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How California Children's Services Programs in the 21 Whole-Child Model Counties Engage with Families

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Abstract

When families are engaged in their children's care – including being provided with the support necessary to allow meaningful participation – health care systems improve, the quality of care improves, and children and families are better served. This brief examines how families are currently engaged in the California Children's Services (CCS) program and provides suggestions for how family roles could be enhanced.

Between May 2016 and June 2017, with support from the Lucile Packard Foundation for Children's Health (LPFCH), an online survey on family engagement was sent to county CCS program administrators. Results from the 21 counties that will soon transition children to Medi-Cal managed care are analyzed in this brief.

Fifteen of the 21 counties seek input from families, primarily through satisfaction surveys (n=12). Four counties have Family Advisory Committees. The most common barrier to family engagement identified by respondents was budget limitations (n=11). The most common benefit reported was increased awareness and understanding of family issues and needs (n=8). Just 5 counties assessed their family engagement efforts as good or very good. With enhanced family engagement efforts and better support to families, county CCS programs and Medi-Cal managed care plans that are assuming care for children enrolled in CCS can benefit from the results of meaningful family participation.[1]

Background

Consumer participation in public health programs has the potential to improve services and promote a more accessible, accountable and appropriate system.[2] However, families of children with special health care needs (CSHCN) in California have not been consistently involved in policy and programmatic planning and decision-making with the government entities upon which they depend for services and supports.[3]

There are many opportunities to improve family engagement in the California Children's Services (CCS) program, including the newest change to the program under the California Department of Health Care Services' (DHCS) Whole-Child Model (WCM), under which children will receive CCS medical services through Medi-Cal managed care plans.

Nearly one-quarter of California families has a child with special health care needs.

Consequently, more than one million children and adolescents in the state have been identified as having a chronic or complex health condition[4] and approximately 200,000 of them, age birth to 21, are actively enrolled and served by the CCS program,[5] which is a part of the Integrated Systems of Care Division of DHCS. Eligibility for the program is based on specific medical diagnoses and family income.[6]

CCS is funded in part through a federal Title V Maternal and Child Health Block Grant that provides core funding to states to improve the health of mothers and children. In California, Block Grant funds are divided between the Maternal, Child and Adolescent Health Program (MCAH) of the Department of Public Health and the Integrated Systems of Care Division of DHCS.

Federal guidance related to the Block Grants encourages states to consistently engage families/consumers in partnership with their state maternal and child health programs. The federal Maternal and Child Health Bureau (MCHB) defines family/consumer partnership as "the intentional practice of working with families for the ultimate goal of positive outcomes in all areas through the life course. Family engagement reflects a belief in the value of the family leadership at all levels from an individual, community and policy level."[7] State programs are asked to document their efforts to sustain and diversify family participation. While state Title V funded programs are aware of the high value the MCHB ascribes to family participation, public health programs serving CSHCN report higher levels of family engagement than maternal and child health (MCH) programs. However, there is significant room for improvement in both programs.[8]

In 2014, LPFCH supported research on family engagement among more than 60 public agencies and programs in California that serve CSHCN.[9] The research found that some state and local government entities do incorporate and support family engagement, but overall involvement is inconsistent. Where families do participate, the roles they play in program planning, implementation and policy-making, and the support they receive to enable meaningful participation, varies tremendously.

Family engagement has many beneficial outcomes, including better quality of care, improved quality of life, decreased parental anxieties and fears, reductions in health care costs, improvement in families' communications and relationships with health professionals, increased patient, family and provider satisfaction, and more efficient use of services.[10] To create a high-quality system of care, the family perspective must be actively pursued and incorporated at all levels of the health care system – direct care, organizational design and governance, and policymaking.[11]

Given their responsibilities for quality of care, the plans also may want to enhance the roles families have played under the CCS program.

In California, while there is a need to broadly increase involvement of families in programmatic and policy activities, adoption of the Whole-Child Model provides an opportunity to examine existing family engagement efforts and identify areas for improvement. In 21 counties, the DHCS is shifting responsibility for the medical care of CCS-enrolled children from the counties' CCS programs to five Medi-Cal managed care plans. These plans are required by state legislation (SB586) to establish family

advisory committees. Since the health plans will be building on CCS precedents and activities, their family engagement planning and activities can benefit from understanding how families are currently engaged in the 21 counties. Given their responsibilities for quality of care, the plans also may want to enhance the roles families have played under the CCS program. In addition, CCS programs in the other 37 counties could benefit from comparing their family engagement efforts with those described in this issue brief.

Methods

In May 2016, the Association of Maternal and Child Health Programs (AMCHP) invited all 58 county CCS administrators to complete an online survey on family engagement in their programs and policies. Forty-five respondents, representing 33 of the 58 counties in California (57%), completed the survey. Of those respondents, 10 were from counties in which the WCM will be implemented.

In June of 2017, with the encouragement of the DHCS, the Foundation sent out an identical survey to the county CCS administrators for the 11 additional counties that will be implementing the WCM to obtain their responses. The findings in this brief are based on the responses from the 21 WCM counties only. The counties are: Del Norte, Humboldt, Lake, Lassen, Marin, Mendocino, Merced, Modoc, Monterey, Napa, Orange, San Luis Obispo, San Mateo, Santa Barbara, Santa Cruz, Shasta, Siskiyou, Solano, Sonoma, Trinity, and Yolo.

Gathering Input from Families

Over two-thirds of the programs (n=15) reported that they encourage or seek input from families. More than half of the counties gather this input via surveys/satisfaction surveys (n=12). A national survey by AMCHP found that 100% of state CSHCN programs sought input from families, so county programs in California are not doing as well in this regard.[12] Additional ways that input is gathered are listed in Table 1.

Table 1: How Programs Gather Input from Families

Mode for gathering input	Number of counties	Percent of counties*
Surveys/satisfaction surveys	12	57%
Family representatives on other advisory groups/task forces	3	14%
Partnerships with family organizations	3	14%
Families representatives as Family Health Liaisons	2	10%
Family representatives on CCS staff	1	5%
Family representatives on County Family-Centered Care Committee	1	5%
Focus groups/structured interviews	1	5%
Public hearings with opportunities to provide input	1	5%
Providing opportunities for input through website	1	5%

* Respondents could select all that applied, so percentage will not total to 100.

Although programs do seek input from families, family consultants are involved as representatives to program advisory groups, committees, task forces and workgroups in just 5 of the counties, and only 1 county describes extensive involvement (defined as more than 75% of its program groups including families).

Family Engagement Activities

Program administrators were asked about several specific family engagement activities. Seven counties currently operate one or more of these activities. Four have a Family Advisory Committee, 4 have a parent health liaison and 2 have a Family-Centered Care Workgroup.

Table 2: Counties Reporting Specific Family Engagement Activities

Family Engagement Activity	Del Norte	Merced	Modoc	Napa	Shasta	San Mateo	Yolo
Family Advisory Committee	X		X			X	X
Parent Health Liaison		X		X	X	X	
Family-Centered Care Workgroup	X			X			

Two counties employ family members as program staff either directly as a county employee or through a contract with another agency. This is much less common in these counties than is reported by states nationally, where 82% of programs employ a family member as staff.[13]

Some county programs provide training for families participating in program activities. The most common training activity is preparation for a specific meeting (n=4). Additional training activities are included in Table 3.

Table 3: Types of Training Offered to Families

Training Activity	Number of counties	Percent of counties*
Specific meeting preparation	4	19%
Mentoring	2	10%
Program/project management skills	1	5%
Awareness and education	1	5%
None at this time	14	67%

* Respondents could select all that applied, so percentage will not total to 100.

Compensation for Families

Unlike for public employees, participation in agency activities by external family representatives uses time and effort that would otherwise be devoted to family matters or their own work. Family organizations have consistently asked for various forms of compensation and support for family representatives. Four counties provided information about the ways they facilitate and compensate families for their participation in program activities. The examples they provided include:

- Transportation stipends and mileage reimbursement from county CCS program funds provided per event in the amount of $10 to $24
- An honorarium/participation stipend from the county Health Plan funds provided per event in the amount of $50-$74
- An hourly wage from county CCS program funds provided via a contract

with a parent-led community-based organization with the wage varying by activities
- Use of alternative ways for families to participate (website, email, Skype, video, conference call, webinar, social media)
- Meeting/event times occur during non-traditional hours and days, evenings, weekends
- Food is provided for families that attend
- On-site childcare is provided during meetings

Benefits of and Barriers to Family Engagement

Counties reported several valuable benefits as a result of family engagement. The most common benefits reported were increased awareness and understanding of family issues and needs (n=8), improved planning and policies resulting in services more directly responsive to family needs (n=6), and increased family/professional partnership and communication (n=5). These and other benefits are listed in Table 4.

Program administrators highlighted several barriers to family engagement. The most common barriers were budget limitations (n=11) including lack of resources/methods to pay family participants for time/expenses (n=8). These and additional barriers are listed in Table 5.

Table 4: Reported Benefits of Family Engagement

Benefit	Number of counties	Percent of counties*
Increased awareness and understanding of family issues and needs	8	38%
Improved planning and policies resulting in services more directly responsive to family needs	6	29%
Increased family/professional partnership and communication	5	24%
Assistance in evaluating program goals, objectives, and performance measures	4	19%
Increased availability of family members able to participate in training, public awareness, and policy development	1	5%
Increased understanding of programs and issues by legislature, state officials and the general public	1	5%

* Respondents could select all that applied, so percentage will not total to 100.

Table 5: Reported Barriers to Family Engagement

Barrier	Number of counties	Percent of counties*
Budget limitations	11	52%
Lack of resources/methods to pay family participants for time/expenses	8	38%
Lack of staff time to train and/or supervise family participants	7	33%
Family time constraints	7	33%
Unable to use technology and/or social media as a means of family engagement (ex. outreach to families, method of providing input, way for families to participate in program meetings)	6	29%
Difficulty keeping family members involved over time	5	24%
Limited access to families who could engage with the program because the program provides few/no direct services	3	14%
Difficulty identifying family participants	2	10%
Lack of training for family participants to support them in roles	2	10%
Concerns about maintaining confidentiality of program data and information	2	10%
Difficulty recruiting representation across geographic areas or from those in remote areas	1	5%
Difficulty with hiring system/merit system/civil service requirements (lack of appropriate job classifications, difficulty meeting job qualifications)	1	5%
Lack of knowledge/support from superiors about the value of family engagement	1	5%
Hiring freezes	1	5%
Difficulty getting families interested in prevention	1	5%

* Respondents could select all that applied, so percentage will not total to 100.

Program administrators reported several training needs so that they could better partner with families. The most common training need was linkages to family groups in their community (n=6). More than one third of program staff were not sure of their training needs (n=8).

Encouragingly, 17 counties are interested in receiving training or getting more information about how to increase family engagement in their programs. Additional training needs are listed in Table 6.

Table 6: Reported Family Engagement Training Needs of Programs

Training Need	Number of counties	Percent of counties*
I'm not sure at this time.	8	38%
Linkages to family groups in our community	6	29%
Difference between education and advocacy	4	19%
Opportunities to participate in community of practice on family engagement	4	19%
Opportunities to work with Family Voices for input in planning next steps related to family engagement	3	14%
Policymaking/impacting public policy	3	14%
CCS/MCAH history, legislation and programs	3	14%
Leadership skills	2	10%
Public speaking	2	10%
Models or examples of successful family engagement in MCAH programs	2	10%
Developing skills to more broadly represent families/family issues	2	10%
Cross-agency training (e.g. special education, office for children)	2	10%
Opportunities for mentoring/peer-to-peer learning with best-practice states and state family leaders	2	10%
Correspondence/effective writing skills	1	5%
Data analysis/interpretation	1	5%
None – there are no needs at this time.	1	5%

* Respondents could select all that applied, so percentage will not total to 100.

Evaluation of Family Engagement Activities

Counties did not give themselves high grades for their effectiveness engaging families in program development and planning. Just 5 counties rated their effectiveness as good or very good. The remaining counties rated their effectiveness as fair (n=9) or poor (n=7). None rated themselves as excellent.

Over half of the counties reported no formal process to evaluate the impact and effectiveness of family engagement (n=12). This is also a problem shared by states among whom only 25% report formally evaluating their efforts.[14] Seven counties use satisfaction surveys to evaluate family engagement activities, 2 did an internal assessment, and 1 sought information from outside family organizations.

Areas for Improvement

Counties have opportunities to improve the way staff members are taught about family engagement. Almost half of counties surveyed (n=10) do not provide any training for new and existing staff. A quarter provide ongoing staff development and training (n=5) and 1 county includes family engagement requirements among staff roles and responsibilities for performance evaluation.

Fifteen county programs reported no requirement for family engagement in service provision contracts, subcontracts or grants with other agencies, and another 4 counties reported not knowing whether this was required.

Based on the results of this survey, there are many areas where family engagement efforts could be improved. County CCS Programs and Medi-Cal managed care plans can implement

additional ways to gather input from families, such as including family representatives on advisory groups and task forces, and partnering with family organizations. Counties should consider establishing Family Advisory Committees, hiring parent health liaisons and/or establishing Family-Centered Care Workgroups. Compensation should be provided to family representatives to account for the time and effort necessary for their participation. The DHCS should consider training opportunities for program staff and Medi-Cal managed care plans to support family engagement efforts. Finally, family engagement efforts should be evaluated and adjusted to maximize their impact.

Recommendations

Having formal, structured family engagement, such as through forming a Family Advisory Committee, is an obvious and necessary starting point to improve quality and satisfaction with health care. In addition to developing Family Advisory Committees, county CCS programs and Medi-Cal managed care plans can implement a range of strategies to enhance their efforts and better support families to participate.

How to support family participation:

- Provide or support training and mentoring to parents and family members to enable leadership roles
- Provide supports such as childcare, stipends for travel and participation
- Identify and partner with support networks for families – for example the Family Resource Centers Network of California and Family Voices of California
- Develop effective materials to educate families and agency staff on the importance of family engagement

How to engage families effectively:

- Involve families as co-leaders in planning and decision-making
- Use a standard measure to assess family engagement in the health care system
- Include family engagement measures in performance measurement
- Convene informational hearings for families to inform elected officials of their needs in terms of policy changes

Suggestions for state level policy:

- Include families' perspectives in developing health care policies and legislation
- Require an audit of family participation by all state agencies that serve CSHCN
- Require each state agency that serves families to include family members in an advisory or decision-making role
- Develop mechanisms to enforce family engagement requirements
- Reward agencies and organizations that perform well on pre-determined family engagement measures
- Establish a cross-sector, state-level Family Advisory Committee that will be responsible for developing a standardized protocol for improving the quality of services
- Assure adequate funding to support the practice of family engagement by government agencies that serve children

When families are appropriately engaged and have been provided with the support necessary to allow effective engagement, health care systems improve, the quality of care provided improves, and children and families are better served.

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ABOUT THE FOUNDATION: The Lucile Packard Foundation for Children's Health is a public charity, founded in 1997. Its mission is to elevate the priority of children's health, and to increase the quality and accessibility of children's health care through leadership and direct investment. Through its Program for Children with Special Health Care Needs, the foundation supports development of a high-quality health care system that results in better health outcomes for children and enhanced quality of life for families.

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