

Report

It Takes a Family:

**An Analysis of Family Participation
in Policymaking for Public Programs
Serving Children with Special Health
Care Needs in California**



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Acknowledgments

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Executive Summary

Parents should participate in decision-making. We need to live with the outcome and we know our own children. We can help make better decisions.

– Kathy Zonana, California Children’s Services Parent Advisory Committee member, Santa Clara

Families and patient advocates long have said, “Nothing about me without me,” meaning that they need to be active participants in decisions that affect their health care and well-being. But how well is their request being honored? This report considers the role of family participation—i.e., by parents or guardians or youth—in government entities such as boards, advisory committees, and task forces that make policy and implementation decisions regarding services for California’s 1.4 million¹ children and youth with special health care needs (CSHCN).

The authors interviewed parents, advocates and administrators (Appendix A); reviewed literature regarding family participation, particularly regarding policy decisions (Appendix B); and conducted preliminary research regarding family participation on more than 60 California state- and county-level government policy entities that have roles in programs that serve children with special health care needs (Appendix C).

While some state and local government entities incorporate and support robust family participation, overall involvement of families is very inconsistent and often fairly anemic in policymaking and implementation decisions. There are substantial differences in the amount of family participation, the role families play in decision-making, and the support offered to families who do participate. This report:

- Reviews information regarding family participation requirements and support offered in a select range of government policy entities serving CSHCN, including health care, disability, education, child welfare and social justice agencies;
- Examines approaches to maximizing the value of family participation; and
- Makes recommendations, including that California state law should institutionalize family participation on government entities that serve CSHCN to ensure that the point of view of families is well represented in decision-making

It is fairly common for the federal government and for California programs serving CSHCN to articulate a commitment to coordinated, family-centered care and participation in decision-making by families. Families and the agencies that serve CSHCN stand to benefit when families are given a seat at the table with an opportunity to contribute to policy decisions. However, the system of care is not generally family-centered and is notoriously uncoordinated and fragmented, and policy decisions in these programs are routinely made without participation by families.

¹ The Child and Adolescent Health Measurement Initiative (CAHMI). (2010, November). *Children with Special Health Care Needs: A Profile of Key Issues in California*. Retrieved from Lucile Packard Foundation for Children’s Health: <http://www.lpfch.org/cshcn/fullreport.pdf>

Appendix C and Table 1 of this report summarize family participation on a select range of government policy entities. They present a picture of a disappointing lack of consistency in:

- the extent of family inclusion;
- the responsibilities—e.g. decision-making or advisory—of the entities upon which parents participate; and
- whether compensation for family members—including for childcare and travel—is provided.

There appears to be a notable lack of decision-making power among entities that do include families except where such decision-making authority has been prescribed by state or federal law.

Maximizing the Value of Family Participation at the Agency Level

Government policy entities serving CSHCN should commit to involving families in their decision-making and to developing the supports necessary for effective family involvement. A checklist on page 17 of this report outlines questions agencies should ask themselves to begin evaluating how well they are fostering family participation. The State of California and local agencies should, at minimum:

- Provide clear guidelines for family engagement, including articulating clear purpose, goals, and responsibilities. This is particularly important for families of CSHCN, many of whom may be unfamiliar with how government policy entities operate and whose time is especially precious;
- Assign an agency staff person families can count on for orientation, information and support; this support would include providing ongoing structures to ensure that families are well informed regarding policies and processes so they can effectively contribute to decisions;
- Shape policy entity membership and authority to maximize effectiveness of family participation; majority participation by families can help increase the likelihood that the voices of families are truly heard and that services are family centered;
- Ensure that family representation reflects the cultural, racial, ethnic, and linguistic diversity of California's CSHCN to facilitate an understanding of barriers to care for various populations, and to support the elimination of disparities in care;
- Provide supports that make it possible for family members to participate, including translation services at meetings; careful scheduling and use of technologies like web conferencing and conference calls; systems to include and gather input from other families; reimbursement for childcare and travel expenses, as well as stipends; and
- Work with family support organizations such as Family Resource Centers that can be good partners in selecting and training family members.

Addressing Family Participation through Legislative Action

The California Legislature should take the following actions:

- Conduct an audit of family participation to determine the current extent of participation on government policy entities serving CSHCN;
- Conduct informational field hearings with affected families regarding the need for greater family participation, and with government agencies regarding their commitment to this participation;
- Create a cross-agency advisory committee to guard against the widespread fragmentation/lack of coordination among programs that serve CSHCN;
- Require family representation and necessary supports on government policy entities of state and local government agencies serving CSHCN;
- Create mechanisms to periodically audit and enforce requirements for family participation; and
- Provide funding adequate to make the necessary institutional changes to support family participation.

Conclusion

The current, uncoordinated system serving CSHCN places tremendous additional burdens on often-overwhelmed families by asking them to try to patch together fragmented services as they attempt to ensure access to essential care for their children. California should stand by its articulated commitment to coordinated, family-centered care by including families in the decision-making processes of the government policy entities of programs that provide services to CSHCN.

Introduction

Terms like “system of care” are often used to refer to the panoply of services available to CSHCN in California. In fact there is no “single system” but rather a complex “series of systems” that exist independently of each other, occasionally overlapping and sometimes conflicting...[resulting] in an extraordinarily complex maze of services...that can confuse even the savviest advocate and result in delayed or denied services for children.²

In California, there is a frequently articulated, but generally unkept, commitment to family-centered, coordinated care—supported by family participation in decision-making—in programs serving children with special health care needs (CSHCN).

The federal Maternal and Child Health Bureau (MCHB), which provides Title V federal funding for California Children's Services (CCS)—the primary funder for health care delivery to children with complex medical conditions—promotes six core outcomes for CSHCN receiving services through Title V. Key among them is that “Families of children and youth with special health care needs partner in decision-making at all levels.”³ Additionally, CCS Performance Measure 5 includes criteria that “Family members participate on advisory committees or task forces and are offered training, mentoring, and reimbursement when appropriate.”⁴

In reality, policy decisions for MCHB-supported programs like CCS, as well as other California programs for CSHCN, are routinely made without participation by families, even though families know their children's needs best and experience firsthand the extraordinary efforts required to negotiate the health care “system” and other programs that serve them.

Nearly 60 percent of California's CSHCN have multiple chronic conditions, and 42 percent of CSHCN need at least five types of health services, many of which are complex services that go well beyond primary care.⁵ Because of the nature of their children's needs, even in the best of systems families of CSHCN face exceptional challenges in providing for their health and well-being:

- California, with its nonsystematic maze of services, has the highest percentage nationwide of CSHCN whose parents experience stress due to parenting.⁵
- About 1 in 6 publicly insured California CSHCN has a family that spends 11 hours or more per week providing or coordinating care.⁶

2 Smith, K., Soman, L., Duenas, J., Garro, N., Burke, M., Robinson, T., & Inkelas, M. (2009, December). *California's Service System for Children and Youth with Special Health Care Needs*. Retrieved from <http://www.lpfch.org/californiaservicesystem/servicesystemreport.pdf>

3 *Core Outcomes: Key Measures of Performance*. (2008). Retrieved from HRSA: The National Survey of Children with Special Health Care Needs Chartbook 2005-2006: <http://mchb.hrsa.gov/cshcn05/mco/intro.htm>

4 Children's Medical Services Plan and Fiscal Guidelines, CCS Performance Measure 5—Family Participation (issued 11/21/11)

5 The Child and Adolescent Health Measurement Initiative (CAHMI). (2010, November). *Children with Special Health Care Needs: A Profile of Key Issues in California*. Retrieved from Lucile Packard Foundation for Children's Health: <http://www.lpfch.org/cshcn/fullreport.pdf>

6 U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. (2013). *California*. Retrieved from National Survey of Children with Special Health Care Needs Chartbook 2009-2010: <http://mchb.hrsa.gov/cshcn0910/state/pages/ca.html>

- 29.4 percent of children with special health care needs in California have families who have had to cut back on or stop working.⁶

The system places tremendous additional burdens on these often overwhelmed families by asking them to patch together fragmented services to ensure access to essential care for their children.

California ranks poorly compared to other states on numerous measures of health care quality for CSHCN:⁵

- The state ranks last in the nation on a minimum quality of care index that assesses adequacy of insurance, provision of basic preventive care, and meeting minimal criteria for having a medical home.
- Approximately four out of five CSHCN fail to receive one or more basic aspects of quality care.
- CSHCN with the greatest complexity of needs are often those who experience the greatest challenges in accessing the high quality services they need.

These problems are exacerbated when families' well-informed point of view is not integrated into the decision-making that has the potential to make these systems more functional. All government programs serving CSHCN should be required to seek family input in ways that are effective and predictable and that lead to better coordinated, more family-centered care.

Family Participation Yields Multiple Benefits

Families and the agencies that serve CSHCN both stand to benefit when families are given a seat at the table and an opportunity to contribute to policy decisions. A review of the literature and findings from interviews conducted for this study (Appendix A) indicate that progress can be made—in big and small ways—to move systems to higher levels of responsiveness to the needs of the children they serve.

- **Increased family-centered perspective:** Families are the experts regarding their children's needs and experiences with California's services for CSHCN. They hold the critical perspective needed to advance coordinated, family-centered care.
- **Increased cultural competence:** By including parents who reflect the demographics of families being served, government agencies can increase the cultural competence and family-centered perspective of their decision-making bodies and of the services they provide.
- **Increased effective outreach to other parents and family members:** Parents are arguably the best and most trusted resources to other parents in their communities. Similar to the rationale for staffing parent support organizations with parents and family members, including families in decision-making on government policy entities increases the capacity of an agency to access harder-to-reach communities.
- **Increased advocacy in the community:** When family members are included on policy entities, such as school boards, they can serve in the community as credible advocates for needed support. In an article about the role of school boards in education reform, Donald McAdams, president of the Center of Reform of School Systems, notes that “board members can be in many different places at the same time and, everywhere, they can talk with credibility about what is and what needs to be done. Collectively, they are the best teacher.”⁷
- **Increased capacity of family members:** By involving parents in decision-making related to policy and governance in a structured, supportive way, agencies are increasing the capacity of individual parents to participate in the short term, as well as to become increasingly engaged in additional productive long-term roles.

According to *Parent Leadership: Successful Strategies*,⁸ evaluating parent leadership is a key component of program development. Although the evaluation of parent leadership is still in early development, a number of outcomes have been identified by family support organizations and public and private programs. When consumers of family support services (i.e., parents and other family members) are an integral part of planning and program development, the following has been found:

7 McAdams, D. R. (2006, Fall). Urban School Boards and Their Communities. *Voices in Urban Education*, pp. 14-21. National Center for Cultural Competence. (2004, April). *Planning for Cultural and Linguistic Competence in Systems of Care...for children & youth with social-emotional and behavior disorders and their families*. Retrieved from Georgetown University Center for Child and Human Development: http://nccc.georgetown.edu/documents/SOC_Checklist.pdf

8 *Parent Leadership: Successful Strategies*. (2002, January). Retrieved from FRIENDS National Resource Center for CBFPS Programs: https://www.google.com/url?sa=t&rect=j&q=&esrc=s&source=web&cd=1&cad=rja&ved=0CC4QFjAA&url=http%3A%2F%2Ffriendsnrc.org%2Fdirect-download-menuitem%2Fdoc_download%2F69-successful-strategies-of-parent-leadership-&ei=WkDHUvaSH4LaoAS614KYDw&usg=AFQjCNEEQ-pS5bZe

- Services are better delivered, more cost effective and more culturally sensitive;
- Customer satisfaction is improved;
- The likelihood of positive family outcomes is higher;
- The system is more responsive;
- Families are better able to use services and help other families;
- Families build skills;
- Communities are healthier as their capacities to better support families are enhanced; and
- Parents model for children ways they can be involved and contribute.

Inconsistencies and Lack of Coordination Abound

Appendix C provides information regarding family participation on a select range of government policy entities. It is notable that no single state-level entity holds responsibility for coordination of services provided to CSHCN. Table 1 summarizes a few aspects of the Appendix C information and points to some key observations:

- There is a striking lack of consistency in approaches taken regarding, for example, the extent of family inclusion, the responsibilities of the entities upon which parents participate, and whether compensation is provided to support family members' participation;
- Travel costs and/or compensation, as well as reimbursement for childcare expenses, are especially important issues for families with CSHCN. Taking time off from other responsibilities and finding difficult-to-obtain, costly substitute care can be stressful for families. Some entities do provide such support:
 - In Los Angeles, the CCS Family Centered Care Committee provides parent members incentive compensation for every hour of family participation on the Committee.
 - The State Interagency Coordinating Council on Early Intervention makes child care reimbursable for parent representatives who require care for their child with special needs while the parent is engaged in Council responsibilities.⁹

Many other government policy entities serving CSHCN provide no such compensations for family representatives.

- Most often, the government policy entities reviewed did not hold decision-making responsibilities but rather were advisory in nature.
- It is rare to see majority participation occur on the government policy entities reviewed *unless* it has been required by state or federal law or regulation. Some important state and federal laws require majority participation on government policy entities and create good precedents for expanding family participation on other California government entities:
 - In California, the Lanterman Developmental Disabilities Services Act requires of Regional Centers that “a minimum of 50 percent of the members of the governing board shall be persons with developmental disabilities or their parents or legal guardians.”¹⁰ The Lanterman Act also requires that at least 20 of the 31 voting members on the California State Council on Developmental Disabilities (SCDD) be persons with disabilities or family members.¹¹ It also establishes that 60 percent of the members of the SCDD Area Boards

9 *Bylaws, State of California Interagency Coordinating Council on Early Intervention*. (2007, November). Retrieved from State of California Department of Developmental Services: http://www.dds.ca.gov/EarlyStart/docs/ByLaws_ICC.pdf

10 *Bill Number SB367 CHAPTERED*. (2013, October 9). Retrieved from Official California Legislative Information: http://www.leginfo.ca.gov/pub/13-14/bill/sen/sb_0351-0400/sb_367_bill_20131009_chaptered.html

11 *Welfare and Institutions Code Section 4520-4523*. (n.d.). Retrieved from Official California Legislative Information: <http://www.leginfo.ca.gov/cgi-bin/displaycode?section=wic&group=04001-05000&file=4520-4523>

must be “persons with developmental disabilities or the immediate relatives, guardians, or conservators of these persons.”¹²

- At a federal level, the Developmental Disabilities Bill of Rights Act establishes that at least 60 percent of the members of State Councils on Developmental Disabilities be “(i) individuals with developmental disabilities; (ii) parents or guardians of children with developmental disabilities; or (iii) immediate relatives or guardians of adults with mentally impairing developmental disabilities who cannot advocate for themselves.”¹³
- California state law requires that “Each county shall appoint an in-home supportive services advisory committee that shall be comprised of not more than 11 individuals. No less than 50 percent of the membership of the advisory committee shall be individuals who are current or past users of personal assistance services paid for through public or private funds or as recipients of services under this article.”¹⁴
- Federally Qualified Health Center agency law requires that in order to qualify as an FQHC the center’s governing board must be “composed of individuals, a majority of whom are being served by the center and who, as a group, represent the individuals being served by the center.”¹⁵
- Federal law requires that states establish an advisory panel “for the purpose of providing policy guidance with respect to special education and related services for children with disabilities in the State” and that “a majority of the members of the panel shall be individuals with disabilities or parents of children with disabilities (ages birth through 26).” California Education Code expands upon that requirement by providing additional guidance about selection.¹⁶
- California Education Code requires that each Special Education Local Plan Area establish a community advisory committee and that “at least the majority of such committee shall be composed of parents of pupils enrolled in schools participating in the local plan, and at least a majority of such parents shall be parents of individuals with exceptional needs.”¹⁷
- Federally, the Head Start Act requires the formation of a policy council at each Head Start agency, and that the majority of members be parents whose children are currently served by the program.¹⁸

12 *Welfare and Institutions Code Sections 4543-4548*. (n.d.). Retrieved from Official California Legislative Information: <http://www.leginfo.ca.gov/cgi-bin/displaycode?section=wic&group=04001-05000&file=4543-4548>

13 *Public Law 106-402*. (n.d.). Retrieved from U.S. Government Printing Office: <http://www.gpo.gov/fdsys/pkg/PLAW-106publ402/html/PLAW-106publ402.htm>

14 *California Welfare and Institutions Code 12301.3*. (n.d.). Retrieved from FindLaw: <http://codes.lp.findlaw.com/cacode/WIC/1/d9/3/3/7/s12301.3>

15 *Authorizing Legislation*. (n.d.). Retrieved from Health Resources and Services Administration: <http://bphc.hrsa.gov/policiesregulations/legislation/index.html>

16 *Advisory Commission (ACSE) Requirements*. (2013, July 30). Retrieved from California Department of Education: <http://www.cde.ca.gov/sp/se/as/acserqmnt.asp>

17 *EDUCATION CODE SECTION 56190-56194*. (n.d.). Retrieved from Official California Legislative Information: <http://www.leginfo.ca.gov/cgi-bin/displaycode?section=edc&group=56001-57000&file=56190-56194>

18 *Head Start Act*. (2008). Retrieved from Head Start: An Office of the Administration for Children and Families Early Childhood Learning & Knowledge Center (ECLKC): <http://eclkc.ohs.acf.hhs.gov/hslc/standards/Head%20Start%20Act>

- While some government policy entities support strong, clear participation by families, this is generally the exception rather than the rule:
 - State law requires that Regional Center governing boards—with *authority* over the functioning of the Centers—be a majority of persons with disabilities or their family members, while many other entities serving CSHCN only provide sporadic and poorly defined *advisory* responsibilities to family members.
 - State law requires that governing boards of Regional Centers reflect the geographic and ethnic characteristics of the area to be served and that they report annually regarding the performance of the Regional Center in providing services that are *linguistically and culturally appropriate*. This is in contrast with many other government policy entities serving CSHCN that have no requirements regarding the diversity of their members, and for those that do, no specified connection between those guidelines and reporting.
 - Some organizations, such as the Child Welfare Council, include requirements in their bylaws regarding *offering support to family members*. Most other government policy entities serving CSHCN have no such formal approaches.
 - The state Interagency Coordinating Council on Early Intervention describes specifically in its bylaws the requirement that the Council produce an “annual report for the Governor and the Secretary of Education on the status of early intervention programs and services for eligible children and their families in California” while many other government policy entities serving CSHCN are *unclear about the group’s responsibilities/purview*.

Maximizing Effectiveness of Family Participation

I need to feel [the policy entity] is organized and meaningful because participation takes a maximum effort by the parents I work with. They need to understand what their role will be in adding value.

– Yvette Baptiste, parent of a child with special health care needs, Executive Director, Eastern Los Angeles Family Resource Center

Making a commitment to effective participation is an important first step for California government policy entities serving CSHCN. Once the commitment is made, there is much that agencies need to do to maximize the likelihood of success. Policy entities should take the following steps to support effective involvement of families in providing advice and in participating in decisions regarding policies related to planning, implementing and monitoring programs that serve their children.

- **Provide clear guidelines for engagement:** A critical factor for success in any group is having clear purpose, goals, and responsibilities. This is particularly true for families of CSHCN whose time is precious. The Federation of Families highlights this element, noting that “policy groups that are successful at sustaining family involvement have clearly defined mission, purposes, policies, operational procedures, responsibilities, lines of authority and accountability, and reliable clerical and administrative support for communication and logistics.”¹⁹ For families—many of whom may be unfamiliar with the operations of government policy entities—it is especially important that entities have clarity regarding their processes.
- **Assign a policy entity staff person families can count on for information and support:** A policy entity staff person sensitive to the needs of families of CSHCN should be designated as a liaison to provide organization and structure to family involvement. According to the Mental Health Services Oversight and Accountability Commission, “frequently stakeholders, particularly those from un-served, underserved and/or inappropriately served racial, ethnic and cultural communities, may be expected to participate in planning activities while experiencing a lack of comfort and familiarity with the process.”²⁰ A designated staff person’s responsibilities would include providing orientation and ongoing education, information and support, including:
 - Familiarizing families with the policy entity’s authority, responsibilities, budget, limitations, and relationship to other agencies;
 - Providing clarity about family members’ roles and responsibilities;

¹⁹ Federation of Families for Children’s Mental Health. (2001, September). *Involving Families in Policy Group Work*. Retrieved from NC Department of Health and Human services: <http://www.ncdhhs.gov/mhddsas/services/serviceschildfamily/Toolbox/collaboratives/ii-involvingfamiliesinpolicygrpwrk.pdf>

²⁰ Client and Family Leadership Committee. (2011, May). *Client-driven, Family-focused Transformation of the Mental Health System Through the California Mental Health Services Act*. Retrieved from Mental Health Services Oversight and Accountability Commission: http://www.mhsoac.ca.gov/MHSOAC_Publications/docs/Publications/TransformationPolicyPaper_May2011.pdf

- Communicating the policy entity's processes, including how often meetings are conducted; for how long and where; typical agenda; and rules for conducting meetings;
- Providing pre- and post-meeting opportunities for family members to be familiarized with agenda items, apprised of background information, and given the opportunity to review what occurred during meetings; and
- Providing feedback about whether and how family members' advice is implemented.

It is a heavy burden for one family member to represent all the families in a community or state. Having a diverse group of peers to work with on a policy group is very appealing to family members because it assures them that the diversity of family experiences, cultures, backgrounds, and perspectives will have a voice at the table.

– Federation of Families for Children's Mental Health²¹

- **Shape policy entity membership and authority to maximize effectiveness of family participation:** There should be an adequate number of family members to assure that family representatives:
 - Do not feel isolated;
 - Are never required to be the only family representative;
 - Feel supported by the presence of other family members; and
 - Are able to competently represent the diversity of CSHCN.

Some California policy entities serving CSHCN already require majority participation by family members. Following is a sampling of state and local government entities that require majority participation by family members. (See Appendix C for greater detail.)

- In Home Supportive Services Advisory Committees
- Federally Qualified Health Center Governing Boards
- Regional Centers
- California State Council on Developmental Disabilities
- California State Council on Developmental Disabilities – Area Boards
- Advisory Committee on Special Education
- Head Start Policy Councils and Policy Committees
- Special Education Local Plan Area Community Advisory Committees
- Alameda County Developmental Disabilities Planning and Advisory Council
- Alameda County Paratransit Advisory and Planning Committee

²¹ Federation of Families for Children's Mental Health. (2001, September). *Involving Families in Policy Group Work*. Retrieved from NC Department of Health and Human services: <http://www.ncdhhs.gov/mhddsas/services/serviceschildfamily/Toolbox/collaboratives/ii-involvingfamiliesinpolicygrpwrk.pdf>

In addition to the requirement in state law that a majority of the governing committee of Regional Centers be families or persons with disabilities, Regional Centers are permitted to have their own Consumer Advisory Committees to offer an even more in-depth family point of view.

Following is a sample of California state and local entities that require family participation, but *do not specify that it be majority participation*:

- California Children’s Services Pilot Program: Enhanced Primary Case Management Pilot Advisory Board
- Child Welfare Council
- Mental Health Services Oversight and Accountability Commission – State Commission
- Local Child Care and Development Planning Councils
- State Interagency Coordinating Council on Early Intervention

In calculating the optimal number of family members to include, it is important to keep in mind that some family members may be unable to attend meetings from time to time because of responsibilities related to their CSHCN.

For us to not include patients speaking Spanish and other languages—it’s just not real. There is slim chance of impacting them if they’re not involved.

– Libby Hoy, parent of a child with special health care needs, and Founder/CEO, Patient and Family Centered Care Partners

■ **Assure that family representation reflects California’s diversity:** Policy entities should reflect the cultural, racial, ethnic, and linguistic diversity of California CSHCN populations to facilitate an understanding of barriers to care for various populations, and to support the elimination of disparities in care. California has a particularly diverse and high-need population of CSHCN. Many of these families are struggling to meet the basic needs of these children.

- Children of color represent approximately 52 percent of the CSHCN population in the state.
- CSHCN who are low income, of color, or publicly insured are more likely than other children with special needs to have poor health status and sub-optimal health care experiences.
- Just 30 percent of publicly insured CSHCN receive coordinated, ongoing, comprehensive care within a medical home.⁵

According to the National Center for Cultural and Linguistic Competence, “Linguistic competence is the capacity of an organization and its personnel to communicate effectively and convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, those who have low literacy skills or are not literate, and individuals with disabilities.”²² This may include, but is not limited to, the need for bilingual/bicultural staff and foreign language interpretation services.

²² National Center for Cultural Competence. (2004, April). *Planning for Cultural and Linguistic Competence in Systems of Care...for children & youth with social-emotional and behavior disorders and their families*. Retrieved from Georgetown University Center for Child and Human Development: http://nccc.georgetown.edu/documents/SOC_Checklist.pdf

■ **Provide supports that make it possible for family members to participate:**

- Translation services at meetings;
- Ability to join meetings by web conferencing and conference calls, when family obligations make in-person attendance difficult;
- Support for activities related to work on the government policy entity, including outreach to gather input from other families;
- Consideration of travel issues when setting meeting locations;
- Reimbursement for childcare and travel expenses; and
- Stipends for attending meetings.

Many parents start by saying they feel intimidated. “I could never do that,” they say. We provide ongoing training about the importance of actual participation—not just sitting there. We support parents to understand their roles and responsibilities and the benefits of their voice.

– Yolanda Gonzales, Director, Child Education and Development Services,
Head Start, Kern County

■ **Work with family support organizations in selecting and training families**

Family Resource Centers, located throughout the state, are staffed by parents of CSHCN. They support family participation in decision-making, and can be partners in training family members.

Family representatives should be chosen as carefully as any other board members. It is a mistake to choose a token family member and make the claim the policy entity has achieved family participation. Among other things, family representatives should be selected for their ability to speak on behalf of the needs of all families, that is, the ability to take the specific—their own child’s story—to the broad. As the PACER Center states in its *From Experience to Influence: The Power of a Parent’s Story*, “When the purpose of [a parent’s] story is to influence decision-making about the way things are done at a system-wide level, [they should match their] example of personal experience to a policy objective.”²³

When parents participating in education-related advisory committees were surveyed, they identified a number of qualities they found important in parent leaders, including someone who is available and approachable, able to listen and understand; has knowledge about the topic at hand and confidence when speaking in front of people; and has the ability to raise issues and encourage open discussion and the ability not to take things personally.²⁴ These are some of the qualities government policy entities should look for in family representatives.

²³ *From Experience to Influence: The Power of a Parent’s Story*. (2006). Retrieved from Pacer Center: <http://www.pacer.org/parent/php/php-cl21.pdf>

²⁴ Boeltzig, H., Kusminsky, M., Foley, S., Robinson, R., Popper, B., & Gutierrez-Wilson, M. (2009, May). Advancing Parent-Professional Leadership: Effective Strategies for Building the Capacity of Parent Advisory Councils in Special Education. *The Institute Brief(27)*. The Institute for Community Inclusion, University of Massachusetts Boston. Retrieved from The Institute for Community Inclusion: http://www.communityinclusion.org/article.php?article_id=278

Self-Assessment

Participation of Families of Children with Special Health Care Needs in Processes Related to Decision Making

A review of the literature and interviews conducted for this study pointed to the effectiveness of family participation that can be fostered through the actions below. Government policy groups should periodically assess themselves to track their progress and make improvements. They can examine each of the nine questions below and ask: 1) Have we achieved this?; 2) If not, what is our plan for achieving it?; and 3) What should be our immediate next steps?

1. Are the policy entity's purpose, goals, and responsibilities clearly articulated and understood by everyone involved?
2. Has the agency assigned a staff person families can count on for information and support?
3. Is there a process in place for thoroughly familiarizing—initially and ongoing—participating families with the agency's and the policy group's operations and processes?
4. Does the policy group's authority allow parents to participate directly in decision-making?
5. Where participation is advisory only, is there a formal, predictable and robust process for engaging families to provide advice?
6. Are there adequate numbers of families participating so that families feel supported by the presence of other families and so there are adequate numbers of family representatives at meetings even when family responsibilities cause some members to be absent?
7. Does the family representation competently represent the cultural, racial, ethnic, and linguistic diversity of California CSHCN? Is there support for family representatives to systematically gather input from other families representing California's diverse communities?
8. Are families provided supports to make effective participation possible including translation services at meetings; the ability to join meetings by web conferencing and conference calls; consideration of travel issues when setting meeting locations; reimbursement for childcare and travel expenses; and stipends for attending meetings.
9. Is the government policy group working with family support organizations in selecting and training families? Is there a process and criteria in place for selecting appropriate family representation and for taking advantage of the expertise of family support organizations in training family representatives?

Recommendations

When money problems happen, family participation is the first thing to go. We need requirements for family participation and we need the funding.

– Laurie Soman, Director, Children's Regional Integrated Service System (CRISS) Project

The California Legislature should take the following actions to ensure appropriate family representation on state and local policy entities of public agencies serving CSHCN.

- **An audit of family participation:** The Legislature—or, alternatively, the California State Auditor—should require each state agency that includes programs that serve CSHCN to report whether those programs include family participation on their policy entities; whether there is an adequate number of family representatives; the process for choosing family representatives; the level of authority/responsibility/participation regarding decision-making; the clarity of roles and the support and training offered to family representatives; the diversity of members and the availability of translation services; and the availability of financial support for transportation and childcare.
- **Informational field hearings:** The Legislature should conduct a series of informational field hearings around the state to engage families of CSHCN in informing the Legislature regarding the level of need for family participation on government policy entities that serve CSHCN, and to hear from government agencies regarding their commitment to family participation on these entities.
- **A cross-agency advisory committee:** As long as the system of care for CSHCN remains fragmented among numerous and uncoordinated government agencies, so too will be the experience of families, adding to the burden on the very people it is intended to serve. Family participation on one entity might dramatically improve/advance care for the individuals served in that program. However, since many CSHCN and their families must interact with numerous systems, it is critical to devise solutions that take into consideration the numerous touch points these families have with government organizations. A state-level permanent Family Advisory Committee should be established to adopt a common definition and standards for family-centered care and to improve quality, family-centeredness and coordination of care. This Family Advisory Committee should include representation from families, family groups, all government agencies that serve CSHCN, and others.
- **Establishment of family representation:** The Legislature should require state and local government agencies that serve CSHCN to:
 - Establish formal opportunities at each level of government to include significant family participation in decision-making regarding planning and implementation of service systems;

- Establish family advisory committees with formal relationships—including shared membership—with decision-making entities to bring further family input to decision-making;
 - Establish and support structured ways for committee members who represent families to be informed by the experiences of other families of CSHCN and to serve as ambassadors to traditionally harder-to-reach communities;
 - Establish mechanisms to support ongoing information, education, training and support for leadership development among families to improve their capacity to participate fully in decision-making at the state and local levels;
 - Provide necessary supports to cover family costs including child care, travel and time; and,
 - Create, adopt and regularly evaluate shared criteria among agencies and provide training for agencies regarding best practices for maximizing the effectiveness of family participation and assuring cultural competency in decision-making.
- **Mechanisms for enforcement:** Mechanisms should be created to periodically audit and enforce requirements for family participation.
- **Adequate resources:** Adequate funding should be provided to make the necessary institutional changes to support family participation on government policy entities serving CSHCN.

Moving Forward in the Absence of Legislative Requirements

While this report calls upon the California Legislature to take decisive steps to require well-supported, effective family participation in creating and implementing policies in programs that serve CSHCN, it also recommends that, until the Legislature takes such actions, government policy entities take *voluntary* actions to foster family participation. These entities should conduct their own internal audits, identify opportunities for family participation in policy decisions, and independently develop the procedures and supports suggested above with confidence that increased family participation will make agencies more effective in reaching their goals of providing family-centered care and improving outcomes for CSHCN.

Regarding the Private Sector

Many families of CSHCN are ineligible for important government programs and may obtain services for their children through private health plans and private providers. It would be wise for policymakers to consider requiring that these private entities create avenues for receiving input into decisions that affect CSHCN and their families.

Table 1

Summary of key information regarding all of the entities included in Appendix C of this brief. Appendix C reviews select boards/committees/task forces/councils/panels of state and local government agencies that serve CSHCN. As with Appendix C, this summary table is divided into the following sections: health, disability, education, and other. Please see Appendix C for more in-depth information on each of these entities.

Legend		Family Participation					Formation			Responsibility			Diversity in Selection							Compensation for Family Members					
		MFPR	MFPI	FPR	FPI	FFP	Federal Law/Regulation	State Law/Regulation	Other	Governing/Decision-Making	Inter-Agency Coordination/Planning	Advisory	General Diversity	Ethnic/Cultural	Socioeconomic Status	Age	Gender	Language	Disability	Geographic Community	Per Diem or for Time	Necessary Expenses	Childcare	Travel	
Family Participation Categories		Where there is no ✓, it means that we were not successful in identifying that information.																							
MPFR: Majority Family Participation Required																									
MPI: Majority Family Participation Identified																									
FPR: Family Participation Required																									
FPI: Family Participation Identified																									
FFP: Family Friendly Participation																									
HEALTH																									
California Children's Services (CCS) Cardiac Technical Advisory Committee								✓			✓														
CCS Community Neonatal Intensive Care Unit (NICU) Multidisciplinary Teams									✓																
CCS Executive Committee									✓																
CCS Intermediate NICU Multidisciplinary Teams									✓																
CCS NICU Technical Advisory Committee											✓														
CCS Pediatric Intensive Care Unit (PICU) Multidisciplinary Teams									✓																
CCS PICU Technical Advisory Committee											✓														
CCS Regional NICU Multidisciplinary Teams									✓																

Legend		Family Participation					Formation			Responsibility			Diversity in Selection							Compensation for Family Members					
		MFPR	MFPI	FPR	FPI	FFP	Federal Law/Regulation	State Law/Regulation	Other	Governing/Decision-Making	Inter-Agency Coordination/Planning	Advisory	General Diversity	Ethnic/Cultural	Socioeconomic Status	Age	Gender	Language	Disability	Geographic Community	Per Diem or for Time	Necessary Expenses	Childcare	Travel	
<p>Family Participation Categories</p> <p>MPFR: Majority Family Participation Required</p> <p>MPI: Majority Family Participation Identified</p> <p>FPR: Family Participation Required</p> <p>FPI: Family Participation Identified</p> <p>FFP: Family Friendly Participation</p>		Where there is no ✓, it means that we were not successful in identifying that information.																							
CCS Pilot Program: Enhanced Primary Case Management – Pilot Advisory Board (PAB)				✓				✓			✓														
California Emergency Medical Services for Children – Technical Advisory Committee					✓			✓			✓														
LA County CCS Family Centered Care Committee			✓					✓			✓										✓				
LA County CCS Transition Committee					✓			✓			✓														
Alameda County CCS Parent Advisory Committee		✓						✓			✓												✓		
Santa Clara County CCS Parent Advisory Committee		✓						✓			✓														
California Mental Health Planning Council				✓			✓	✓			✓	✓	✓		✓	✓			✓						
California Mental Health Services Authority (CalMHSA) – Advisory Committee						✓					✓	✓	✓		✓				✓						
San Francisco Mental Health Services Act (MHSA) – Advisory Committee						✓					✓	✓													
Shasta County Mental Health Services Act (MHSA) – Advisory Committee					✓						✓	✓													
Child Health and Disability Prevention Program (CHDP)																									
Covered California Plan Management and Delivery System Reform Advisory Group											✓		✓	✓					✓						

Legend		Family Participation					Formation			Responsibility			Diversity in Selection							Compensation for Family Members				
<p>Family Participation Categories</p> <p>MPFR: Majority Family Participation Required</p> <p>MPI: Majority Family Participation Identified</p> <p>FPR: Family Participation Required</p> <p>FPI: Family Participation Identified</p> <p>FFP: Family Friendly Participation</p>		Where there is no ✓, it means that we were not successful in identifying that information.					Federal Law/Regulation	State Law/Regulation	Other	Governing/Decision-Making	Inter-Agency Coordination/Planning	Advisory	General Diversity	Ethnic/Cultural	Socioeconomic Status	Age	Gender	Language	Disability	Geographic Community	Per Diem or for Time	Necessary Expenses	Childcare	Travel
Department of Health Care Services (DHCS) Stakeholder Advisory Committee (SAC)											✓													
Federally Qualified Health Centers		✓					✓		✓			✓			✓			✓	✓					
Health Care Program for Children in Foster Care																								
In Home Supportive Services Advisory Committee (County Level)		✓						✓			✓													
Medi-Cal Managed Care – Advisory Workgroup						✓		✓			✓													
CalOptima – Member Advisory Committee		✓						✓			✓													
LA Care Health Plan – Executive Community Advisory Committee					✓		✓				✓													
Mental Health/Developmental Disability Collaborative				✓			✓			✓														
Mental Health Services Oversight and Accountability Commission (MHSOAC) State Commission			✓				✓	✓		✓														
Mental Health Services Oversight and Accountability Commission (MHSOAC) Client and Family Leadership Committee			✓								✓		✓											

Legend	Family Participation					Formation			Responsibility			Diversity in Selection							Compensation for Family Members				
	MFPR	MFPI	FPR	FPI	FFP	Federal Law/Regulation	State Law/Regulation	Other	Governing/Decision-Making	Inter-Agency Coordination/Planning	Advisory	General Diversity	Ethnic/Cultural	Socioeconomic Status	Age	Gender	Language	Disability	Geographic Community	Per Diem or for Time	Necessary Expenses	Childcare	Travel
<p>Family Participation Categories</p> <p>MPFR: Majority Family Participation Required</p> <p>MPI: Majority Family Participation Identified</p> <p>FPR: Family Participation Required</p> <p>FPI: Family Participation Identified</p> <p>FFP: Family Friendly Participation</p>	Where there is no ✓, it means that we were not successful in identifying that information.																						
Mental Health Services Oversight and Accountability Commission (MHSOAC) Cultural and Linguistic Competency Committee			✓								✓		✓										
Mental Health Services Oversight and Accountability Commission (MHSOAC) Services Committee			✓								✓		✓										
Office of Health Equity Advisory Committee (OHE-AC)				✓		✓					✓	✓											✓
Olmstead Committee				✓			✓				✓	✓	✓				✓	✓	✓				
SAMHSA – Alameda SAMHSA Early Connections Full Partnership				✓			✓	✓				✓											
DISABILITY																							
Alameda County Developmental Disabilities Planning and Advisory Council – Board of Directors		✓						✓	✓														
California Department of Developmental Services Consumer Advisory Committee	✓						✓			✓		✓						✓	✓				✓
California State Council on Developmental Disabilities	✓					✓			✓														
California State Council on Developmental Disabilities – Area Boards	✓					✓			✓										✓				

Legend		Family Participation					Formation			Responsibility			Diversity in Selection							Compensation for Family Members					
		MFPR	MFPI	FPR	FPI	FFP	Federal Law/Regulation	State Law/Regulation	Other	Governing/Decision-Making	Inter-Agency Coordination/Planning	Advisory	General Diversity	Ethnic/Cultural	Socioeconomic Status	Age	Gender	Language	Disability	Geographic Community	Per Diem or for Time	Necessary Expenses	Childcare	Travel	
<p>Family Participation Categories</p> <p>MPFR: Majority Family Participation Required</p> <p>MPI: Majority Family Participation Identified</p> <p>FPR: Family Participation Required</p> <p>FPI: Family Participation Identified</p> <p>FFP: Family Friendly Participation</p>		Where there is no ✓, it means that we were not successful in identifying that information.																							
Contra Costa County Developmental Disabilities Council – Board of Directors											✓														
Regional Centers		✓					✓		✓																
State Interagency Coordinating Council on Early Intervention				✓			✓				✓		✓	✓				✓	✓		✓	✓			
EDUCATION																									
Advisory Commission on Special Education (ASCE)		✓					✓	✓			✓											✓		✓	
Alameda Task Force on Inclusive Child Care								✓																	
California School for the Blind – Community Advisory Committee					✓			✓			✓														
California School for the Deaf, Fremont								✓																	
California School for the Deaf, Riverside – Community Advisory Committee		✓						✓			✓														
Head Start Health Services Advisory Committee				✓							✓		✓												
Head Start Parent Committee		✓									✓											✓	✓		
Head Start Policy Councils and Policy Committees		✓					✓		✓													✓	✓		
Improving Special Education Services (ISES) Stakeholder Group								✓		✓															

Legend		Family Participation					Formation			Responsibility			Diversity in Selection							Compensation for Family Members					
		MFPR	MFPI	FPR	FPI	FFP	Federal Law/Regulation	State Law/Regulation	Other	Governing/Decision-Making	Inter-Agency Coordination/Planning	Advisory	General Diversity	Ethnic/Cultural	Socioeconomic Status	Age	Gender	Language	Disability	Geographic Community	Per Diem or for Time	Necessary Expenses	Childcare	Travel	
<p>Family Participation Categories</p> <p>MPFR: Majority Family Participation Required</p> <p>MPI: Majority Family Participation Identified</p> <p>FPR: Family Participation Required</p> <p>FPI: Family Participation Identified</p> <p>FFP: Family Friendly Participation</p>		Where there is no ✓, it means that we were not successful in identifying that information.																							
Local Child Care and Development Planning Councils (LPCs)				✓						✓			✓							✓					
Special Education Advisory Committee						✓		✓				✓								✓					
Special Education Local Planning Area (SELPA) Community Advisory Committees (CACs)		✓					✓				✓														
State Advisory Council (SAC) on Early Learning & Care							✓				✓														
OTHER																									
Alameda Paratransit Advisory and Planning Committee (PAPCO)		✓						✓			✓														
California Blue Ribbon Commission on Children in Foster Care					✓			✓			✓														
Child Welfare Council				✓			✓			✓											✓				
Family and Juvenile Law Advisory Committee							✓				✓														
First 5 State Commission							✓		✓																
First 5 County Commissions							✓		✓																
Los Angeles County Blue Ribbon Commission on Child Protection								✓																	

Appendix A: List of Interviewees

Jill Abramson, MD, MPH, Chief
Medical Policy and Consultation Section
Department of Health Care Services
Systems of Care Division

Yvette Baptiste, Executive Director
Eastern Los Angeles Family Resource Center

Christina Bethell, PhD, MBA, MPH
Professor of Pediatrics, Oregon Health and Science
University; Director, Child and Adolescent Health
Measurement Initiative

Polly Bleavins, Resource Coordinator
North County Alpha Resource Center

Eileen Crumm, Executive Director
Family Resource Network

Robert Dimand, MD, Chief Medical Officer
California Children's Medical Services

Juno Duenas, Executive Director
Support for Families

Dean Germano, CEO
Shasta Community Health Center

Yolanda Gonzales, Director
Child Education and Development Services
Head Start, Kern County

Libby Hoy, Founder/CEO
Patient and Family Centered Care Partners

Heidi Hudson, Administrator
CCS Program, Santa Clara County

Jennifer Kent, Principal (former)
Health Management Associates

Linda Joy Landry, Steering Committee Chair
Family Resource Centers Network of California

Monica Linarez, Program Manager for Health
and Education
Parents Can

Wendy Longwell, Parent Liaison
Rowell Family Empowerment

Pip Marks, Manager
Family Voices of California

Peter Miller, MD, Former CCS Director

Margie Gutierrez-Padilla, LCSW
Early Connections Coordinator
Alameda County Behavioral Health Care Services

Sylvia Pizzini, Assistant Secretary
California Health and Human Services

Shelley Rouillard, Chief Deputy Director
CA Dept of Managed Health Care

Katie Schlageter, Family Health Services
Deputy Director
California Children's Services Administrator
Alameda County Public Health Department

Tim Shannon, Lobbyist
Children's Specialty Care Coalition

Kathi Smith RN, MN, Associate Director
for Administration
USC University Center for Excellence in Developmental
Disabilities

Sandi Soliday, Alameda County
Public Health Department
Developmental Disabilities Council

Laurie A. Soman, Director
CRISS Project
Director
Alameda County Medical Home Project
Senior Policy Analyst
Lucile Packard Children's Hospital

Trish Stanionis, Executive Director
Yolo Family Service Agency

Diane Storman, Exceptional Family Resource Center

Margaret Tatar, Chief
Medi-Cal Managed Care Division
Department of Health Care Services

Karen I. Wayman, PhD, LPCH Endowed Director of
Family-Centered Care
Lucile Packard Children's Hospital
Child Development Specialist
Stanford University School of Medicine Dept of Pediatrics
Division of Hepatology & Gastroenterology

Jana Weaver, Parent Member
Parent Advisory Committee, CCS Program, Santa Clara
County

Kathy Zonana, Parent Member
Parent Advisory Committee, CCS Program, Santa Clara
County

Appendix B: Resources

Helpful Information Regarding Family Participation

- Agency for Healthcare Research and Quality. (2008, April). *Guide to Developing a Community-Based Patient Safety Advisory Council*. Retrieved from Agency for Healthcare Research and Quality: <http://www.ahrq.gov/professionals/quality-patient-safety/patient-safety-resources/resources/patient-safety-advisory-council/patient-safety-advisory-council.pdf>
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Appendix C: Levels of Family Participation in Select Organizations

Appendix C reviews select boards/committees/task forces/councils/panels of state and local government agencies that serve children with special health care needs (CSHCN). The information below is divided into the following sections: health, disability, education, and other. Where available, information is listed regarding the nature of family participation on the committee, including whether:

- majority participation by families is required on the entity (MFPR);
- majority participation by families has been identified (MFPI);
- some participation by families is required on the entity (FPR);
- where a requirement of participation has not been identified, whether some voluntary participation by families has been identified (FPI);
- there is a family-friendly requirement of participation by some of the following, without indicating a specific requirement that family members themselves participate: family members; consumers/patients; and/or consumer/patient organizations (FFP);

in addition to:

- the committee's authority/responsibility;
- whether the entity derives its authority/responsibility from legislation or elsewhere; and
- special notes where appropriate. N/I below indicates "not identified."

Health

California Children's Services (CCS) Cardiac Technical Advisory Committee²⁵

Family Participation: Not required/not currently included.

Committee's Authority/Responsibility: The committee provides technical advice to CCS from medical experts.

Authorizing Legislation/Formation: This was created by the CCS Branch Chief.

CCS Community Neonatal Intensive Care Unit (NICU) Multidisciplinary Teams

Family Participation: Not required²⁶

Committee's Authority/Responsibility: Coordination of patient care in the community NICU²⁷

Authorizing Legislation/Formation: N/I

²⁵ All information about this committee came from the following source: Robert Dimand, M.D. (2014, January 16). CMO, California CCS. (M. O'Sullivan, Interviewer)

²⁶ "There shall be an identified NICU multidisciplinary team...which shall consist of, at a minimum, a CCS-paneled neonatologist, a clinical nurse specialist, a respiratory care practitioner and a CCS-paneled medical social worker with current experience and practice in neonatal care and whose professional requirements are defined in Section 3.25.2/F. Optional members of the Community NICU multidisciplinary team may include, but are not limited to, the following: CCS-paneled clinical registered dietitian, CCS-paneled occupational therapist and CCS-paneled physical therapist" California Children's Services Manual of Procedures, Chapter 3 - Provider Standards, Community NICU. (1999, January 1). Retrieved from California Department of Health Care Services: <http://www.dhcs.ca.gov/services/ccs/Documents/CommunityNICU.pdf>

²⁷ "There shall be an identified NICU multidisciplinary team...which shall have the responsibility for the coordination of all aspects of patient care" (California Children's Services Manual of Procedures, Chapter 3 - Provider Standards, Community NICU, 1999). Retrieved from: <http://www.dhcs.ca.gov/services/ccs/Documents/CommunityNICU.pdf>

CCS Executive Committee²⁸

Family Participation: Not required/not currently included

Committee's Authority/Responsibility: N/I

Authorizing Legislation/Formation: N/I

CCS Intermediate NICU Multidisciplinary Teams

Family Participation: Not required

Committee's Authority/Responsibility: Coordination of patient care in the intermediate NICU²⁹

Authorizing Legislation/Formation: N/I

CCS NICU Technical Advisory Committee³⁰

Family Participation: Not required/not currently included

Committee's Authority/Responsibility: The committee provides technical advice to CCS from medical experts.

Authorizing Legislation/Formation: This was created by the CCS Branch Chief.

CCS Pediatric Intensive Care Unit (PICU) Multidisciplinary Teams

Family Participation: Not required³¹

Committee's Authority/Responsibility: Coordination of patient care in the intermediate PICU³²

Authorizing Legislation/Formation: N/A

CCS PICU Technical Advisory Committee³³

Family Participation: Not required/ not currently included.

Committee's Authority/Responsibility: The committee provides technical advice to CCS from medical experts.

Authorizing Legislation/Formation: This was created by the CCS Branch Chief.

28 All information about this committee came from the following source: Robert Dimand, M.D. (2014, January 16). CMO, California CCS. (M. O'Sullivan, Interviewer)

29 "There shall be an identified NICU multidisciplinary team...which shall have the responsibility of coordination of all aspects of patient care" California Children's Services Manual of Procedures, Chapter 3 - Provider Standards, Intermediate NICU. (1999, January 1). Retrieved from California Department of Health Care Services: <http://www.dhcs.ca.gov/services/ccs/Documents/IntermediateNICU.pdf>

30 All information about this committee came from the following source: Robert Dimand, M.D. (2014, January 16). CMO, California CCS. (M. O'Sullivan, Interviewer)

31 "There shall be an identified PICU multidisciplinary team...Which shall consist of, at a minimum, a CCS-paneled pediatric intensivist, a clinical nurse specialist, a respiratory care practitioner and a medical social worker whose professional requirements are defined in Section 3.32/F. Optional members of the PICU multidisciplinary team may include, but are not limited to, the following CCS-paneled providers: clinical registered dietitian, occupational therapist and physical therapist" California Children's Services Manual of Procedures, Chapter 3 - Provider Standards, Pediatric Intensive Care Units (PICUs). (1999, January 1). Retrieved from California Department of Health Care Services: <http://www.dhcs.ca.gov/services/ccs/Documents/PICU.pdf>

32 "There shall be an identified PICU multidisciplinary team... Which shall be responsible for the coordination of all aspects of patient care" California Children's Services Manual of Procedures, Chapter 3 - Provider Standards, Pediatric Intensive Care Units (PICUs). (1999, January 1). Retrieved from California Department of Health Care Services: <http://www.dhcs.ca.gov/services/ccs/Documents/PICU.pdf>

33 All information about this committee came from the following source: Robert Dimand, M.D. (2014, January 16). CMO, California CCS. (M. O'Sullivan, Interviewer)

CCS Regional NICU Multidisciplinary Teams

Family Participation: Not required³⁴

Committee's Authority/Responsibility: Coordination of patient care in the regional NICU³⁵

Authorizing Legislation/Formation: N/I

CCS Pilot Program: Enhanced Primary Case Management – Pilot Advisory Board (PAB)

(Alameda County Health Care Services Agency) FPR

Family Participation: Yes. One-third of members will be parents or youth.³⁶

Committee's Authority/Responsibility: Advisory³⁷

Authorizing Legislation/Formation: N/I

Special Note(s):

There is also a PAB family subcommittee planned. Among other things, this subcommittee will have interpretation and translation services available.³⁸

California Emergency Medical Services for Children³⁹ – Technical Advisory Committee FPI

Family Participation: Identified, but not required.⁴⁰

Committee's Authority/Responsibility: Not specified.

Authorizing Legislation/Formation: N/I

34 Governing language: "There shall be an identified NICU multidisciplinary team...which shall consist of, at a minimum, a CCS-paneled neonatologist, a clinical nurse specialist, a respiratory care practitioner and a CCS-paneled medical social worker with current experience and practice in neonatal care and whose professional requirements are defined in Section 3.25.1/F. Optional members of the Regional NICU multidisciplinary team may include, but are not limited to, the following: CCS-paneled clinical registered dietitian, CCS-paneled occupational therapist and CCS-paneled physical therapist" California Children's Services Manual of Procedures, Chapter 3 - Provider Standards, Regional NICU. (1999, January 1). Retrieved from California Department of Health Care Services: <http://www.dhcs.ca.gov/services/ccs/Documents/RegionalNICU.pdf>

35 "There shall be an identified NICU multidisciplinary team...which shall have the responsibility of coordination of all aspects of patient care" California Children's Services Manual of Procedures, Chapter 3 - Provider Standards, Regional NICU. (1999, January 1). Retrieved from California Department of Health Care Services: <http://www.dhcs.ca.gov/services/ccs/Documents/RegionalNICU.pdf>

36 (n.d.). Alameda County CCS Pilot Demonstration Project, Section G: Demonstration Pilot Advisory Board.

37 "The PAB will provide advice on the development, implementation and ongoing activities of the Pilot to the Pilot Administration which will draw on the expertise of PAB members in developing and reviewing proposed Pilot policies and procedures concerning access to care, care delivery, and evaluation of care." (n.d.). Alameda County CCS Pilot Demonstration Project, Section G: Demonstration Pilot Advisory Board.

38 (n.d.). Alameda County CCS Pilot Demonstration Project, Section G: Demonstration Pilot Advisory Board.

39 "The goal of the EMSC program is to ensure that acutely ill and injured children have access to high quality, coordinated, and comprehensive emergency and critical care services appropriate for the special needs of children...The EMSC program manager at the EMS Authority provides technical assistance to the local EMS agencies in the integration of EMSC into their local EMS system. The technical assistance by EMS Authority includes an emphasis on quality of care, continuity of care, family-centered care, cultural diversity, care for children with special needs, and rehabilitation." EMS Systems Division - EMS for Children. (n.d.). Retrieved from California Emergency Medical Services Authority: http://www.emsa.ca.gov/EMS_for_Children

40 Currently one parent, as well as some child experts, sits on the committee. Robert Dimand, M.D. (2014, January 16). CMO, California CCS. (M. O'Sullivan, Interviewer)

LA County CCS Family Centered Care Committee⁴¹ MFPI

Family Participation: Families comprise the majority⁴²

Committee's Authority/Responsibility: Advisory⁴³

Authorizing Legislation/Formation: In 2002, the LA County CCS formed the LA County CCS Family-Centered Care Committee (FCC) in response to MCH Title V performance standard number five.

Special Note(s):

Parents receive both support for their role and compensation for their time.⁴⁴

LA County CCS Transition Committee⁴⁵ FPI

Family Participation: The committee includes one family member⁴⁶

Committee's Authority/Responsibility: Advisory⁴⁷

Authorizing Legislation/Formation: The committee was established by LA County CCS.

Special Note(s):

The California Department of Health Care Services September 23, 2010, CCS Information Notice No. 10-20, "Statewide Guidelines for Health Care Transition Planning for Children with Special Health Care Needs" provides guidance related to transition planning for CSHCN.⁴⁸

Alameda County CCS Parent Advisory Committee⁴⁹ MFPR

Family Participation: Participants have to be family members⁵⁰

Committee's Authority/Responsibility: Advisory⁵¹

Authorizing Legislation/Formation: The committee was formed by Alameda County CCS.

Special Note(s):

Parents are given a stipend for child care (if needed).

Spanish language translation is available.

41 All information about this committee came from the following sources: Baptiste, Y. (2014, January 26). Executive Director, Eastern Los Angeles Family Resource Center. (Email correspondence with M. O'Sullivan); and, Stephen Melli, M.D. (2014, January 16). Assistant Medical Director, LA County CCS. (M. O'Sullivan, Interviewer)

42 The committee currently includes six family representatives and several CCS staff.

43 The FCC is an advisory body to LA County CCS.

44 In 2013, LA County CCS contracted with the Family Resource Centers Network of Los Angeles County to support better resourced family participation—including family members who chair the committee—as well as improved community connections for CCS families to receive parent support. The FCC parent members receive incentive compensation for every hour of family participation on the Committee.

45 All information about this committee came from the following source: Stephen Melli, M.D. (2014, January 16). Assistant Medical Director, LA County CCS. (M. O'Sullivan, Interviewer).

46 The Committee includes a family member from the Los Angeles CCS Family Centered Care Committee who works as part of the Committee to insure a family centered approach in the establishment of transition policy/procedures and communication with clients/families.

47 LA County CCS established and convenes its Transition Committee to advise LA County CCS regarding transition planning.

48 Retrieved from: <http://www.dhcs.ca.gov/services/ccs/Pages/CCSIN.aspx#2010>

49 All information for this committee came from the following source: Eileen Crumm, MPA, PhD (2014, January 27). Executive Director, Family Resource Network of Alameda County. (Email correspondence with M. O'Sullivan)

50 "Participants must be a family member (ie. have a child served by CCS within the last 3 years), and live in Alameda County...There are 8 active members of the committee, two FRN staff and one CCS liaison," who is a CCS staff member. From: Eileen Crumm, MPA, PhD (2014, January 27). Executive Director, Family Resource Network of Alameda County. (Email correspondence with M. O'Sullivan)

51 "The group wrote a charter for itself and is now working on the materials that CCS uses with families to try to make them more family friendly and culturally appropriate." Eileen Crumm, MPA, PhD (2014, January 27). Executive Director, Family Resource Network of Alameda County. (Email correspondence with M. O'Sullivan)

Santa Clara County CCS Parent Advisory Committee⁵² MFPR

Family Participation: Majority family participation is required.

Committee's Authority/Responsibility: Advisory

Authorizing Legislation/Formation: The committee was formed by Santa Clara County CCS and Santa Clara County Public Health Department.

California Mental Health Planning Council⁵³ FPR

Family Participation: While majority of council members are persons with mental disabilities, family members, or organizations advocating for people with mental disabilities, legislative language does not outline a number that must be persons with mental disabilities or family members.⁵⁴

Committee's Authority/Responsibility: Review, Advisory, and Recommendation. There are numerous duties outlined in state statutes.⁵⁵

Authorizing Legislation/Formation: Federal: Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) Reorganization Act of 1991 (became Public Law 102-321).⁵⁶ State: CA Welfare and Institutions Codes 5514, 5771-5772, 5820, 5821.⁵⁷

Special Note(s):

Diversity of membership: Members must represent a balance of state and local levels. They also "should be balanced according to demography, geography, gender, and ethnicity. Members should include representatives with interest in all target populations, including, but not limited to, children and youth, adults, and older adults."⁵⁸

The Director of Health Care Services appoints council members.⁵⁹

52 All information about this committee came from the following source: Heidi Hudson. (2013, September 6). CCS Administrator, Santa Clara County Public Health Department. (M. O'Sullivan, Interviewer)

53 "The California Mental Health Planning Council is mandated by federal and state statute to advocate for children with serious emotional disturbances and adults and older adults with serious mental illness, to provide oversight and accountability for the public mental health system, and to advise the Administration and the Legislature on priority issues and participate in statewide planning" California Mental Health Planning Council (CMHPC). (2013, November 12). Retrieved from California Department of Health Care Services: <http://www.dhcs.ca.gov/services/mh/Pages/MH-PlanningCouncil.aspx>

54 "Members of the planning council shall be appointed in a manner that will ensure that at least one-half are persons with mental disabilities, family members of persons with mental disabilities, and representatives of organizations advocating on behalf of persons with mental disabilities. Persons with mental disabilities and family members shall be represented in equal numbers" California Mental Health Planning Council State Statutes. (n.d.). Retrieved from California Department of Health Care Services: <http://www.dhcs.ca.gov/services/MH/Documents/Advocacy%20Committee/CA%20Mental%20Health%20Planning%20Council%20State%20Statutes.pdf>

55 California Mental Health Planning Council State Statutes. (n.d.). Retrieved from California Department of Health Care Services: <http://www.dhcs.ca.gov/services/MH/Documents/Advocacy%20Committee/CA%20Mental%20Health%20Planning%20Council%20State%20Statutes.pdf>

56 Bill Summary and Status, 102nd Congress (1991-1992), S.1306. (n.d.). Retrieved from The Library of Congress: <http://thomas.loc.gov/cgi-bin/bdquery/z?d102:SN01306>:

57 California Mental Health Planning Council State Statutes. (n.d.). Retrieved from California Department of Health Care Services: <http://www.dhcs.ca.gov/services/MH/Documents/Advocacy%20Committee/CA%20Mental%20Health%20Planning%20Council%20State%20Statutes.pdf>

58 California Mental Health Planning Council State Statutes. (n.d.). Retrieved from California Department of Health Care Services: <http://www.dhcs.ca.gov/services/MH/Documents/Advocacy%20Committee/CA%20Mental%20Health%20Planning%20Council%20State%20Statutes.pdf>

59 (California Mental Health Planning Council State Statutes. (n.d.). Retrieved from California Department of Health Care Services: <http://www.dhcs.ca.gov/services/MH/Documents/Advocacy%20Committee/CA%20Mental%20Health%20Planning%20Council%20State%20Statutes.pdf>

California Mental Health Services Authority (CalMHSA)⁶⁰ – Advisory Committee FFP

Family Participation: Half of the advisory committee are “stakeholder members,” which could be consumers or groups/organizations.⁶¹

Committee’s Authority/Responsibility: Advisory⁶²

Authorizing Legislation/Formation: The Advisory Committee was created “to serve as a hub of communication and disseminate program information to stakeholders, partners, the Executive Committee and the Board of Directors.”⁶³

Special Note(s):

Diversity: “Each stakeholder member shall occupy a position of influence and be empowered to speak for his/her organization, and shall contribute to diverse representation of consumers and families, cultural groups, and age spans and geographic regions. Stakeholder members are selected by application to CalMHSA.”⁶⁴

San Francisco Mental Health Services Act (MHSA)⁶⁵ – Advisory Committee

Family Participation: While about 30% of the original membership “was comprised of individuals who have or have had personal experience as consumers of mental health services,”⁶⁶ the website does not specify the current composition.

Committee’s Authority/Responsibility: Advisory. The meetings “serve as platforms to discuss the progress of MHSA implementation and provide updates about further State implementation of the other components of MHSA.”⁶⁷

Authorizing Legislation/Formation: “The MHSA Advisory Committee was formed in FY2005-06. At the end of the initial planning process, all the task force members were requested to apply for membership in the new MHSA Advisory Committee. About half of the defunct task force became members of the MHSA Advisory Committee and additional members were recruited to ensure diverse community representation.”⁶⁸

Shasta County Mental Health Services Act (MHSA) – Advisory Committee

Family Participation: The committee includes “several community members that represent a diverse group of stakeholders,” however, the website does not specify whether any of the community members are consumers or

60 “The mission of CalMHSA is to provide member counties a flexible, efficient, and effective administrative/fiscal structure focused on collaborative partnerships and pooling efforts in: Development and implementation of common strategies and programs; Fiscal integrity, protections, and management of collective risk; and, Accountability at state, regional, and local levels” Welcome to the California Mental Health Services Authority. (2013). Retrieved from California Mental Health Services Authority: <http://calmhsa.org/>

61 “The Advisory Committee shall consist of twelve members. Six of the members shall be current members of the Board of Directors, and of these six, one shall be a member of the Executive Committee and each of the other five shall represent a CMHDA region. There shall be six stakeholder members, five of which shall represent a CMHDA region. One Board member and one stakeholder shall act as co-Chairs of the Advisory Committee.” California Mental Health Services Authority Bylaws. (2012, October 11). Retrieved from California Mental Health Services Authority: <http://calmhsa.org/wp-content/uploads/2011/11/CalMHSA-Bylaws-revision-10-11-12-FINAL1.pdf>

62 “The Advisory Committee shall advise the Executive Committee and/or the Board of Directors regarding the following subjects: Regular reporting from Program Partners in key areas related to Core Principles adopted by the Authority; Development and administration of a system for compiling, analyzing and reporting stakeholder feedback on the statewide PEI and other programs; New programs or structures to be created, including program monitoring, compliance, and reporting of results; Member services and expansion of the Authority’s services” California Mental Health Services Authority Bylaws. (2013, October 11). Retrieved from California Mental Health Services Authority: <http://calmhsa.org/wp-content/uploads/2011/11/CalMHSA-Bylaws-revision-10-11-12-FINAL1.pdf>

63 California Mental Health Services Authority Bylaws. (2012, October 11). Retrieved from California Mental Health Services Authority: <http://calmhsa.org/wp-content/uploads/2011/11/CalMHSA-Bylaws-revision-10-11-12-FINAL1.pdf>

64 California Mental Health Services Authority Bylaws. (2012, October 11). Retrieved from California Mental Health Services Authority: <http://calmhsa.org/wp-content/uploads/2011/11/CalMHSA-Bylaws-revision-10-11-12-FINAL1.pdf>

65 “The Mental Health Services Act (MHSA), also known as Prop. 63, was approved by California voters in November 2004 and became law in January 2005. MHSA expands mental health services to persons who have serious mental illness or who are seriously emotionally disturbed and whose service needs are not being met through other funding sources. MHSA is funded through an additional 1% income tax on Californians whose annual income exceeds \$1 million” Homepage. (n.d.). Retrieved from Mental Health Services Act of San Francisco: <http://sfmhsa.org/index.htm>

66 About Us. (n.d.). Retrieved from Mental Health Services Act of San Francisco: http://sfmhsa.org/about_us.html

67 About Us. (n.d.). Retrieved from Mental Health Services Act of San Francisco: http://sfmhsa.org/about_us.html

68 About Us. (n.d.). Retrieved from Mental Health Services Act of San Francisco: http://sfmhsa.org/about_us.html

family members.⁶⁹

Committee's Authority/Responsibility: Advisory. The committee provides “input and guidance for the planning, implementation and oversight of the Mental Health Services Act.”⁷⁰

Authorizing Legislation/Formation: N/I

Child Health and Disability Prevention Program (CHDP)⁷¹

Family Participation: N/I

Committee's Authority/Responsibility: N/I

Authorizing Legislation/Formation: N/I

Special Note(s):

While CHDP is mandated on a state level, it is operated locally.⁷²

Covered California Plan Management and Delivery System Reform Advisory Group⁷³

Family Participation: In 2014, membership will include “educated health care consumers who are qualified health plan enrollees.”⁷⁴

Committee's Authority/Responsibility: Advisory⁷⁵

Authorizing Legislation/Formation: N/I

Special Note(s):

Diversity of membership: “Covered California strives to ensure that Health Plan Advisory Group members represent California’s cultural, geographic and economic diversity.”⁷⁶

69 MSHA Advisory Committee. (n.d.). Retrieved from Shasta County: http://www.co.shasta.ca.us/index/hhsa_index/mental_wellness/mhsa_admin/mhsa_advisory_committee_copy1.aspx

70 MSHA Advisory Committee. (n.d.). Retrieved from Shasta County: http://www.co.shasta.ca.us/index/hhsa_index/mental_wellness/mhsa_admin/mhsa_advisory_committee_copy1.aspx

71 “The CHDP program provides complete health assessments for the early detection and prevention of disease and disabilities for low-income children and youth. A health assessment consists of a health history, physical examination, developmental assessment, nutritional assessment, dental assessment, vision and hearing tests, a tuberculin test, laboratory tests, immunizations, health education/anticipatory guidance, and referral for any needed diagnosis and treatment...The CHDP program oversees the screening and follow-up components of the federally mandated Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program for Medi-Cal eligible children and youth” CDHP Program Overview. (2013). Retrieved from California Department of Health Care Services: <http://www.dhcs.ca.gov/services/chdp/Pages/ProgramOverview.aspx>

72 The current Children’s Medical Services Plan notes that “The CHDP program is financed and has standards established at the State level. The Program is operated at the local level by local health departments for each county and three cities” Children’s Medical Services Plan and Fiscal Guidelines. (2011, November 21). Retrieved from California Department of Health Care Services: <http://www.dhcs.ca.gov/formsandpubs/publications/Documents/CMS/PFG/current/PFGCurrentFull.pdf>

73 “The purpose of the Health Plan Advisory Group is to collect California-specific perspectives from key experts and stakeholders, provide advice and recommendations and serve as a sounding board to the Covered California Board and staff to assist in the continual refinement of policies and strategies to ensure Covered California offers high quality and affordable health plans and that it operates in way that promotes better value and improves the health care delivery system.” Covered California. (n.d.). Plan Management and Delivery System Reform Advisory Group Charter. Retrieved from California Health Benefit Exchange: <http://www.healthexchange.ca.gov/StakeHolders/Documents/Charter%20-%20Plan%20Management%20and%20Delivery%20System%20Reform%20Advisory%20Group.pdf>

74 “Members are recognized experts in their fields, including: Health plans; Health care providers; Health care delivery and public health experts from independent academic, research or public health entities; Small business representatives and self-employed individuals; Consumer advocates with direct and substantial experience in health care; Large employers or large employer coalitions with direct and substantial experience in purchasing health care; California Department of Insurance (ex officio representative); Department of Managed Health Care (ex officio representative); Beginning in 2014, educated health care consumers who are qualified health plan enrollees.” Covered California. (n.d.). Plan Management and Delivery System Reform Advisory Group Charter. Retrieved from California Health Benefit Exchange: <http://www.healthexchange.ca.gov/StakeHolders/Documents/Charter%20-%20Plan%20Management%20and%20Delivery%20System%20Reform%20Advisory%20Group.pdf>

75 “Insurance plans offered in Covered California must be certified to ensure they meet federal and state requirements for “qualified health plans.” The Group provides input on qualified health plan contracting strategies and ongoing benefit design issues as well as strategies to promote health care value and drive delivery system reform.” Covered California. (n.d.). Plan Management and Delivery System Reform Advisory Group Charter. Retrieved from California Health Benefit Exchange: <http://www.healthexchange.ca.gov/StakeHolders/Documents/Charter%20-%20Plan%20Management%20and%20Delivery%20System%20Reform%20Advisory%20Group.pdf>

76 Covered California. (n.d.). Plan Management and Delivery System Reform Advisory Group Charter. Retrieved from California Health Benefit Exchange: <http://www.healthexchange.ca.gov/StakeHolders/Documents/Charter%20-%20Plan%20Management%20and%20Delivery%20System%20Reform%20Advisory%20Group.pdf>

Department of Health Care Services (DHCS) Stakeholder Advisory Committee (SAC)⁷⁷

Family Participation: Family participation is not required⁷⁸

Committee's Authority/Responsibility: Advisory

Authorizing Legislation/Formation: After Assembly Bill 4x 6 was passed in 2009, the SAC was brought together to support preparation of an implementation plan.⁷⁹ The committee has continued to exist to support both 1115 Bridge to Reform Waiver implementation and health care reform.⁸⁰

Federally Qualified Health Centers⁸¹ MFPR

Family Participation: Yes. Consumers served by the health center comprise the majority⁸²

Committee's Authority/Responsibility: Governing & Decision-Making

Authorizing Legislation/Formation: Designation of an FQHC has to do with receiving a grant (or having been determined to meet the same requirements) under Section 330 of the Public Health Service (PHS) Act⁸³

Special Note(s):

There is specific guidance that the consumers should be representative of broader consumer demographics (age, race, sex, and if possible, SES)

Health Care Program for Children in Foster Care

Family Participation: N/I

Committee's Authority/Responsibility: N/I

Authorizing Legislation/Formation: N/I

Special Note(s):

Currently, HCPCFC is overseen by local CDHP programs.⁸⁴

and%20Delivery%20System%20Reform%20Advisory%20Group.pdf

77 "The purpose of the SAC is to provide DHCS with valuable input on ongoing 1115 Bridge to Reform Waiver implementation efforts as well as help DHCS successfully bridge to national health care reform" DHCS Stakeholder Advisory Committee (SAC). (2013). Retrieved from California Department of Health Care Services : <http://www.dhcs.ca.gov/Pages/DHCSStakeholderAdvisoryCommittee.aspx>

78 "SAC members are recognized stakeholders/experts in their fields, including but not limited to, beneficiary advocacy organizations, and representatives of various Medi-Cal provider groups" DHCS Stakeholder Advisory Committee (SAC). (2013). Retrieved from California Department of Health Care Services : <http://www.dhcs.ca.gov/Pages/DHCSStakeholderAdvisoryCommittee.aspx>

79 California Section 1115 Comprehensive Demonstration Project Waiver; A Bridge to Reform: A Section 1115 Waiver Proposal. (2010, June 3). Retrieved from California Department of Health Care Services: <http://www.dhcs.ca.gov/provgovpart/Documents/A%20Bridge%20to%20Reform%206-10-2010.pdf>

80 DHCS Stakeholder Advisory Committee (SAC). (2013). Retrieved from California Department of Health Care Services : <http://www.dhcs.ca.gov/Pages/DHCSStakeholderAdvisoryCommittee.aspx>

81 "For more than 45 years, HRSA-supported health centers have provided comprehensive, culturally competent, quality primary health care services to medically underserved communities and vulnerable populations. Health centers are community-based and patient-directed organizations that serve populations with limited access to health care." Governance. (n.d.). Retrieved from Health Resources and Services Administration: <http://bphc.hrsa.gov/policiesregulations/governance/index.html>

82 "At least 51 percent of the board's members must be patients or "consumers" of the health center. These consumer board members must reasonably represent the individuals served by the health center in terms of demographic factors: ethnicity; race; sex; Where possible, it is encouraged that socioeconomic status be considered as well." Governance. (n.d.). Retrieved from Health Resources and Services Administration: <http://bphc.hrsa.gov/policiesregulations/governance/index.html>

83 Federally Qualified Health Center, Rural Health Fact Sheet Series. (2013, January). Retrieved from Department of Health and Human Services: <http://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/downloads/fqhc-factsheet.pdf>

84 Currently, HCPCFC is overseen by local CDHP programs All County Information Notice No. I-55-99. (1999, September 2). Retrieved from California Department of Health Care Services: http://www.cdss.ca.gov/getinfo/acin99/I-55_99.pdf

In Home Supportive Services Advisory Committee (County Level) MFPR

Family Participation: The majority of members are individuals who are current or past users.⁸⁵

Committee's Authority/Responsibility: Advisory⁸⁶

Authorizing Legislation/Formation: California Welfare and Institutions Code Section 12301.3⁸⁷

Medi-Cal Managed Care – Advisory Workgroup⁸⁸ FFP

Family Participation: Consumer Advocates are included, but it is unclear whether consumers themselves are included.

Committee's Authority/Responsibility: Advisory

Authorizing Legislation/Formation: This workgroup is one of multiple task forces and workgroups that Medi-Cal Managed Care Division (MMCD) created to “ensure that stakeholders have ample opportunity to advise, provide input and make recommendations regarding program services, operational issues and areas for quality improvement.”⁸⁹

CalOptima⁹⁰ – Member Advisory Committee MFPR

Family Participation: Yes, consumers comprise the majority.⁹¹

Committee's Authority/Responsibility: Advisory

Authorizing Legislation/Formation: This Member Advisory Committee was formed as one of a handful of member advisory committees to the Board of Directors.⁹²

LA Care Health Plan – Executive Community Advisory Committee⁹³ FFP

Family Participation: Yes, consumers and consumer advocates comprise the majority.

Committee's Authority/Responsibility: Advisory

Authorizing Legislation/Formation: Welfare and Institutions Code 14087.966⁹⁴

85 “Each county shall appoint an in-home supportive services advisory committee that shall be comprised of not more than 11 individuals. No less than 50 percent of the membership of the advisory committee shall be individuals who are current or past users of personal assistance services paid for through public or private funds or as recipients of services under this article.” California Welfare and Institutions Code 12301.3. (n.d.). Retrieved from FindLaw: <http://codes.lp.findlaw.com/cacode/WIC/1/d9/3/3/7/s12301.3>

86 “The advisory committee shall submit recommendations to the county board of supervisors on the preferred mode or modes of service to be utilized in the county for in-home supportive services.” California Welfare and Institutions Code 12301.3. (n.d.). Retrieved from FindLaw: <http://codes.lp.findlaw.com/cacode/WIC/1/d9/3/3/7/s12301.3>

87 California Welfare and Institutions Code 12301.3. (n.d.). Retrieved from FindLaw: <http://codes.lp.findlaw.com/cacode/WIC/1/d9/3/3/7/s12301.3>

88 “MMCD facilitates quarterly meetings with plan representatives and consumer advocacy representatives to discuss a wide array of issues, including quality of care. Meetings provide an opportunity for MMCD staff to provide program updates and for stakeholders to raise concerns about issues that affect enrolled members. As an aid to these quarterly meetings MMCD shares various informative quarterly reports. These reports help both MMCD and the health plans to further improve the quality of care” Medi-Cal Managed Care Task Forces and Workgroups. (2013). Retrieved from California Department of Health Care Services: <http://www.dhcs.ca.gov/services/Pages/MMCDTFandWorkgroups.aspx#adwg>

89 Medi-Cal Managed Care Task Forces and Workgroups. (2013). Retrieved from California Department of Health Care Services: <http://www.dhcs.ca.gov/services/Pages/MMCDTFandWorkgroups.aspx#adwg>

90 “CalOptima is a county organized health system that administers health insurance programs for low-income families, children, seniors and persons with disabilities in Orange County.” From: About Us. (2014). Retrieved from CalOptima: <https://www.caloptima.org/en/AboutUs.aspx>

91 This advisory group has 15 member slots allocated to 15 specific constituencies: “adult beneficiaries; children; consumer; family support; foster children; long-term care representatives; Medi-Cal beneficiaries; medically indigent persons; Orange County Health Care Agency; Orange County Social Services Agency; persons with disabilities; persons with mental illness; persons with special needs; recipients of CalWORKs; and, seniors.” From: Member Advisory Committee. (2014). Retrieved from CalOptima: <https://www.caloptima.org/en/AboutUs/BoardandAdvisoryCommittees/MAC.aspx>

92 Board and Advisory Committees. (2014). Retrieved from CalOptima: <https://www.caloptima.org/en/AboutUs/BoardandAdvisory-Committees.aspx>

93 “The Executive Community Advisory Committee (ECAC) is an advisory committee to L.A. Care’s Board of Governors. The 11 [Regional Community Advisory Committee] Chairs form the ECAC. The ECAC committee advises the Board of Governors about things that should be changed to help serve the community better” L.A. Care Members. (2013). Retrieved from L.A. Care Health Plan: <http://www.lacare.org/aboutlacare/community/rcacmembers>

94 “(a)The governing body for each geographic region served by the local initiative shall establish a regional community advisory

Mental Health/Developmental Disability Collaborative⁹⁵ FPI

Family Participation: The collaborative website lists “family members” among the individuals involved.⁹⁶

Committee’s Authority/Responsibility: The collaborative strengthens relationships and coordinates resources and efforts between agencies.

Authorizing Legislation/Formation: The collaborative was established to replace the Mental Health Task Force (MHTF). The MHTF, was established in 1996, and in 1998 the Welfare and Institutions Code⁹⁷ was amended “to increase cooperation and collaboration between regional centers and county mental health agencies.” Their website notes that “the MHTF continued as a forum to meet this mandate.”⁹⁸

Mental Health Services Oversight and Accountability Commission (MHSOAC) State Commission⁹⁹ FPR

Family Participation: Yes. Among the 16 members, the commission includes “two persons with a severe mental illness, a family member of an adult or senior with a severe mental illness...In making appointments, the Governor shall seek individuals who have had personal or family experience with mental illness.”¹⁰⁰

Committee’s Authority/Responsibility: Oversight and Advisory¹⁰¹

Authorizing Legislation/Formation: Section 10 of the Mental Health Services Act. Welfare and Institutions Code section 5845(a)

committee to ensure community involvement. (b) Each regional community advisory committee shall have no more than 35 members, a majority of whom shall be consumers and consumer advocates, but may also include providers.(c)(1)The chairpersons of the regional community advisory committees shall comprise an executive community advisory committee.(2) It is the intent of the Legislature that a majority of the executive community advisory committee shall be consumers and consumer advocates, plus two at-large members.(d) The executive community advisory committee shall make recommendations, and shall report on its activities, to the governing body and shall be able to place matters of the governing body’s agenda for consideration” Welfare and Institutions Code Section 14087.96-14087.9725 . (n.d.). Retrieved from Official California Legislative Language: <http://www.leginfo.ca.gov/cgi-bin/displaycode?section=wic&group=14001-15000&file=14087.96-14087.9725>

95 “The Collaborative strengthens relationships between agencies that provide mental health services to persons with developmental disabilities and provides an opportunity for agencies to address issues facing this population. The Collaborative also monitors legislation for potential impact on constituents, and maintains information about community resources providing mental health services to persons with developmental disabilities” Mental Health / Developmental Disability Collaborative. (2013, July 31). Retrieved from State of California Department of Developmental Services: http://www.dds.ca.gov/HealthDevelopment/MHSA_Collaborative.cfm

96 “The Collaborative includes representatives from the Association of Regional Center Agencies, the California Mental Health Directors Association, The Arc, regional centers, California Institute for Mental Health, private mental health service providers, family members, and both the Departments of Mental Health and Developmental Services” Mental Health / Developmental Disability Collaborative. (2013, July 31). Retrieved from State of California Department of Developmental Services: http://www.dds.ca.gov/HealthDevelopment/MHSA_Collaborative.cfm

97 This part of the Welfare and Institutions code is part of the Lanterman Developmental Disabilities Services Act.

98 Mental Health / Developmental Disability Collaborative. (2013, July 31). Retrieved from State of California Department of Developmental Services: http://www.dds.ca.gov/HealthDevelopment/MHSA_Collaborative.cfm

99 In November 2004, California voters passed Proposition 63, the Mental Health Services Act (MHSA) The law calls for the establishment of the Mental Health Services Oversight and Accountability Commission (MHSOAC)... The MHSOAC oversees the Adults and Older Adults Systems of Care Act; Human Resources; Innovative Programs; Prevention & Early Intervention Programs; and the Children’s Mental Health Services Act. The Commission replaced the advisory committee which had been established pursuant to Welfare and Institutions Code Section 5814...Our Mission: Provide vision and leadership, in collaboration with clients, their family members, and underserved communities, to ensure Californians understand mental health is essential to overall health. Hold public mental health systems accountable. Provide oversight for eliminating disparities; promote wellness, recovery and resiliency; and ensure positive outcomes for individuals living with serious mental illness and their families.” About MHSOAC. (2013). Retrieved from California Mental Health Services Oversight & Accountability Commission: http://www.mhsoac.ca.gov/About_MHSA/About_MHSA.aspx

100 Mental Health Services Act. (n.d.). Retrieved from California Department of Mental Health: http://www.mhsoac.ca.gov/docs/MHSA_Amended_July2013.pdf

101 “The role of the Mental Health Services Oversight and Accountability Commission (MHSOAC) is to oversee the implementation of the Mental Health Services Act (MHSA). The MHSOAC is also responsible for developing strategies to overcome stigma. At any time, the MHSOAC may advise the Governor or the Legislature on mental health policy...In the past, the MHSOAC has been responsible for review and approval of county plans for the Prevention & Early Intervention (PEI) and Innovation Program components of the MHSA. After the passage of Assembly Bill 100 (AB100) in March 2011, the role of the Commission shifted from review and approval of county plans to providing training and technical assistance for county mental health planning as needed. Additionally, the Commission evaluates MHSA-funded programs throughout the State. When AB 1467 passed in June 2012, the MHSOAC’s role of training and technical assistance and evaluation expanded; approval of county Innovation plans by the MHSOAC was also reinstated. The MHSOAC receives all county 3-year plans, annual updates, and annual Revenue and Expenditure Reports.” About MHSOAC. (2013). Retrieved from California Mental Health Services Oversight & Accountability Commission: http://www.mhsoac.ca.gov/About_MHSA/About_MHSA.aspx

Mental Health Services Oversight and Accountability Commission (MHSOAC) Client and Family Leadership Committee¹⁰² FPR

Family Participation: MHSOAC's Rules of Procedure (Section 5.1) requires that all standing committees have a maximum of 15 members and include at least two consumers and two family members of consumers.¹⁰³

Committee's Authority/Responsibility: Advisory as well as responsibility for organizing and engaging in specific activities.

Authorizing Legislation/Formation: N/I

Special Note(s):

The CFLC developed a policy paper for the MHSOAC on "transforming the mental health system through client and family leadership."¹⁰⁴

In addition to rules about consumer representation, committees are required to have at least two "members of underserved ethnic and cultural communities."¹⁰⁵

Mental Health Services Oversight and Accountability Commission (MHSOAC) Cultural and Linguistic Competency Committee¹⁰⁶ FPR

Family Participation: MHSOAC's Rules of Procedure (Section 5.1) requires that all standing committees have a maximum of 15 members and include at least two consumers and two family members of consumers.¹⁰⁷

Committee's Authority/Responsibility: Advisory as well as responsibility for organizing and engaging in specific activities.

Authorizing Legislation/Formation: N/I

Special Note(s):

In addition to rules about consumer representation, committees are required to have at least two "members of underserved ethnic and cultural communities."¹⁰⁸

Mental Health Services Oversight and Accountability Commission (MHSOAC) Services Committee¹⁰⁹ FPR

Family Participation: MHSOAC's Rules of Procedure (Section 5.1) requires that all standing committees have a maximum of 15 members and include at least two consumers and two family members of consumers.¹¹⁰

102 The purpose of the Client and Family Leadership Committee is to "ensure the perspective and participation of diverse community members reflective of California populations and who have lived experience of severe mental health issues, including their parents/caregivers and family members, is a significant factor in all MHSOAC decisions and recommendations" Client and Family Leadership Committee 2013 Charter. (2013, January 14). Retrieved from California Mental Health Oversight & Accountability Commission: http://www.mhsoac.ca.gov/Committees/docs/Charters/2013/CFLC_Charter2013.pdf

103 Rules of Procedure: Committees. (2011, May 26). Retrieved from Mental Health Services Oversight and Accountability Commission: http://www.mhsoac.ca.gov/meetings/docs/Meetings/2012/Apr/CLCC_042412_Tab2_RulesProcedure.pdf

104 Client and Family Leadership Committee. (2011, May). Client-driven, Family-focused Transformation of the Mental Health System Through the California Mental Health Services Act. Retrieved from Mental Health Services Oversight and Accountability Commission: http://www.mhsoac.ca.gov/MHSOAC_Publications/docs/Publications/TransformationPolicyPaper_May2011.pdf

105 Rules of Procedure: Committees. (2011, May 26). Retrieved from Mental Health Services Oversight and Accountability Commission: http://www.mhsoac.ca.gov/meetings/docs/Meetings/2012/Apr/CLCC_042412_Tab2_RulesProcedure.pdf

106 The purpose of the Cultural and Linguistic Competency Committee is to "to ensure that the perspective and participation of individuals, parents, caregivers and families across the lifespan, who are members of racial, ethnic, and cultural communities, are significant factors in all MHSOAC decisions and recommendations." Cultural and Linguistic Competency Committee 2013 Charter. (2013). Retrieved from Mental Health Services Oversight and Accountability Commission: http://www.mhsoac.ca.gov/Committees/docs/Charters/2013/CLCC_Charter2013.pdf

107 Rules of Procedure: Committees. (2011, May 26). Retrieved from Mental Health Services Oversight and Accountability Commission: http://www.mhsoac.ca.gov/meetings/docs/Meetings/2012/Apr/CLCC_042412_Tab2_RulesProcedure.pdf

108 Rules of Procedure: Committees. (2011, May 26). Retrieved from Mental Health Services Oversight and Accountability Commission: http://www.mhsoac.ca.gov/meetings/docs/Meetings/2012/Apr/CLCC_042412_Tab2_RulesProcedure.pdf

109 The purpose of the services committee is to "To ensure compliance with Welfare and Institutions Code (WIC) Sections 5846 and 5847 the Mental Health Services Oversight and Accountability Commission.(MHSOAC) Services Committee will make recommendations to the MHSOAC regarding Mental Health Services Act (MHSA) programs and services." MHSOAC Services Committee 2013 Charter. (2013). Retrieved from Mental Health Services Oversight and Accountability Commission: http://www.mhsoac.ca.gov/Committees/docs/Charters/2013/Services_Charter2013.pdf

110 Rules of Procedure: Committees. (2011, May 26). Retrieved from Mental Health Services Oversight and Accountability Commission: http://www.mhsoac.ca.gov/meetings/docs/Meetings/2012/Apr/CLCC_042412_Tab2_RulesProcedure.pdf

Committee's Authority/Responsibility: Advisory as well as responsibility for organizing and engaging in specific activities.

Authorizing Legislation/Formation: N/A

Special Note(s):

In addition to rules about consumer representation, committees are required to have at least two “members of underserved ethnic and cultural communities.”¹¹¹

Office of Health Equity Advisory Committee (OHE-AC) FPI

Family Participation: Consumers are included on the committee,¹¹² although legislative language is broad and not specific regarding inclusion of actual consumers or their families.¹¹³

Committee's Authority/Responsibility: Advisory.

Authorizing Legislation/Formation: Health and Safety Code Section 131000-131020

Special Note(s):

The committee has been provided with extensive and detailed travel reimbursement guidelines.¹¹⁴

The application form for the advisory committee asks individuals about affiliation with “vulnerable community groups,” and “knowledge and experience regarding specific issues affecting vulnerable communities and vulnerable places to increase positive health and mental health outcomes,” and also asks applicants to state “how [they] will obtain input from constituencies that you represent and how [they] will communicate the issues addressed by the Committee with community members.”¹¹⁵

Olmstead Committee ¹¹⁶ FPI

Family Participation: Yes, the website notes that family members are part of the committee.¹¹⁷

Committee's Authority/Responsibility: Advisory

Authorizing Legislation/Formation: An executive order from the Governor in 2008 replaces one from 2003, and authorizes the Secretary of Health and Human Services to form an advisory committee.¹¹⁸

Special Note(s):

Committee members are appointed by the Secretary of Health and Human Services.¹¹⁹

111 Rules of Procedure: Committees. (2011, May 26). Retrieved from Mental Health Services Oversight and Accountability Commission: http://www.mhsoac.ca.gov/meetings/docs/Meetings/2012/Apr/CLCC_042412_Tab2_RulesProcedure.pdf

112 “The OHE-AC consists of a broad range of experts, advocates, clinicians, and consumers who understand the important issues of health and mental health disparities related to unserved and underrepresented communities” Office of Health Equity Advisory Committee (OHE-AC). (2013, September 16). Retrieved from California Department of Public Health: <http://www.cdph.ca.gov/programs/Pages/AdvisoryCommittee.aspx>

113 “The advisory committee shall be composed of representatives from applicable state agencies and departments, local health departments, community-based organizations working to advance health and mental health equity, vulnerable communities, and stakeholder communities that represent the diverse demographics of the state.” Health and Safety Code Section 131000-131020. (n.d.). Retrieved from Official California Legislative Information: <http://www.leginfo.ca.gov/cgi-bin/displaycode?section=hsc&group=130001-131000&file=131000-131020>

114 Office of Health Equity Advisory Committee Travel Guidelines. (2013, September). Retrieved from California Department of Public Health: <http://www.cdph.ca.gov/programs/Documents/OHE-AC-Travel-Guidelines.pdf>

115 California Department of Public Health Office of Health Equity (OHE) Advisory Committee Application Form. (2012, November). Retrieved from California Department of Public Health: <http://www.cdph.ca.gov/pubsforms/forms/CtrlForms/cdph1025.pdf>

116 “The State of California convened the Olmstead Advisory Committee in 2005 to help inform policies and practices that impact Californians’ abilities to receive services in the least restrictive environment and to avoid unnecessary institutionalization. The Olmstead Advisory Committee developed the Olmstead Policy Filter to advise the Health and Human Services Agency on the extent to which a policy (legislative, regulatory, budgetary) meets the intent of the Olmstead decision.” California Olmstead Plan; Update on Its Implementation. (2012, November). Retrieved from California Health & Human Services Agency: <http://www.chhs.ca.gov/OLMDOC/California%20Olmstead%20Plan%20Update-%20November%202012.pdf>

117 “The Olmstead Advisory Committee Members represent consumers, family members, providers and advocates.” Olmstead Advisory Committee. (2013). Retrieved from California Health & Human Services Agency: <http://www.chhs.ca.gov/Pages/OlmsteadAdvisoryCommittee.aspx>

118 California Olmstead Plan Information. (n.d.). Retrieved from PAS Center for Personal Assistance Services: http://www.pascenter.org/state_based_stats/olmstead/olmstead_home.php?state=california

119 Executive Order S-10-08. (2008). Retrieved from California Office of the Governor Edmund G. Brown Jr. : <http://gov.ca.gov/news.php?id=10606>

Diversity of membership: the executive order notes that “the Secretary should take into account the diversity of California’s citizenry with respect to culture, language, geography, and disability in formulating the membership of his or her advisory group.”¹²⁰

SAMHSA – Alameda SAMHSA Early Connections¹²¹ Full Partnership¹²² MFPI

Family Participation: Yes, family members are a significant part of the Full Partnership, often comprising the majority even if not a codified requirement.^{123, 124}

Committee’s Authority/Responsibility: Governing

Authorizing Legislation/Formation: Family participation is one of three strategic directions of the Early Connections pilot.¹²⁵

Special Note(s):

Diversity of Membership: the strategic plan establishes the intention for family leadership to reflect the diversity of families served.¹²⁶

Early Connections’ Strategic Plan establishes the direction of “developing capacity for and integrating family leadership,” one goal of which is to have family members on every board. There are a number of family supports, including leadership trainings, outlined to help reach this goal.¹²⁷

In addition, the strategic plan sets forth an intention of a cultural humility approach to help shift culture toward family-driven programs, policies and practices.¹²⁸

Disability

Alameda County Developmental Disabilities Planning and Advisory Council – Board of Directors¹²⁹ FPI

Family Participation: Yes. The Board of Directors includes family members.¹³⁰

Committee’s Authority/Responsibility: Information, Planning and Advocacy¹³¹

Authorizing Legislation/Formation: The Council “was designated by the Board of Supervisors in 1970 as the

120 Executive Order S-10-08. (2008). Retrieved from California Office of the Governor Edmund G. Brown Jr. : <http://gov.ca.gov/news.php?id=10606>

121 “Implemented by Alameda County Behavioral Health Care Services, First 5 Alameda County and United Advocates for Children and Families, Early Connections is a community effort to promote wellbeing of children ages birth to five who are at risk for or have social, emotional, behavioral and related developmental concerns. Guided by the “system of care” framework, Early Connections seeks to strengthen and sustain Alameda County’s services and supports so that they are more accessible, integrated, family driven and culturally and linguistically responsive.” National Initiatives. (2013). Retrieved from First 5 Alameda County: <http://www.ackids.org/national-initiatives>

122 The Full Partnership is a “broad-based, decision-making body” of the Alameda County SAMHSA Early Connections program. From: Results. (2012). Retrieved from Bright Research Group: <http://www.brightresearchgroup.com/results/>

123 Full Partnership. (n.d.). Retrieved from Early Connections: A System of Care for Young Children and their Families: <https://sites.google.com/site/acearlyconnect/action-teams/full-partnership>

124 Results. (2012). Retrieved from Bright Research Group: <http://www.brightresearchgroup.com/results/>

125 Early Connections 2013-2015 Strategic Plan.

126 Early Connections 2013-2015 Strategic Plan.

127 Early Connections 2013-2015 Strategic Plan.

128 Early Connections 2013-2015 Strategic Plan.

129 “The Mission of the Developmental Disabilities Planning and Advisory Council is to advocate for the right of people with developmental disabilities to be assisted in the fullest development of their mental, physical and spiritual potentials, and the right to community living in the least restrictive environment.” Developmental Disabilities Planning and Advisory Council. (n.d.). Retrieved from Alameda County Public Health Department: <http://www.acphd.org/ddc.aspx>

130 “...elected from the general membership at the Annual Meeting, the Board is comprised of self-advocates, parents, relatives, members of the public and professionals in the field of developmental disabilities.” Alameda County Developmental Disabilities Planning and Advisory Council. (n.d.). Retrieved from Alameda County Public Health Department: http://www.acphd.org/media/95924/brochure_eng.pdf

131 “The Developmental Disabilities Council provides educational presentations, informational and referral services, and advocacy for policy and resource development in the areas of health, employment, housing, mental health, education, social services and transportation.” Developmental Disabilities Planning and Advisory Council. (n.d.). Retrieved from Alameda County Public Health Department: <http://www.acphd.org/ddc.aspx>

official planning body for developmental disabilities in Alameda County.”¹³²

Special Note(s):

Members serve without compensation.

California Department of Developmental Services Consumer Advisory Committee¹³³ **MFPR**

Family Participation: Yes. This advisory committee is comprised entirely of people with developmental disabilities.¹³⁴

Committee’s Authority/Responsibility: Advisory – “Advise the Director of the Department of Developmental Services and his or her staff on issues involving policies, programs, legislation, and regulations affecting the delivery of services and supports to people with developmental disabilities in California.”¹³⁵

Authorizing Legislation/Formation: The Director of the Department of Developmental Services created the Consumer Advisory Committee (CAC) in 1992

Special Note(s):

Selection for participation on the committee is made by “The Director of the Department of Developmental Services, in consultation with the Chair of the CAC.”¹³⁶

The CAC has also been involved with “developing advocacy media that provide insight on legal rights and strategies for people to live the life they want.”^{137,138}

132 Alameda County Developmental Disabilities Planning and Advisory Council. (n.d.). Retrieved from Alameda County Public Health Department: http://www.acphd.org/media/95924/brochure_eng.pdf

133 “The Director of the Department of Developmental Services created the Consumer Advisory Committee (CAC) in 1992 to give consumers a voice at DDS. The CAC gives DDS information about important issues that effect consumers in California and provides consumers information about things that DDS is doing. The CAC makes decisions from information they receive from the community about DDS issues and community priorities. The CAC’s vision ‘My Life-My Way.’” Consumer Advisory Committee. (2013, November 15). Retrieved from State of California Department of Developmental Services: <http://www.dds.ca.gov/ConsumerCorner/CAC.cfm>

134 “Membership on the Consumer Advisory Committee is open to any person with a developmental disability in the State of California who utilizes services from a regional center or developmental center and who: a) is a member of a local People First or self-advocacy group, b) has been nominated by their People First or self-advocacy group, and c) sends an application package to the Department of Developmental Services. . .Composition of the consumers selected as members of the Consumer Advisory Committee shall be balanced geographically, ethnically, and by type of disability. The membership shall consist of no more than fifteen (15) consumers. Two members shall be selected from developmental center applicants.” Department of Developmental Services Consumer Advisory Committee Bylaws. (2003, October 16). Retrieved from State of California Department of Developmental Services - Consumer Advisory Committee: http://www.dds.ca.gov/ConsumerCorner/docs/CAC_ByLaws.pdf

135 Department of Developmental Services Consumer Advisory Committee Bylaws. (2003, October 16). Retrieved from State of California Department of Developmental Services - Consumer Advisory Committee: http://www.dds.ca.gov/ConsumerCorner/docs/CAC_ByLaws.pdf

136 Department of Developmental Services Consumer Advisory Committee Bylaws. (2003, October 16). Retrieved from State of California Department of Developmental Services - Consumer Advisory Committee: http://www.dds.ca.gov/ConsumerCorner/docs/CAC_ByLaws.pdf

137 Department of Developmental Services Community Advisory Committee. (2009). Leadership Through Personal Change. Retrieved from State of California Department of Developmental Services: http://www.dds.ca.gov/ConsumerCorner/docs/CACNewsletter_Spring09.pdf

138 Materials developed by the CAC can be found among the publications on the consumer part of the website, here: <http://www.dds.ca.gov/ConsumerCorner/Publications.cfm>

California State Council on Developmental Disabilities¹³⁹ MFPR

Family Participation: Yes. Persons with disabilities or their parents/guardians comprise more than a majority with 20 of 31 seats¹⁴⁰

Committee's Authority/Responsibility: Engagement and Planning

Authorizing Legislation/Formation: Lanterman Developmental Disabilities Services Act (Specifically, Welfare and Institutions Code Sections 4520-4523)

Special Note(s):

Thirteen of 31 voting slots come from the area boards and represent persons with developmental disabilities or their parents/guardians (5 must be persons with developmental disabilities). An additional seven member appointed at large must all be individuals with developmental disabilities or their family members.

California State Council on Developmental Disabilities – Area Boards^{141,142} MFPR

Family Participation: Persons with developmental disabilities or their families comprise more than a majority (60%)¹⁴³

Committee's Authority/Responsibility: Local advocacy, capacity building and systemic change activities

Authorizing Legislation/Formation: Lanterman Developmental Disabilities Services Act (Specifically, Welfare and Institutions Code Sections 4543-4548)

Special Note(s):

Members are appointed by the governing bodies of the counties within the area (each county appointing an equal number).¹⁴⁴

139 "The State Council on Developmental Disabilities (Council) is established by state (Lanterman Act at Welfare and Institutions Code, section 4520 et. seq.) and federal law (Developmental Disabilities and Bill of Rights Act) to ensure that individuals with developmental disabilities and their families participate in the planning, design and receipt of the services and supports they need which promote increased independence, productivity, inclusion and self-determination. Federal law requires the Council to identify methods to improve and increase services for individuals and their families, and to submit these to the federal government in the form of a State Plan. This Plan identifies priority areas for improving and increasing services and supports for individuals and their families. Plan goals, objectives and strategies are achieved through by SCDD and area board activities and Community Program Development Grants. The Plan is approved by the federal Administration on Developmental Disabilities." What is the State Council on Developmental Disabilities. (2010). Retrieved from California State Council on Developmental Disabilities: <http://www.sccd.ca.gov/aboutus.htm>

140 At least 20 of the 31 voting members have to be persons with disabilities or family members. There is extensive legislative language regarding composition. Welfare and Institutions Code Section 4520-4523. (n.d.). Retrieved from Official California Legislative Information: <http://www.leginfo.ca.gov/cgi-bin/displaycode?section=wic&group=04001-05000&file=4520-4523>

141 There are 13 Area Boards throughout California. The State formally recognized the need for these boards in the authorizing legislation: "The Legislature further finds that the state faces unique challenges because of its size and diversity, and neighborhoods and communities lack the support necessary to monitor system functions and ensure the legal, civil, and service rights of persons with developmental disabilities. Therefore, local area boards on developmental disabilities shall be established to conduct the local advocacy, capacity building, and systemic change activities required by the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 (Public Law 106-402 (42 U.S.C. Sec. 15001))" Welfare and Institutions Code Section 4520-4523. (n.d.). Retrieved from Official California Legislative Information: <http://www.leginfo.ca.gov/cgi-bin/displaycode?section=wic&group=04001-05000&file=4520-4523>

142 A list of area boards can be found at the following link: <http://www.sccd.ca.gov/areaboards.htm>.

143 "Sixty percent from persons with developmental disabilities or the immediate relatives, guardians, or conservators of these persons." Welfare and Institutions Code Sections 4543-4548. (n.d.). Retrieved from Official California Legislative Information: <http://www.leginfo.ca.gov/cgi-bin/displaycode?section=wic&group=04001-05000&file=4543-4548>

144 Welfare and Institutions Code Sections 4543-4548. (n.d.). Retrieved from Official California Legislative Information: <http://www.leginfo.ca.gov/cgi-bin/displaycode?section=wic&group=04001-05000&file=4543-4548>

Contra Costa County Developmental Disabilities Council – Board of Directors¹⁴⁵

Family Participation: Family participation on the Board of Directors is not mentioned on the website.

Committee’s Authority/Responsibility: Planning and Advisory: “the Council is the official advisory body to the Board of Supervisors for individuals with developmental disabilities and their families.”¹⁴⁶

Authorizing Legislation/Formation: N/I

Regional Centers¹⁴⁷ MFPR

Family Participation: Yes. Families or persons with disabilities comprise the majority of the committee, with no fewer than 25% of committee members being persons with developmental disabilities.¹⁴⁸

Committee’s Authority/Responsibility: Governance & Decision-Making

Authorizing Legislation/Formation: Lanterman Developmental Disabilities Services Act

Special Note(s):

Regional center governing boards are required to annually review the performance of the regional center at providing linguistically and culturally appropriate services; and, provide training and support to board members (which is reviewed by the Department of Developmental Services). Legislative language notes that regional centers are allowed to have consumer advisory committees. In addition, the regional center boards are required to create a provider advisory committee,¹⁴⁹ one member of which serves on the regional center board.

State Interagency Coordinating Council on Early Intervention¹⁵⁰ FPR

Family Participation: Yes, the council has at least 20% parent representation.¹⁵¹

Committee’s Authority/Responsibility: Advisory – Advise and assist the lead agency (department of Developmental Disabilities) in a range of responsibilities related to ensuring effective coordination and implementation of early intervention services; the committee also prepares an “annual report for the Governor and the Secretary of Education on the status of early intervention programs and services for eligible children and their families in California.”¹⁵²

¹⁴⁵ “The mission of the Developmental Disabilities Council of Contra Costa County is to promote the coordination, improvement, and growth of services and supports to individuals with developmental disabilities and their families, and to advocate for their needs.”

Developmental Disabilities Council. (n.d.). Retrieved from Contra Costa Health Services: <http://cchealth.org/groups/ddc/>

¹⁴⁶ Developmental Disabilities Council. (n.d.). Retrieved from Contra Costa Health Services: <http://cchealth.org/groups/ddc/>

¹⁴⁷ “Regional centers are nonprofit private corporations that contract with the Department of Developmental Services to provide or coordinate services and supports for individuals with developmental disabilities. They have offices throughout California to provide a local resource to help find and access the many services available to individuals and their families.” Information about Regional Centers. (2013). Retrieved from State of California Department of Developmental Services: <http://www.dds.ca.gov/RC/Home.cfm>

¹⁴⁸ California Welfare and Institutions Code, in the section about developmental services requires the following of its regional centers’ governing boards: “A minimum of 50 percent of the members of the governing board shall be persons with developmental disabilities or their parents or legal guardians. No less than 25 percent of the members of the governing board shall be persons with developmental disabilities” Bill Number SB367 CHAPTERED. (2013, October 9). Retrieved from Official California Legislative Information: http://www.leginfo.ca.gov/pub/13-14/bill/sen/sb_0351-0400/sb_367_bill_20131009_chaptered.html

¹⁴⁹ Legislative language: “The governing board shall appoint an advisory committee composed of a wide variety of persons representing the various categories of providers from which the regional center purchases client services. The advisory committee shall provide advice, guidance, recommendations, and technical assistance to the regional center board in order to assist the regional center in carrying out its mandated functions. The advisory committee shall designate one of its members to serve as a member of the regional center board.” Bill Number SB367 CHAPTERED. (2013, October 9). Retrieved from Official California Legislative Information: http://www.leginfo.ca.gov/pub/13-14/bill/sen/sb_0351-0400/sb_367_bill_20131009_chaptered.html

¹⁵⁰ “The mission of the ICC is to promote and enhance a coordinated family service system for infants and toddlers, birth to 3 years, who have, or are at risk for having a disability, and their families, utilizing and encouraging a family centered approach, family-professional partnerships, and interagency collaboration.” Bylaws, State of California Interagency Coordinating Council on Early Intervention. (2007, November). Retrieved from State of California Department of Developmental Services: http://www.dds.ca.gov/EarlyStart/docs/ByLaws_ICC.pdf

¹⁵¹ Legislative language: “(A) Parents.--Not less than 20 percent of the members shall be parents of infants or toddlers with disabilities or children with disabilities aged 12 or younger, with knowledge of, or experience with, programs for infants and toddlers with disabilities. Not less than 1 such member shall be a parent of an infant or toddler with a disability or a child with a disability aged 6 or younger.” Individuals with Disabilities Education Improvement Act of 2004. (2004, May 21). Retrieved from United States Legislative information: [http://beta.congress.gov/bill/108th-congress/house-bill/1350/text?q={%22search%22:\[%22Individuals%20with%20Disabilities%20Education%20Improvement%20Act%22\]}](http://beta.congress.gov/bill/108th-congress/house-bill/1350/text?q={%22search%22:[%22Individuals%20with%20Disabilities%20Education%20Improvement%20Act%22]})

¹⁵² These responsibilities are listed in greater detail in the bylaws. Bylaws, State of California Interagency Coordinating Council on Early Intervention. (2007, November). Retrieved from State of California Department of Developmental Services: <http://www.dds.>

Authorizing Legislation/Formation: California Early Intervention Services Act; funding is through the Individuals with Disabilities Education Act

Special Note(s):

The CA State Interagency Coordinating Council on Early Intervention's bylaws build upon the federal guidelines regarding membership by advising that "These parents will represent the socioeconomic, ethnic, disability and geographic diversity of the state"¹⁵³

All members are appointed by the Governor.

Compensation: "Members serve without compensation; however, they may be reimbursed for reasonable and necessary expenses incurred in connection with the performance of their duties as ICC members. Child care is reimbursable for parent representatives who require care for their child with special needs while the parent is engaged in ICC responsibilities."¹⁵⁴

Education

Advisory Commission on Special Education (ACSE)¹⁵⁵ MFPR

Family Participation: Yes. Families comprise the majority.¹⁵⁶

Committee's Authority/Responsibility: Recommendation/Advice at the State Level. Broad areas of responsibility include:

"[To] study and provide assistance and advice to the State Board of Education, the Superintendent of Public Instruction, the Legislature, and the Governor in new or continuing areas of research, program development, and evaluation in special education."

To report to those entities regarding specific activities, funding priorities & procedures, unmet needs, and recommendations related to special education.¹⁵⁷

Authorizing Legislation/Formation: Federal (20 USC 1412(a)(21)) and State Statute (EC 33590-33596)

Special Note(s):

The commission is also supposed to be reflective of the state population more broadly.

Actual/necessary expenses (such as travel expenses) are reimbursed.

ca.gov/EarlyStart/docs/ByLaws_ICC.pdf

153 Bylaws: "A. at least twenty percent (20%) parents of infants, toddlers, or children with disabilities aged twelve or younger who have knowledge of, or experience with programs for infants and toddlers with disabilities. These parents will represent the socioeconomic, ethnic, disability and geographic diversity of the state, if possible. B. at least one member shall be a parent of an infant, toddler or child with a disability aged six (6) or younger." Bylaws, State of California Interagency Coordinating Council on Early Intervention. (2007, November). Retrieved from State of California Department of Developmental Services: http://www.dds.ca.gov/EarlyStart/docs/ByLaws_ICC.pdf

154 Bylaws, State of California Interagency Coordinating Council on Early Intervention. (2007, November). Retrieved from State of California Department of Developmental Services: http://www.dds.ca.gov/EarlyStart/docs/ByLaws_ICC.pdf

155 "The Commission is an advisory body required by Federal (20 USC 1412(a)(21)) and State Statute (EC 33590-6). The ACSE provides recommendations and advice to the State Board of Education, the Superintendent of Public Instruction, the Legislature, and the Governor in new or continuing areas of research, program development and evaluation in California special education" Advisory Commission on Special Education (ACSE). (2013, July 30). Retrieved from California Department of Education: <http://www.cde.ca.gov/sp/se/as/acse.asp>

156 Legislative Language: "SPECIAL RULE - A majority of the members of the panel shall be individuals with disabilities or parents of children with disabilities (ages birth through 26)." Advisory Commission (ACSE) Requirements. (2013, July 30). Retrieved from California Department of Education: <http://www.cde.ca.gov/sp/se/as/acserqrmnt.asp>

157 "The commission shall report to the State Board of Education, the Superintendent of Public Instruction, the Legislature, and the Governor not less than once a year on the following with respect to special education: (1) Activities enumerated in Section 56100 that are necessary to be undertaken regarding special education for individuals with exceptional needs. (2) The priorities and procedures utilized in the distribution of federal and state funds.(3) The unmet educational needs of individuals with exceptional needs within the state.(4) Recommendations relating to providing better education services to individuals with exceptional needs, including, but not limited to, the development, review, and revision, of the definition of "appropriate" as that term is used in the phrase "free and appropriate public education" for the purposes of the federal Individuals with Disabilities Education Act (20 U.S.C. Sec. 1400 et seq.). Advisory Commission (ACSE) Requirements. (2013, July 30). Retrieved from California Department of Education: <http://www.cde.ca.gov/sp/se/as/acserqrmnt.asp>

Alameda Task Force on Inclusive Child Care¹⁵⁸

(Alameda County Child Care Planning Council)

Family Participation: N/I

Committee's Authority/Responsibility: Planning

Authorizing Legislation/Formation: N/I

California School for the Blind – Community Advisory Committee¹⁵⁹ FPI

Family Participation: Yes, parents are included on the CAC.

Committee's Authority/Responsibility: Advisory

Authorizing Legislation/Formation: N/A

California School for the Deaf, Fremont¹⁶⁰

Family Participation: N/I

Committee's Authority/Responsibility: N/I

Authorizing Legislation/Formation: N/I

California School for the Deaf, Riverside – Community Advisory Committee¹⁶¹ MFPR

Family Participation: Yes. Families comprise the majority.¹⁶²

Committee's Authority/Responsibility: Advisory

Authorizing Legislation/Formation: None

158 “The Task Force on Inclusive Child Care (part of the Early Care and Education Committee) of the Alameda County Child Care Planning Council works collaboratively with community partners to develop an infrastructure for support of quality inclusive child care in Alameda County.” Task Force on Inclusive Child Care. (2012). Retrieved from Alameda County Child Care Planning Council: <http://www.acgov.org/childcare/specialneeds.htm>

159 “The Community Advisory Committee (CAC) is an organization of parents, CSB staff, and community members who play an important role in an advisory capacity to the school. This committee meets throughout the school year. All parents are encouraged to participate. For parents unable to attend these meetings, minutes are available.” Parent / Student Handbook 2007 - 2009. (2007, July). Retrieved from California School for the Blind: <http://www.csb-cde.ca.gov/Documents/Parent%20Handbook%202007-09.doc>

160 Mission: “The California School for the Deaf is recognized for academic rigor and direct instruction in American Sign Language and English. Through our fully-accredited programs, visual learning environment and strong partnerships with families and communities, our students experience rich language opportunities, develop appreciation for diversity, and lead fulfilling lives.” Mission. (2012, December 10). Retrieved from California School for the Deaf: <http://www.csdf.k12.ca.us/about/mission.php>

161 “We are CSDR’s Community Advisory Committee (CAC)! It is our priority to examine how CSDR programs and services affect all students from the youngest children enrolled in the Parents Infant Program (PIP) to those students preparing to leave high school. It is our belief that all children who come to CSDR enjoy learning and can excel in a positive educational environment.” Community Advisory Committee. (n.d.). Retrieved from California School for the Deaf Riverside: <http://www.csdrcde.ca.gov/community-advisory-committee/>

162 “CAC consists of twelve parents, nine staff members, and three individuals representing community organizations, all of whom share something in common: a stake in CSDR’s students and programs. Community Advisory Committee. (n.d.). Retrieved from California School for the Deaf Riverside: <http://www.csdrcde.ca.gov/community-advisory-committee/>

Head Start Health Services Advisory Committee¹⁶³ FPR

Family Participation: The committee includes some parents.¹⁶⁴

Committee's Authority/Responsibility: Policy and Procedure Development

Authorizing Legislation/Formation: N/I

Special Note(s):

Diversity: The committee represents the racial and ethnic groups served by Head Start within its local region.¹⁶⁵

Head Start Parent Committee MFPR

Family Participation: All members are current parents.¹⁶⁶

Committee's Authority/Responsibility: Advise on planning and implementation, participate in activities, and support hiring and screening of staff.¹⁶⁷

Authorizing Legislation/Formation: N/I

Special Note(s):

Head Start reimburses expenses such as travel and child care.¹⁶⁸

Head Start Policy Councils and Policy Committees MFPR

Family Participation: Yes. Families comprise the majority.¹⁶⁹

Committee's Authority/Responsibility: Policy; Share in Decision-Making with Governing Bodies.¹⁷⁰ These committees work with staff and governing bodies to approve a large range of policies (from grantmaking to personnel), serve as links to parent committees, and assist/provide support to parent committees.

Authorizing Legislation/Formation: The Head Start Act requires the formation of a policy council at each Head Start agency, and that the majority of members be current parents.¹⁷¹

¹⁶³ The local Health Services Advisory Committees support “assists in the development of health policies and procedures and supports Head Start’s objective to provide continuous and accessible health care for children and families.” Head Start and Health Services. (2013, March 19). Retrieved from Head Start: An Office of the Administration of Children and Families Early Learning & Knowledge Center: http://eclkc.ohs.acf.hhs.gov/hslc/tta-system/health/Health/Health%20and%20Wellness/Health%20and%20Wellness%20Program%20Staff/health_art_00580_090105.html#17

¹⁶⁴ “This committee includes Head Start parents and staff, health and human services professionals, and other community volunteers who are representative of the racial and ethnic groups served by the local Head Start program. Head Start programs may invite representatives from Medicaid, SCHIP, and managed care organizations in the community to participate in the HSAC. The committee members meet to discuss program issues in the medical, dental, mental health, nutrition, and human services fields.” Head Start and Health Services. (2013, March 19). Retrieved from Head Start: An Office of the Administration of Children and Families Early Learning & Knowledge Center: http://eclkc.ohs.acf.hhs.gov/hslc/tta-system/health/Health/Health%20and%20Wellness/Health%20and%20Wellness%20Program%20Staff/health_art_00580_090105.html#17

¹⁶⁵ Head Start and Health Services. (2013, March 19). Retrieved from Head Start: An Office of the Administration of Children and Families Early Learning & Knowledge Center: http://eclkc.ohs.acf.hhs.gov/hslc/tta-system/health/Health/Health%20and%20Wellness/Health%20and%20Wellness%20Program%20Staff/health_art_00580_090105.html#17

¹⁶⁶ “Parent Committees must be comprised exclusively of the parents of children currently enrolled at the center level for center-based programs or at the equivalent level for other program options.” 1304.50 Program Governance. (n.d.). Retrieved from Head Start: An Office of the Administration for Children and Families Early Childhood Learning & Knowledge Center (ECLKC): <http://eclkc.ohs.acf.hhs.gov/hslc/standards/Head%20Start%20Requirements/1304/1304.50%20Program%20governance..htm>

¹⁶⁷ “The Parent Committee must carry out at least the following minimum responsibilities: (1) Advise staff in developing and implementing local program policies, activities, and services; (2) Plan, conduct, and participate in informal as well as formal programs and activities for parents and staff; and (3) Within the guidelines established by the governing body, Policy Council, or Policy Committee, participate in the recruitment and screening of Early Head Start and Head Start employees. 1304.50 Program Governance. (n.d.). Retrieved from Head Start: An Office of the Administration for Children and Families Early Childhood Learning & Knowledge Center (ECLKC): <http://eclkc.ohs.acf.hhs.gov/hslc/standards/Head%20Start%20Requirements/1304/1304.50%20Program%20governance.htm>

¹⁶⁸ 1304.50 Program Governance. (n.d.). Retrieved from Head Start: An Office of the Administration for Children and Families Early Childhood Learning & Knowledge Center (ECLKC): <http://eclkc.ohs.acf.hhs.gov/hslc/standards/Head%20Start%20Requirements/1304/1304.50%20Program%20governance.htm>

¹⁶⁹ “At least 51 percent of the members of these policy groups must be the parents of currently enrolled children“ (1304.50 Program Governance). Retrieved from: <http://eclkc.ohs.acf.hhs.gov/hslc/standards/Head%20Start%20Requirements/1304/1304.50%20Program%20governance.htm>

¹⁷⁰ (1304.50 Program Governance). Retrieved from: <http://eclkc.ohs.acf.hhs.gov/hslc/standards/Head%20Start%20Requirements/1304/1304.50%20Program%20governance.htm>

¹⁷¹ Head Start Act. (2008). Retrieved from Head Start: An Office of the Administration for Children and Families Early Childhood

Special Note(s):

Head Start reimburses expenses such as travel and child care.¹⁷²

Improving Special Education Services (ISES) Stakeholder Group¹⁷³

Family Participation: N/I

Committee's Authority/Responsibility: Planning, Development, and Reporting

Authorizing Legislation/Formation: ISES was created by the CDE by combining other groups. However, the work of ISES relates to fulfilling state requirements of the Individuals with Disabilities Education Act (IDEA), as well as requirements of “competitively awarded [State Personnel Development Grant (SPDG)] funds.”¹⁷⁴

Special Note(s):

The federal State Personnel Development Grant (SPDG) “supports and develops partnerships with schools and families by providing training, technical assistance, and resources to both special education and general education.”¹⁷⁵

Local Child Care and Development Planning Councils (LPCs)^{176,177} FPR

Family Participation: At least 20% of council members are consumers.¹⁷⁸

Committee's Authority/Responsibility: Coordination and Planning

Authorizing Legislation/Formation: Education Code, Chapter 2.3, Article 1, Section 8499 and Article 2, Sections 8499.3, 8499.5 and 8499.7

Special Note(s):

Diversity of Membership: “Every effort shall be made to ensure that the ethnic, racial, and geographic composition of the local planning council is reflective of the ethnic, racial, and geographic distribution of the population of the county.”¹⁷⁹

Selection: “The board of supervisors and the superintendent of schools shall each appoint one-half of the

Learning & Knowledge Cneter (ECLKC): <http://eclkc.ohs.acf.hhs.gov/hslc/standards/Head%20Start%20Act>
 172 1304.50 Program Governance. (n.d.). Retrieved from Head Start: An Office of the Administration for Children and Families Early Childhood Learning & Knowledge Cneter (ECLKC): <http://eclkc.ohs.acf.hhs.gov/hslc/standards/Head%20Start%20Requirements/1304/1304.50%20Program%20governance.htm>

173 “Previously CDE has relied on several diverse planning groups to address such things as personnel development, monitoring and accountability, and fiscal management. It became apparent that all of these groups should become part of a unified planning process guided by the SPP. In January of 2007, CDE, along with the required partners reconstituted the scope and function of the Partnership Committee on Special Education (PCSE) and the Key Performance Indicator Stakeholder Committee (KPISC). The California Department of Education combined the members of the two former planning groups and created the Improving Special Education Services (ISES): Through Planning, Personnel Development, and Performance Reporting Group. The ISES group meets two times per year” Improving Special Education Services (ISES) & State Performance and Personnel Development Plan (SPPDP). (2013, November 22). Retrieved from California Services for Technical Assistance and Training (CalSTAT): <http://www.calstat.org/spdgises.html>

174 Improving Special Education Services (ISES) & State Performance and Personnel Development Plan (SPPDP). (2013, November 22). Retrieved from California Services for Technical Assistance and Training (CalSTAT): <http://www.calstat.org/spdgises.html>

175 About CalStat. (2013, October 16). Retrieved from California Services for Technical Assistance and Training: <http://www.calstat.org/index.html>

176 “The primary mission of the Local Child Care and Development Planning Councils (LPCs) is to plan for child care and development services based on the needs of families in the local community. LPCs are intended to serve as a forum to address the child care needs of all families in the community for all types of child care, both subsidized and non-subsidized. There are currently LPCs representing each county in California.” Local Child Care and Development Planning Councils. (2013, August 13). Retrieved from California Department of Education: <http://www.cde.ca.gov/sp/cd/re/lpc.asp>

177 There are currently LPCs representing each county in California. A complete list can be found here: <http://www.cde.ca.gov/sp/cd/re/lpccontacts.asp>

178 “The local planning council shall be comprised as follows: (A) Twenty percent of the membership shall be consumers. (B) Twenty percent of the membership shall be child care providers, reflective of the range of child care providers in the county. (C) Twenty percent of the membership shall be public agency representatives. (D) Twenty percent of the membership shall be community representatives, who shall not be child care providers or agencies that contract with the department to provide child care and development services. (E) The remaining 20 percent shall be appointed at the discretion of the appointing agencies.” Education Code Section 8499.3-8499.7. (n.d.). Retrieved from Official California Legislative Information: <http://www.leginfo.ca.gov/cgi-bin/displaycode?section=edc&group=08001-09000&file=8499.3-8499.7>

179 Education Code Section 8499.3-8499.7. (n.d.). Retrieved from Official California Legislative Information: <http://www.leginfo.ca.gov/cgi-bin/displaycode?section=edc&group=08001-09000&file=8499.3-8499.7>

members...The board of supervisors and county superintendent of schools may designate an existing child care planning council or coordinated child and family services council as the local planning council, as long as it has or can achieve the [required] representation...¹⁸⁰

Special Education Advisory Committee¹⁸¹ **FFP**

Family Participation: The committee consists of nine members from Northern California and nine members from Southern California. The majority of committee members are required to be “parents or those who represent parents and students.”¹⁸²

Committee's Authority/Responsibility: Advisory – The committee provides non-binding advice to OAH on the mediation and due process hearing process.¹⁸³

Authorizing Legislation/Formation: “The Interagency Agreement between the California Department of Education and the Office of Administrative Hearings and California Education Code section 56504.5, subdivision (c)(8) requires the establishment of a voluntary Advisory Committee”¹⁸⁴

Special Note(s):

While CA law requires there be a committee, it doesn't mandate parent participation, indicating that the parent participation requirement was added as the committee was formed.¹⁸⁵

Special Education Local Planning Area (SELPA) Community Advisory Committees (CACs)^{186,187} **MFPR**

Family Participation: The majority of the committee members must be parents, and at least a majority those individuals should be parents of students with exceptional needs.¹⁸⁸

Committee's Authority/Responsibility: Advisory – Authority is defined on a local level, although there are a number of supportive and advisory functions defined on the state level as well related to advising on the local

180 Education Code Section 8499.3-8499.7. (n.d.). Retrieved from Official California Legislative Information: <http://www.leginfo.ca.gov/cgi-bin/displaycode?section=edc&group=08001-09000&file=8499.3-8499.7>

181 “The purpose of the Advisory Committee is to provide non-binding recommendations to the Office of Administrative Hearings for improvements to the special education hearing and mediation process. All Advisory Committee Meetings are public meetings... In particular, the Advisory Committee will consult with OAH in areas such as revisions to the OAH website, forms, documents, scheduling procedures, staff training, training materials, the parent procedure manual, the consumer brochure, outreach to families, and proposed revisions to laws and rules.” Special Education Advisory Committee. (2013). Retrieved from CA Office of Administrative Hearings: <http://www.dgs.ca.gov/oah/SpecialEducation/Programs/SEAdvisoryCommittee.aspx>

182 “The Advisory Committee is composed the Southern California Region and the Northern California Region, with nine volunteer members in each region. A minimum of five members in each region will be parents or those who represent parents and students. The four remaining members in each region are comprised of advocates, attorneys, and school employees among other interested stakeholders” Special Education Advisory Committee. (2013). Retrieved from CA Office of Administrative Hearings: <http://www.dgs.ca.gov/oah/SpecialEducation/Programs/SEAdvisoryCommittee.aspx>

183 Special Education Advisory Committee Summary of Items Discussed July 1 and July 2, 2008. (2008, July 1-2). Retrieved from <http://www.documents.dgs.ca.gov/oah/SE/Summary%20of%20July%202008%20Advisory%20Committee%20Meetings.pdf>

184 Special Education Advisory Committee. (2013). Retrieved from CA Office of Administrative Hearings: <http://www.dgs.ca.gov/oah/SpecialEducation/Programs/SEAdvisoryCommittee.aspx>

185 CAL. EDC. CODE § 56504.5 : California Code - Section 56504.5. (n.d.). Retrieved from FindLaw: <http://codes.lp.findlaw.com/cacode/EDC/2/d4/30/5/s56504.5>

186 “A community advisory committee (CAC) is a group, comprised primarily of parents of students with exceptional education needs, that provides advice to the governing board of a special education local planning area (SELPA). CACs are often also referred to as ‘special education advisory committees’ (SEACs) or ‘parent advisory committees’ (PACs). Under California Education Code Sections 56190-56194, each of the 122 SELPAs in California must establish a CAC...The CAC provides a venue through which parents may collaborate with education professionals “to make certain that the appropriate services are provided on an individualized basis for every child with a disability...The Local Plan developed and maintained in each community by the people who live there, is the basis of these improvements and the foundation of services.” Community Advisory Committees. (2013, June). Retrieved from Family Empowerment and Disability Council: <http://www.calfedc.org/uploads/3/2/6/6/3266057/issuebriefcacakm062513final-formatted.pdf>

187 A list of California SELPAs can be accessed here: <http://www.cde.ca.gov/sp/se/as/caselpas.asp>

188 “The community advisory committee shall be composed of parents of individuals with exceptional needs enrolled in public or private schools, parents of other pupils enrolled in school, pupils and adults with disabilities, regular education teachers, special education teachers and other school personnel, representatives of other public and private agencies, and persons concerned with the needs of individuals with exceptional needs...At least the majority of such committee shall be composed of parents of pupils enrolled in schools participating in the local plan, and at least a majority of such parents shall be parents of individuals with exceptional needs.” EDUCATION CODE SECTION 56190-56194. (n.d.). Retrieved from Official California Legislative Information: <http://www.leginfo.ca.gov/cgi-bin/displaycode?section=edc&group=56001-57000&file=56190-56194>

plan, recommending priorities, assisting in parent education and awareness, and encouraging community involvement.¹⁸⁹

Authorizing Legislation/Formation: California Education Code Section 56190 – 56194. Note: “The California Legislature implements the provisions of IDEA through the California Master Plan for Special Education. This plan was first implemented statewide in 1980 with the passage of Senate Bill 1870.”¹⁹⁰

Special Note(s):

There are rules in place to ensure that SELPAs involve CACs in developing, updating, and revising the local annual service plans.¹⁹¹

CAC members are “appointed by, and responsible to, the governing board of each participating district or county office, or any combination thereof participating in the local plan. Appointment shall be in accordance with a locally determined selection procedure that is described in the local plan. Where appropriate, this procedure shall provide for selection of representatives of groups specified in Section 56192 by their peers.”¹⁹²

State Advisory Council (SAC) on Early Learning & Care¹⁹³

Family Participation: Not required.

Committee’s Authority/Responsibility: Advisory: “The California State Advisory Council on Early Learning and Care (SAC) will make recommendations on the future policy direction for early learning and related services for young children in California.”¹⁹⁴

Authorizing Legislation/Formation: Improving Head Start for School Readiness Act of 2007 (PL 110-134)

Other

Alameda Paratransit Advisory and Planning Committee (PAPCO)¹⁹⁵

(Alameda County Transportation Commission) MFPR

Family Participation: All members are consumers.¹⁹⁶

189 “The community advisory committee shall have the authority and fulfill the responsibilities that are defined for it in the local plan. The responsibilities shall include, but need not be limited to, all the following: (a) Advising the policy and administrative entity of the special education local plan area regarding the development, amendment, and review of the local plan. The entity shall review and consider comments from the community advisory committee. (b) Recommending annual priorities to be addressed by the plan. (c) Assisting in parent education and in recruiting parents and other volunteers who may contribute to the implementation of the plan. (d) Encouraging community involvement in the development and review of the local plan. (e) Supporting activities on behalf of individuals with exceptional needs. (f) Assisting in parent awareness of the importance of regular school attendance.” EDUCATION CODE SECTION 56190-56194 . (n.d.). Retrieved from Official California Legislative Information: <http://www.leginfo.ca.gov/cgi-bin/displaycode?section=edc&group=56001-57000&file=56190-56194>

190 California Special Education Local Plan Areas. (2012, November 8). Retrieved from California Department of Education: <http://www.cde.ca.gov/sp/se/as/caselpas.asp>

191 “SELPAs must certify that their CAC has provided advice on the local plan, that parents participated in the development and update of the plan, and that the CAC has reviewed the plan and any necessary revisions to the plan. Assurance of these activities is made in writing by the CAC chairperson at the time that the SELPA submits the local plan to CDE.” Community Advisory Committees. (2013, June). Retrieved from Family Empowerment and Disability Council: <http://www.calfedc.org/uploads/3/2/6/6/3266057/issuebriefcacakm062513finalformatted.pdf>

192 EDUCATION CODE SECTION 56190-56194 . (n.d.). Retrieved from Official California Legislative Information: <http://www.leginfo.ca.gov/cgi-bin/displaycode?section=edc&group=56001-57000&file=56190-56194>

193 “The State Advisory Council (SAC) on Early Learning and Care is a governor-appointed leadership body that ensures statewide collaboration among early childhood programs that will help to define future policy for children birth to kindergarten.” State Advisory Council on Early Learning and Care. (2013, July 30). Retrieved from California Department of Education: <http://www.cde.ca.gov/sp/cd/ce/>

194 State Advisory Council on Early Learning and Care. (2013, July 30). Retrieved from California Department of Education: <http://www.cde.ca.gov/sp/cd/ce/>

195 “PAPCO makes decisions on transportation funding for seniors and people with disabilities to address planning and coordination issues regarding paratransit services in Alameda County. PAPCO members advise Alameda CTC on the development and implementation of paratransit programs, including a grant program.” Advisory Committees. (2012). Retrieved from Alameda County Transportation Commission: http://www.alamedactc.org/app_pages/view/14

196 “All 23 members must be Alameda County residents who use transportation that supports seniors and people with disabilities.” Advisory Committees. (2012). Retrieved from Alameda County Transportation Commission: http://www.alamedactc.org/app_pages/view/14

Committee's Authority/Responsibility: Advisory and Planning

Authorizing Legislation/Formation: PAPCO is one of a number of community advisory committees that advises the Alameda County Transportation Commission.

California Blue Ribbon Commission on Children in Foster Care¹⁹⁷ FPI

Family Participation: Yes, when it was formed, there were both former foster youth¹⁹⁸ and parents/guardians¹⁹⁹ on the committee

Committee's Authority/Responsibility: Advisory as well as responsibility for creating specific initiatives

Authorizing Legislation/Formation: A task force appointed by the California Supreme Court Chief Justice.

Child Welfare Council²⁰⁰ FPR

Family Participation: Yes, the committee is required to have at least four foster youth or former foster youth²⁰¹, and parents are also allowed to serve.²⁰²

Committee's Authority/Responsibility: Advisory – this group is “responsible for improving the collaboration

197 “In 2006, when Chief Justice Ronald M. George first appointed the California Blue Ribbon Commission on Children in Foster Care, he charged it with providing recommendations to the Judicial Council of California on the ways in which the courts and their child welfare partners could improve safety, permanency, well-being, and fairness outcomes for children and families in the state. After the commission issued its recommendations in August 2008, Chief Justice George reappointed the commission for another three years, starting in June 2009, to work on implementing the recommendations. . . In March 2012, Chief Justice Tani G. Cantil-Sakauye reappointed the commission to work on the implementation of its recommendations. During the BRC annual meeting in May 2012, she also charged the commission with creating an initiative to keep kids in school and out of court.” California Blue Ribbon Commission on Children in Foster Care. (2013). Retrieved from California Courts: The Judicial Branch of California: <http://www.courts.ca.gov/brc.htm>

198 “The commission consists of members from a variety of disciplines, including judges, legislators, child welfare administrators, former foster youth, caregivers, philanthropists, tribal leaders, advocates for children and parents, and others providing leadership on the issues that face foster children and their families and the courts and agencies that serve them.” California Blue Ribbon Commission on Children in Foster Care. (2010, August). Implementation Progress Report: Building a Brighter Future for California's Children. Retrieved from California Courts: The Judicial Branch of California: <http://www.courts.ca.gov/documents/brc-progress-0810.pdf>

199 While “advocates” are listed, but not parents, in his opening speech to the rest of the committee when they were first formed, the judge who was selected as the chair – Judge Carlos R. Moreno – discusses how he and his wife took custody of his niece a number of years before, and that she specifically had autism and severe developmental delays. A Brief History of the California Blue Ribbon Commission on Children in Foster Care. (2012). Retrieved from California Courts: The Judicial Branch of California: http://www.courts.ca.gov/documents/BRC_Briefing_Binder_Draft050712.pdf

200 “The California Child Welfare Council was established by the Child Welfare Leadership and Accountability Act of 2006 (Welfare and Institutions Code Sections 16540 – 16545) and serves as an advisory body responsible for improving the collaboration and processes of the multiple agencies and the courts that serve the children in the child welfare system. The Council is co-chaired by the Secretary of the California Health and Human Services Agency and the designee of the Chief Justice of the California Supreme Court, and membership is comprised of state departments, county departments, nonprofit service providers, advocates, parents and former foster youth. The Council is charged with monitoring and reporting on the extent to which the agencies and courts are responsive to the needs of children in their joint care” California Child Welfare Council. (2013). Retrieved from California Health & Human Services Agency: <http://www.chhs.ca.gov/Pages/CACChildWelfareCouncil.aspx>

201 The council shall be comprised of the following members: (a) The Secretary of California Health and Human Services, who shall serve as cochair. (b) The Chief Justice of the California Supreme Court, or his or her designee, who shall serve as cochair (c) The Superintendent of Public Instruction, or his or her designee. (d) The Chancellor of the California Community Colleges, or his or her designee. (e) The executive director of the State Board of Education. (f) The Director of Social Services. (g) The Director of Health Services. (h) The Director of Mental Health. (i) The Director of Alcohol and Drug Programs. (j) The Director of Developmental Services. (k) The Director of the Youth Authority. (l) The Administrative Director of the Courts. (m) The State Foster Care Ombudsperson. (n) Four foster youth or former foster youth. (o) The chairpersons of the Assembly Human Services Committee and the Assembly Judiciary Committee, or two other Members of the Assembly as appointed by the Speaker of the Assembly. (p) The chairpersons of the Senate Human Services Committee and the Senate Judiciary Committee, or two other members appointed by the President pro Tempore of the Senate. (q) Leaders and representatives of county child welfare, foster care, health, education, probation, and mental health agencies and departments, child advocacy organizations; labor organizations, recognized professional associations that represent child welfare and foster care social workers, tribal representatives, and other groups and stakeholders that provide benefits, services, and advocacy to families and children in the child welfare and foster care systems, as recommended by representatives of these groups and as designated by the cochairs” Welfare and Institutions Code Sections 16540-16545. (n.d.). Retrieved from Official California Legislative Information: <http://www.leginfo.ca.gov/cgi-bin/displaycode?section=wic&group=16001-17000&file=16540-16545>

202 California Child Welfare Council. (2013). Retrieved from California Health & Human Services Agency: <http://www.chhs.ca.gov/Pages/CACChildWelfareCouncil.aspx>

and processes of the multiple agencies and the courts that serve the children in the child welfare system”²⁰³

Authorizing Legislation/Formation: Child Welfare Leadership and Accountability Act of 2006 (Welfare and Institutions Code, Sections 16540-16545)

Special Note(s):

Mission: “We provide an effective, collaborative forum for the three branches of government, foster youth and their families, and key stakeholders to advocate for effective and promising strategies and adequate resources to improve outcomes for children, youth and families involved with or at risk of involvement with the child welfare system.”²⁰⁴

Parent and Youth Discussion Group: “To ensure that the consumer voice is fully present at Council meetings, Council staff meet via conference call with parent and youth representatives on the Council before and after each Council meeting to discuss the agenda items for the upcoming meeting, answer any questions they may have, and give them the opportunity to prepare for the Council meeting. The post-meeting call is to debrief the Council’s discussion of each agenda item and to provide clarification on any of the points made during the meeting.”²⁰⁵

Compensation: “Members shall serve without compensation, with the exception of foster youth members, who shall be entitled to reimbursement for all actual and necessary expenses incurred in the performance of their duties.”²⁰⁶

Monitoring and reporting: “The Council is charged with monitoring and reporting on the extent to which the agencies and courts are responsive to the needs of children in their joint care.”²⁰⁷

Family and Juvenile Law Advisory Committee²⁰⁸

Family Participation: Not required.²⁰⁹

Committee’s Authority/Responsibility: Advisory²¹⁰ – “The committee makes recommendations to the council for improving the administration of justice in all cases involving marriage, family, or children.”

Authorizing Legislation/Formation: The basic function and membership of this committee is codified in California Rules of Court – Rule 10.43.

203 California Child Welfare Council. (2013). Retrieved from California Health & Human Services Agency: <http://www.chhs.ca.gov/Pages/CAChildWelfareCouncil.aspx>

204 The California Child Welfare Council. (2012, September). Retrieved from California Health and Human Services Agency: http://www.chhs.ca.gov/CWCDOC/CA_Child_Welfare_Council_At-A-Glance.pdf

205 California Child Welfare Council Operations Manual. (2012, Jun). Retrieved from California Health & Human Services Agency: http://www.chhs.ca.gov/CWCDOC/Operations_Handbook.pdf

206 Welfare and Institutions Code Sections 16540-16545. (n.d.). Retrieved from Official California Legislative Information: <http://www.leginfo.ca.gov/cgi-bin/displaycode?section=wic&group=16001-17000&file=16540-16545>

207 California Child Welfare Council. (2013). Retrieved from California Health & Human Services Agency: <http://www.chhs.ca.gov/Pages/CAChildWelfareCouncil.aspx>

208 “The Judicial Council of California’s Family and Juvenile Law Advisory Committee makes recommendations to the council for improving the administration of justice in all cases involving marriage, family, or children. The committee is staffed by the Center for Families, Children & the Courts of the Administrative Office of the Courts (AOC), the council’s staff agency” Fact Sheet: Family and Juvenile Law Advisory Committee. (2012, August). Retrieved from California Courts: The Judicial Branch of California: <http://www.courts.ca.gov/documents/fjla.pdf>

209 “Under rule 10.43 of the California Rules of Court, the Family and Juvenile Law Advisory Committee includes members in the categories of appellate court justice, trial court judicial officer, judicial administrator, child custody mediator, family law attorney, juvenile law attorney, chief probation officer, child welfare director, Court Appointed Special Advocate (CASA) director, county counsel, domestic violence advocate, district attorney, child support attorney, and public interest children’s rights attorney” Fact Sheet: Family and Juvenile Law Advisory Committee. (2012, August). Retrieved from California Courts: The Judicial Branch of California: <http://www.courts.ca.gov/documents/fjla.pdf>

210 Title 10. Judicial Administration Rules. (n.d.). Retrieved from California Courts: The Judicial Branch of California: http://www.courts.ca.gov/documents/title_10.pdf

First 5 State Commission²¹¹

Family Participation: Not required.

Committee's Authority/Responsibility: Statewide Governance

Authorizing Legislation/Formation: The California Children and Families Act

First 5 County Commissions

Family Participation: Not required. However, the language on a county level creates a number of categories that counties can choose from to select slots not designated for other positions, and one of those choices reads "recipients of project services included in county [First 5] strategic plan."²¹²

Committee's Authority/Responsibility: Local Governance

Authorizing Legislation/Formation: The California Children and Families Act

Special Note(s):

Sonoma County is an example of one county that has created a parent seat.

Los Angeles County Blue Ribbon Commission on Child Protection²¹³

Family Participation: N/I

Committee's Authority/Responsibility: Strategy Development and Accountability

Authorizing Legislation/Formation: This Commission was created through a motion approved by the Board of Supervisors.

211 "The California Children and Families Act, passed by voters in 1998, called for the formation of a State Commission to oversee and support the funding of education, health, and child care programs for children ages 0 to 5 and their families. This Commission, also known as First 5 California, works with 58 First 5 county commissions statewide to develop and fund programs for young children that are tailored to the needs of local communities." First 5 California Commission. (2010). Retrieved from First 5 California: http://www.cafc.ca.gov/commission/commission_members.html

212 Proposition 10 Statutes. (2011, March 24). Retrieved from First 5 California: http://www.cafc.ca.gov/pdf/about/about_legislation_prop_10.pdf

213 "The Blue Ribbon Commission, pursuant to the Board of Supervisors' motion approved on June 25, 2013, believes that the children of Los Angeles County have a right to grow up free from abuse and neglect. The Commission further believes that abused or neglected children have a right to be protected against further injury...To ensure these rights and improve safety for children, as measured by reduced serious injuries due to abuse and neglect, less recurrence of maltreatment and fewer child fatalities, the Commission will focus on systemic change and comprehensive countywide approaches that extend beyond DCFS to include Public Health, Health Services, Mental Health, the Sheriff, the Medical Examiner, First Five and other agencies and organization that may later be identified; and the various memoranda of understanding involved. The Commission will identify strategies that reflect the broad countywide responsibility for welfare and safety and ensure accountability from the entities ranging from the Board of Supervisors to front line practitioners." Los Angeles County Blue Ribbon Commission on Child Protection. (2013). Retrieved from Los Angeles County Blue Ribbon Commission on Child Protection: <http://www.blueribboncommissionla.com/>