSHCN directors are concerned about overloading a limited number of parents with activities.

MO has involved families on a variety of committees, including the Title V MCH Block Grant application review, and has proposed the use of funds for a statewide Oral Health Task Force, Genetics Advisory Committee and subcommittees and the ECCS Grant Advisory Council. Families are also given the opportunity to provide feedback related to Title V CYSHCN program publications and other materials. Regional family partners working with local organizations recruit parents, who receive transportation stipends for participating on committees.

Regional Title V CYSHCN program staff and family partners support one another, through advice and consultation. The state also collaborates with a number of organizations that provide support for family activities, such as the University of MO – Kansas City's Institute for Human Development which was awarded Integrated Community Services for CYSHCN and Family-to-Family Health Information Center (F2F HIC) grants. Both of these grants have representation from the Title V CYSHCN program, Family Partners and the MO chapter of FV. One of the key goals of the F2F HIC grant is to build significant partnerships among consumers, families and professionals to address the needs of families from diverse racial, ethnic and cultural backgrounds.

One key activity is MO's Annual Retreat for Families. The Title V CYSHCN program provides the funding for approximately 60 families (more than 100 participants) to gather for a weekend to network and discuss issues surrounding CYSHCN. Families apply to attend, and the state covers the cost of food and lodging. The retreat is organized and led by the FPP, which is in charge of securing speakers and exhibitors. Past topics include transition to adult care, medical home, personal safety and alternatives to guardianship.

MO measures FP through an evaluation of the FPP. Currently, the FPP tracks the number of contacts they make in a month and the type of resources that families are referred to. The state also makes every effort to fund family staff to attend the AMCHP Annual Conference. MO would like to expand its network of families, develop additional family leaders and fund stipends for all family participants.

## **NEW HAMPSHIRE: DEVELOPING LEADERS FOR A NEW SYSTEM OF CARE**

NH Title V MCH programs are located within the Department of Health and Human Services. The Title V MCH program is located within the Division of Public Services, and the Special Medical Services serving CYSHCN is located within the

Division of Community Based Services. NH, like most states, is experiencing severe budget cuts. Because the state lacks a tax-based revenue system, it has little flexibility to raise revenue and must rely heavily on federal funding.

Without an infrastructure of county or local health departments, NH relies on contracted services with community-based agencies and individuals based within the state agency to provide most direct clinical services. However, when the Title V CYSHCN program moved away from providing many specialty clinic services, Title V CYSHCN programs fell back into the private system. The state has a Medicaid waiver similar to Katie-Beckett, called Home Care for Children with Severe Disabilities, which provides some children with health care coverage.

The Title V CYSHCN program has steadily expanded its approach to FP, and the Title V MCH program was able to hire two parent consultants through a Special Projects of Regional and National Significance (SPRANS)<sup>v1</sup> grant. After the grant expired, the state continued to employ one parent consultant. Initially, the focus of the parent-consultant role was to help families access services. Through decades of leadership changes in the Title V MCH program, the parent consultant has remained a consistent component of the Title V CYSHCN program, and has evolved from FP to leadership and policy development.

The NH Title V CYSHCN program contracts with FV of NH to fund three full-time employees as parent consultants. The Title V CYSHCN program also contracts with P2P of NH and maintains a part-time contract with a parent advocate for its Early Hearing Detection and Intervention Program. The parent advocate educates, supports, and assists families of infants and young children with potential or confirmed hearing loss through the process of screening, testing and diagnosis. The Title V MCH program has developed requirements within its contracts for all community health centers and agencies that provide services to ensure that family leadership is developed and enhanced by board of director leadership and advisory panels. While FP is enforced, its level of effectiveness is difficult to assess. The Title V MCH and CYSHCN programs involve families as members of various advisory groups, including the NH Birth Conditions Advisory Group and the ECCS grant. FV helps identify potential family members and provides a participation stipend for families, and has created a Youth Advisory Committee. NH's Title V MCH program also involves families in an interagency initiative on infant mental health.

Respondents felt that FP in the Title V MCH Block Grant review, rule making and needs assessment have made the greatest difference in the state.

- *Block Grant:* Title V MCH programs conducted an electronic survey to set priorities, which was distributed by FV. The survey was conducted through a listserv, and 400 responses were gathered.
- *Rule Making:* The Title V MCH program always seeks

input from FV parent consultants when making any kind of administrative rule or policy change. Parent consultants also participate in Title V MCH, Medicaid and Child Protective Services rule-change discussions.

- *Newborn Screening Panel:* NH noted the particular importance of families serving on the state Newborn Screening Panel. Because of the passionate presence of families of children with cystic fibrosis, the panel agreed to an expanded level of screening conditions, resulting in a significant number of positive screens.

Both the Title V MCH and CYSHCN directors noted that finding families to serve on committees that are not condition-specific (e.g. autism or birth conditions) can be a challenge. For example, initially identifying parents to participate on the ECCS Grant Committee was difficult because families could not understand its purpose. It's difficult to engage young, busy parents of typically developing children in statewide systems-building initiatives that do not appear to have tangible connections to their families. As a result, NH's Title V MCH programs are exploring ways to utilize Web 2.0 technology to gather feedback and better understand family concerns. NH does not currently conduct a comprehensive evaluation of family activities in the state. FV uses data from its information and referral services to ensure that issues are aligned appropriately with actual needs of families. FV also measures the number of people that parent consultants connect with, and how many receive effective follow-up care. For the completion of Title V MCH Block Grant Form 13, FV staff provides information and evaluation. Leaders in NH say that the key to successful FP is to put time into the relationship. One respondent stated, "It takes time and effort for a Title V MCH program to develop effective FP. Provide information, talk to them before the meeting, explain the acronyms, make sure they understand and then follow-up afterwards."

## NEW YORK: BUILDING FAMILY NETWORKS AND YOUTH LEADERSHIP

NY's Title V CYSHCN program employs one family member as a full-time, paid state employee. The Title V CYSHCN program has built a network of families across the state through its Family Champions Program (FCP). The NY Title V CYSHCN program has involved families since 1990, originally as part of a MCHB/HRSA grant for Families as Trainers. When the grant ended, the parent staff position became a Title V CYSHCN position. Throughout the years, NY has moved families from basic involvement into policy-making activities, as well as expanded the role of families in individual medical practices.

The Title V CYSHCN program works with FV, P2P and Families Together (for mental health issues). FV currently receives a number of in-kind services (e.g. telephone and office space). The Title V CYSHCN program provides childcare, transportation, lodging and participation stipends, as well as stipends for family champions who serve in an advisory role to state health department programs. NY staff noted that

scarce financial resources for family members are a constant barrier to expanding FP. The state struggles with time constraints and the need for flexible schedules among family staff. To address these issues, staff utilizes creative locations, conference calls and webinars. Additional activities that include FP are:

- *Block Grant Review and Reporting:* NY conducts extensive outreach to families during their block grant review. The state provides training to families in order to understand the block grant review process and conduct surveys. During the actual block grant review, parents provide responses which are then shared with the MCH Advisory Council.
- *Family Champions Program:* The FCP, which originally started in 2005 as advising the NY Department of Health on access to care, has evolved into a local program with a solid regional infrastructure. Fifty-five families applied for 20 openings and represented a wide range of ethnicities, disabilities and localities. In many cases, the local family champion has become the parent leader for that area.
- *Youth Advisory Committee (YAC):* This committee consists of 15-25 youth members, who work on a variety of issues including a pocket-sized portable health care summary, an insurance fact sheet and a needs assessment. To control costs and accommodate various disabilities and locations, the committee holds quarterly and semi-annual conference calls. When the committee meets in person, the state provides accommodations, including attendant care.
- *Youth Leadership Committee (YLC):* The YLC was created to assist youth, young adults and families toward the transition to adult medical homes. Applications were sent to youth organizations to attract a diverse range of youth aged 15-25, and were scored on a basis of geographic, cultural and condition-specific diversity.

Within MCH, state Title V leaders say the opportunity to have a parent serve on the MCH Advisory Council would be a great start. At the same time, staff noted the challenge of getting family members with a healthy child involved.

NY works to actively involve families in evaluation efforts. Both youth and families complete Title V MCH Block Grant Form 13, with NY's scores climbing increasingly higher. NY is working to maintain and strengthen the regional infrastructure of its FCP, and expand the role of the YLC. Ideally, the state would like to have a higher number of coordinated training for families across agencies. At the same time, they would like to continue with quality improvement efforts that involve families. Most importantly, NY stresses the need to share information about FP with the entire department to maintain its importance during state budget cuts.

## OREGON: CONNECTING FAMILIES IN THE COMMUNITY

OR's Title V MCH and CYSHCN programs are located in

separate departments. The Title V MCH program is located within the Office of Family Health in the Department of Human Services, and the CYSHCN program is located within the OR Center for Children and Youth with Special Health Needs (OCCYSHN), part of the Child Development and Rehabilitation Center (CDRC) at OR Health and Sciences University (OHSU). This fragmentation poses a challenge for building a coordinated effort around FP. In addition, OR is experiencing budget cuts, organizational changes and decreased grant funding within OCCYSHN, which has had an impact on maintaining family staff and expanding the Family Involvement Network.

Families were initially hired as staff of the CDRC at OHSU in 1994 when they were awarded a consumer participation grant from MCHB to help families understand managed care. The plan for OCCYSHN's Family Participation Network (FPN) was developed in 1998, by the Title V CYSHCN director and a family member. In 2000, family staff grew to three part-time employees: each bringing personal experience and a connection with other families and family organizations either in areas of chronic medical conditions, mental health or developmental delays. Initially, family staff provided parent perspectives on CYSHCN-related issues to OCCYSHN, served on internal committees and worked to find opportunities to expand the FPN. With funding from a medical home grant followed by integrated services grants in 2000, and in 2004, the Title V CYSHCN program was able to recruit, train and support families to participate on local community-based multidisciplinary teams, and maintain and expand the scope of work for family staff. According to one respondent, "Family participation is now not something new. It's the standard. It has really affected the staff and local teams. They expect families to be there now."

OR currently has one part-time staff position at the state level through the OCCYSHN. Although there were formerly three part-time family members on staff, budget cuts have caused a reduction to just one staff at this time. The family staff member is funded at a level that allows her to receive benefits through OHSU. As a program lead for FP, the family staff member provides critical input into the various systems-level work in which CYSHCN is engaged, and is considered a key strength to the current FP program. She also provides essential training and support to other family staff working directly in community-based initiatives. The Title V CYSHCN program employs 11 families at the community level. These families receive hourly wages, and are considered temporary employees of the university. Family staff receives ongoing training and support to:

- Serve as team members on multidisciplinary teams to assure family perspectives are included in team decisions, and to support families who need assistance with care coordination
- Participate in quality-improvement initiatives and needs-assessment activities with the OCCYSHN program

Family staff is enlisted to participate in OCCYSHN trainings both as speakers and participants, and provide input on program activities. Family staff is typically offered stipends or honorariums for participation. Currently, families and consumers participate in specific project advisory groups and task forces. Both OCCYSHN and the Office of Family Health (OFH) value the contributions of families and recognize the need for partnership with families. OCCYSHN has allocated funding to maintain current levels of FP. However, with funds increasingly constrained, it's not clear how the state can expand the FP and statewide network.

OR's Title V CYSHCN program also involves families as trainers, presenters and family mentors. The state works with family organizations, community-based groups and CaCoon (a public health nurse home visiting service) local-care coordinators to identify families for activities. Family and other program staff partner with family organizations by regularly participating in meetings and presenting at family organization conferences. Examples include:

- Regular connection and in-kind support to OR's FV and F2F HIC
- Participating in, and partial sponsorship of, FV Regional Leadership and Training Conferences
- Providing honoraria to Northwest Down Syndrome Association families for speaking and sharing a photo exhibit at the annual conference
- Providing financial support for families to attend educational events, such as FV, OR Parent Training and Information Centers (PTIs – these centers serve families of CYSHCN with a focus on helping families to navigate the education system, assist them as they help their children meet developmental, functional and academic goals, and provide them with training and information to prepare their children to lead productive lives) statewide training and OCCYSHN training events
- Including family organizations and representatives on project and program advisory panels

OCCYSHN and the OR Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program have a close partnership. OCCYSHN family staff participate as faculty and coordinate the LEND Family Mentoring Program. Many FPN members serve as family mentors to LEND students and receive additional honoraria from the LEND program. OR's Title V CYSHCN program has been challenged with a high turnover rate among family positions. In response, OCCYSHN employs two family members at each local-level position, so that at least one is available at all times. As part of an academic institution, there are many challenges in finding appropriate job classifications for families. Current staff positions are typically classified as research assistants.

OR's size, rural characteristics, travel costs and OCCYSHN budget limitations pose a challenge to families from rural communities at the level needed by the program. The program uses telephone and web-based conference calls, but reports that face-to-face and community-based meetings are critical to

sustaining and supporting FP and partnerships. For the OR Title V CYSHCN program, key FP activities are currently centered on:

- Community Connections Network: Family Liaisons serve on community-based, multidisciplinary teams, and family staff train and provide them with ongoing support. Families serve as team members on nearly all of the teams. Their role is to provide input to the team on family-centered care and parent perspectives, identify local resources for families and support families that meet with the team for assistance with the care of their child. They also provide follow-up assistance to the family.
- Under a previous grant, four Family Liaisons worked with local practice sites as part of a clinical quality-improvement team.
- A Youth Advisory Group was started with funding from the initial integrated services grant. Youth involvement and an emphasis on youth transition to adult care remains a high priority.

OR's Title V CYSHCN program receives a high level of positive feedback from team members about the value of FP, but does not yet have a comprehensive approach to evaluation. Title V MCH staff say the existence of the MCHB performance measure for family participation has helped make the case for increased FP. OCCYSHN staff report that the FPN and the presence of families at the CYSHCN program has had a positive impact on other units of the CDRC, including specialty clinical programs and practitioners, a LEND training program, FP in the Oregon Institute on Disability and Development, and internal administrative and leadership committees. OR would ideally like to have a more connected statewide network of families, and an increased number of families linked to private practices and public health initiatives. One respondent reported, "True family participation takes time spent on key relationships, financial commitment and a continuity of support."

## **WASHINGTON: OPERATIONALIZING FAMILY INVOLVEMENT**

WA's Title V MCH and CYSHCN programs are located in the Office of Maternal and Child Health. WA's CYSHCN program is not a direct payer of services to CYSHCN. Instead, the state relies on a partnership with the state Medicaid program to cover medical costs for financially-eligible children. Title V MCH leaders are concerned that recent changes in interpretation of federal Medicaid law have limited the program's ability to claim Medicaid administrative-match funds for portions of state and local public health staff time, making the state budget even tighter.

When the state Title V CYSHCN program shifted from covering the costs for direct services, it began contracting with parent organizations. In 2000, the Title V CYSHCN program created the position of State FP Coordinator. Within the Title V CYSHCN program, FP is now expected and institutionalized. Within Title V MCH, the previous FP coordinator assessed

areas of FP. The Title V MCH program is willing and interested in involving consumers in policy and program development, but it has not become institutionalized. Within MCH, Washington is working to develop a continuum of FP as an integral part of the program, but at this time, it is more project specific. In 2009 the child and adolescent health section was combined with the maternal and infant health section to form the Maternal, Infant, Child, and Adolescent Health (MICAH) section. The MICAH section has shown the greatest interest in FP with their ECCS grant. The grant involves parents of young children in its advisory committee. In addition, other sections of MCH including oral health, the Immunization Program's CHILD Profile, and Genetics and Newborn Hearing Screening, involve parents in policy and program development activities, as well as in the development of educational materials.

The Title V CYSHCN program recruits families to participate through a variety of methods including contracting with various parent organizations, and referrals from community partners and providers. The FP coordinator is a member of the Family Leadership and Involvement Committee for the state Part C council and works closely with other state agencies that have parent involvement committees. In addition, the Title V CYSHCN program provides participation stipends for parents for ongoing involvement in various task forces and committees, including an Epilepsy Grant Partnership Committee,<sup>vii</sup> the Combating Autism Advisory Council, a special project on translations of medical home materials and participation on the Medical Home Leadership Network team. According to the Title V CYSHCN director, "Having a structured routine for parents with all the details and the practical tips really makes things work better." The Title V CYSHCN program has an established process for payments to family members. Funds from other sections of Title V MCH and from new grants are fed into the system to increase participation of family members.

Within Title V MCH, families serve on the State Genetics Advisory Committee, which provides advice and counsel to the Genetic Services Section of the Department of Health regarding human genetic issues, and services and programs for the state. WA is also a member of the Genetic Alliance, an umbrella organization consisting of consumer advocacy groups reflecting a variety of birth defects and heritable conditions.

WA's Title V CYSHCN program contracts with the WA State P2P Support Program, which oversees a statewide network of local coordinators (15 community-based parent programs). WA P2P is funded by CYSHCN, the state Department of Developmental Disabilities (DDD) and other programs. Due to the deficit in the state budget, DDD decreased their funding to the P2P program significantly, which led to a decrease in P2P programs, even forcing some to close completely. As of June 30, 2010, there are only 15 P2P programs even though CYSHCN continued funding the program and increased funds with autism and epilepsy grants. While WA does not contract with FV, they do work collaboratively with the Family-to-Family Health Information Center, a family support and education service which is affiliated with Family Voices.

In addition, the Title V CYSHCN program provides funding to the WA State Fathers' Network (WSFN), which serves as a support system for fathers of CYSHCN. There are currently 15 local chapters across the state, some of which target Latino fathers. The WSFN has developed a very successful website which could be used as a model for other states. WA continues to increase recruitment of diverse families. The epilepsy grant allowed contract activities for working with several new Spanish-speaking Latino families in rural WA. The Combating Autism Advisory Council, developed by the autism grant engages two culturally diverse family representatives.

Additional activities that involve FP include:

- *Block Grant Review*: The FP coordinator recruited parents of CYSHCN to review the 2009 Title V MCH Block Grant Report application. This allowed more family members to understand the breadth of Title V activities in the state and provide feedback to state leaders on pressing issues.
- *Medical Home*: The CYSHCN program works with the University of WA to assure at least one parent is a member of each Medical Home Leadership Network team. These teams have increased family presence in the medical home, and they need to be maintained. Participants feel that their success in developing parent involvement in medical home teams can be replicated across states.
- *Newborn Screening*: WA is conducting outreach to parents whose children have been identified as failing the hearing screen, but who received no follow-up care to determine the infant's hearing status. These parents are in a unique position to assist the program in better understanding the barriers that parents face in receiving care for their newborns.
- *Project LAUNCH*: A federal grant called Project LAUNCH (Linking Actions for Unmet Needs in Children's Health) from the Substance Abuse and Mental Health Services Administration (SAMHSA) plans to include parents on their advisory committees. The project is designed to promote the wellness of young children ages birth to 8 years by addressing their physical, emotional, social and behavioral development.
- *School-Based Health Centers*: The MICAH section highlights the value of including parent and youth involvement as a subcontract requirement for school-based health centers.
- *Contracts*: WA developed coordinated contract activities in two contracts. Staff at Seattle Children's Hospital Center for Children with Special Needs provided a facilitated training for P2P and WSFN support group leaders to increase skills in support facilitation. Next year the contract activities will include developing statewide standards to guide support group meetings.

WA would like to increase assessments of its family activities, including its contract with P2P and WSFN. Both networks provide assistance to families across the state and can track the number of parents reached. Developing statewide standard guidelines will assist in assessment of support programs. As the CYSHCN director noted, "We think they are great but we have no tangible data on impacts." Respondents noted that they do not use a formal evaluation process, beyond self-

assessment to complete Title V MCH Block Grant Form 13.

In the current financial climate, WA is particularly concerned about maintaining its network of FP. New grant funding to MICAH and CYSHCN programs has allowed broader family participation in program and policy development. Subcontracts of grant funds have been recognized as a tool for the required inclusion of FP. Grants for epilepsy and autism have presented opportunities for FP and mechanisms to help develop parent and youth leaders from more diverse backgrounds and rural areas. Through these grants, WA has tested new ideas in FP, which they will implement more broadly in the future. In particular, parents and youth were mentored on sharing their stories to maximize the impact of personal experiences and express their needs in interacting with providers, educators, community venues and in the education of others. As the WA Title V leaders recognize, "Parents and youth have very powerful voices to be tapped." The FP coordinator recently completed filming four Spanish-speaking Latino mothers and one sibling who spoke of their experience of having children/siblings with epilepsy.

## CONCLUSION

The information provided in this publication is meant to provide examples of family participation initiatives and strategies currently taking place among state Title V MCH and CYSHCN programs. The publication is not a complete list of initiatives, but highlights examples of strategies being implemented to ensure strong family participation within state Title V programs. AMCHP continues to support increased family participation broadly among all states. While there has been a significant increase in the level and types of family involvement and employment, there is still a need to share strategies and mechanisms to recruit, hire, monitor, and evaluate family employees and consultants.

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<sup>i</sup> The CYSHCN performance measure for FP refers to “the percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive.” As part of their annual Title V MCH Block Grant application, states are required to complete Form 13: Characteristics Documenting Family Participation in Children with Special Health Care Needs Programs. States were asked to rate six characteristics documenting family participation in CYSHCN programs. The six characteristics include the following: 1) Family members participate on advisory committees or task forces and are offered training, mentoring, and reimbursement, when appropriate; 2) Financial support (financial grants, technical assistance, travel and child care) is offered for parent activities or parent groups; 3) Family members are involved in the CYSHCN elements of the Title V MCH Block Grant Application process; 4) Family members are involved in in-service training of CYSHCN staff and providers; 5) Family members are hired as paid staff or consultants to the state CYSHCN program (a family member is hired for his or her expertise as a family member); and 6) Family members of diverse cultures are involved in all of the above activities.

<sup>ii</sup> Wells, Nora and Betsy Anderson, Families in Program and Policy FiPPs CSHCN Report: Interviews on Family Participation with State Title V Children with Special Health Care Needs Programs, Family Voices, 2002. Appendix D, pp. 46-50. Wells, Nora and Betsy Anderson, Family in Program and Policy FiPPs MCH Report: Interviews on Family Participation with State Title V Maternal and Child Health Programs, Family Voices, 2005. Appendix D, pp. 47-50.

<sup>iii</sup> Chart is based on interview questions developed from the following publication: Wells, Nora and Betsy Anderson, Families in Program and Policy FiPPs MCH Report: Interviews on Family Participation with State Title V Children with Special Health Care Needs Programs, Family Voices, 2005. Appendix D, pp. 50.

<sup>iv</sup> For the completion of Form 13, states are asked to rate six characteristics documenting family participation in CYSHCN programs. The six characteristics are 1) Family members participate on advisory committees or task forces and are offered training, mentoring and reimbursement, when appropriate; 2) Financial support (financial grants, technical assistance, travel and child care) is offered for parent activities or parent groups; 3) Family members are involved in the CYSHCN elements of the Title V MCH Block Grant application process; 4) Family members are involved in in-service training of CYSHCN staff and providers; 5) Family members are hired as paid staff or consultants to the state CYSHCN program (a family member is hired for his or her expertise as a family member); and 6) Family members of diverse cultures are involved in all of the above activities.

<sup>v</sup> Family-to-Family Health Information Centers (F2F HICs) are funded by the Family Opportunity Act of 2006, and are administered through the HRSA Maternal and Child Health Bureau. F2F HICs are staffed by knowledgeable parents and professionals, providing invaluable help to families through information, education, training, support and referral services. Some F2F HICs are independent family-run organizations, while others are broad based nonprofit

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agencies or organizations with a strong commitment to children and youth with special health care needs.

<sup>vi</sup> Special Project of Regional and National Significance (SPRANS): Funding for SPRANS grants comes from the Title V Maternal and Child Health Services Block Grant.