



MENTAL HEALTH SERVICES  
OVERSIGHT AND ACCOUNTABILITY COMMISSION

**DRAFT**

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**CLIENT AND FAMILY LEADERSHIP COMMITTEE**

**Minutes**

**July 17, 2012**

**2:00 pm to 4:00 pm**

**MHSOAC Offices**

**1300 17<sup>th</sup> Street, Suite 1000**

**Sacramento, CA 95811**

**Committee Members:**

**Staff:**

**Other Attendees:**

<p>Eduardo Vega, Chair*  Ralph Nelson, Jr., M.D.  Vice-Chair*  Khatera Aslami*  Kathleen Casela*  Carmen Diaz*  Shannon Jaccard*  Steve Leoni*  Abby Lubowe*  Gregory Wright*  Sally Zinman*</p>	<p>Dee Lemonds  Kevin Hoffman  Matt Lieberman</p>	<p>Emilia Arellano*  Delphine Brody  Amber Burkan*  Kathleen Derby  Bob Feldman*  Rigel Flaherty*  George Fry*  Karen Hart*  Maxine Hayden*  Richard Hayes*  Mark Jarmagz*  Charlene Jimerson*  Janna Kaplan*  Terri Keister*  Sharon Kuehn*  Karin Lettau  Donna Ewing Marto*  Vickie Mendoza*  Raja Mitry*  Keris Myrick*  Toni Rucker*  Mickey Shipley*  Michael Szczerbaty*  Janice Tran*  Deborah Van Dunk*</p>
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\*Participated via telephone

Committee members absent: Donna Barry, Jennifer Jones, Darlene Prettyman, Ruth Tiscareno, and Jorge Wong.

### **Welcome/Introductions**

Eduardo Vega, Committee Chair, convened the meeting at 2:05 pm.

- All meeting participants introduced themselves.

### **Panel/Committee Discussion on Consumer-Run Programs and Guidance Document**

Highlights of the panel and committee discussion are as follows:

- Chair Vega opened the discussion. He commented that the issue before the CFLC is not simple and it is difficult to create a consensus document. He asked the question: How does a program run, serviced or delivered by consumers differentiate itself from other programs? Chair Vega stated the CFLC would start by looking at federal Substance Abuse and Mental Health Services Administration (SAMHSA) guidelines and not create a completely new document for California.
- Chair Vega highlighted three SAMHSA terms: 1) consumer controlled, 2) consumer centered, and 3) consumer driven. He stated that SAMHSA just started using the term consumer controlled rather than consumer operated. Consumer controlled refers to an organization that is managed and controlled by consumers. Consumer controlled organization must have a board of directors comprised of more than 50% consumers. Consumer centered refers to mental health services that focus on consumer driven care. Consumer driven refers to mental health treatment in which consumers are the primary decision makers about the care offered. Chair Vega expressed interest in examining staffing, management, and governance of mental health consumer-operated or controlled organizations.
- Chair Vega noted that the panel had been given an evidence based tool kit from SAMHSA on Consumer-Operated Services. Chair Vega noted the panel and the CFLC had also been given several questions to focus the discussion and he reviewed these questions. He asked that Medi-Cal be taken off the question list for the day. Staff noted that an additional question was added on consumer-run programs that serve children. Staff introduced the panel. The panel was comprised of:
  - Khatera Aslami, Executive Director, Peers Envisioning and Engaging in Recovery Services (PEERS), Oakland, CA
  - Delphine Brody, Leadership Team Member, California Network of Mental Health Clients, Sacramento
  - Shannon Jaccard, Executive Director, NAMI San Diego
  - Donna Marto, Chief Executive Officer, Family and Youth Roundtable, San Diego, CA
  - Keris Myrick, M.B.A., M.S., Ph.D., President and Chief Executive Officer, Project Return Peer Support Network, Commerce, CA

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- Sally Zinman, Interim Executive Director, California Association of Mental Health Peer Run Organizations (CAMHPRO)
- Staff asked for comments on the content of the SAMHSA tool kit— agreement or disagreement.
- Panel member Donna Marto asked if a child or a family member is a consumer and Chair Vega responded that a consumer is in the domain of adults.
- Panel member Keris Myrick commented that the SAMHSA consumer operated tool kit was a year to a year and a half old and that the glossary terms were more recent. Keris Myrick had no problem with the tool kit definitions of consumer operated programs. She stated there is a need to document the 51% consumer controlled principle for governance in organizational by-laws.
- Panel member Delphine Brody commented that the California Network of Mental Health Clients has been 100% consumer controlled and the 51% minimum for governance is controversial.
- Staff asked whether there should be a focus on service delivery programs or on the agencies that advocate. Staff commented that this tool kit is focused on agencies that deliver services. Keris Myrick commented that services and advocacy are both in the tool kit. She said her organization used the tool kit as a guideline but established 75% as their requirement for consumer representation on her governing board.
- Chair Vega asked: What constitutes a consumer-operated agency or program? He commented that an agency or program can do many things and an agency or program is different from consumer delivered services. Panel member Sally Zinman agreed that consumer operated services can mean a whole spectrum of things. She stated she was impressed with the tool kit, but thought it was watered down and that it needs to be more specific. Ms. Zinman noted that the values of the organization are the most important focus, such as non-hierarchical structure, voluntary organization, and holistic approach. She cited other foundational documents such as Judy Chamberlain's book "On Our Own", and another book called "Mental Health Clients Helping Each Other." Ms. Zinman commented that 51% is not enough consumer representation on a governing board; there is a need for 66% or 75% representation to be consumer controlled. She commented that consumer operated means management and administration, if not all staff, are consumers.
- Panel member Khatera Aslami commented that evaluation is important as well as management, governance, and policymaking. Ms. Aslami commented on page four of the tool kit and would add "based on self-determination." She also stated that individuals should be treated with dignity, respect, and high regard. The six values listed in the tool kit are not enough. She commented that hope is the core value of her organization. Hope consists of connecting with someone. Ms. Aslami commented that there needs to be a strength-based approach with

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- empowerment, collaboration and community building. Experience needs to be shared to eliminate stigma.
- Panel member Delphine Brody commented on other California Network organizational values including: accountability, respect, dignity, trust, integrity, honesty and authentic communication, and education. Regarding the tool kit, Ms. Brody commented that the helper's principle on page 2 is not universally agreed upon. She believes that the power difference between staff and members is recognized in peer support relationships.
  - Chair Vega acknowledged there is a range of consumer operated programs. He also noted the issues of governance and decision making. Chair Vega also mentioned the issue of consumer representation on staff.
  - Panel member Shannon Jaccard liked the tool kit. She liked the independence and autonomous principles in the tool kit. She noted that at NAMI San Diego 95% of the staff is either a family member or a consumer. She stated her concern about setting up an "us vs. them" dynamic in this discussion. At NAMI, consumers and non-consumers are intertwined. She is not sure how to talk about family support as separate and noted there aren't many family-run organizations. Chair Vega commented that many agencies are not consumer operated but have some consumer operated programs within; there are differences between organizations and programs. The kit does not do a good job with clarifying this distinction.
  - Chair Vega posed the question: Is an organization that is funded by a county consumer-run? Ms. Jaccard responded that her organization is not a provider but provides personal experiences. Sally Zinman asked: Is the focus of the guidance document project on consumer operated services or something else? Khatera Aslami supports a document for both consumer-operated organizations and family advocacy. Ms. Aslami asked if advocacy is moving towards individual voice or family advocacy. Panel member Donna Marto suggested one guidance document for adults and one for children. She commented that the mental health community can't agree on who the consumer is when talking about children's services. Children are often treated as mini-adults and they are not mini-adults; they are in discovery. The tool kit is adult-focused and not a lot of it would fit with children.
  - Keris Myrick commented on cultural relevancy. She asked: How do people identify as a consumer within their own culture? Terms such as empowerment may not be culturally relevant for some people. She expressed concern with being overly prescriptive for communities.
  - Chair Vega asked: Based on the SAMHSA toolkit, what can we do to be helpful to local communities? He commented that exclusion can hamper development of consumer empowerment.
  - Chair Vega asked: What if a county wanted to fund a consumer operated service but the service was not consumer controlled? He asked: What happens then? Chair Vega confirmed it was his intent to use the guidance

document for funding situations. Khatera Aslami commented that Alameda County has defined consumer-run programs and has created some documents that apply to this issue. She offered to send the documents to the MHSOAC or to bring them to the next committee meeting.

- Comment that this discussion was adult oriented and children are not little adults. Children are still growing and should not be discussed in terms like recovery; they are resilient. Comment that this panel needed more parents. Donna Marto commented that her organization considers itself a consumer led organization and they are made up of family members. Chair Vega responded that it would be good to have a guidance document on a parent-driven organization but he hoped to focus here on a classic consumer-driven organization.
- Comment that the children's turn never seems to come and that the CFLC should commit to a children's document.
- Comment on the SAMHSA kit, page 4, and the role for people who are not consumers. Comment that a consumer is a person with lived experience with mental illness and this does not directly include family members; family members are in the position to be collaborators. Comment that the mental health system is moving towards people getting support in the community and people need to build networks for when they are no longer receiving services.
- Delphine Brody commented that client-survivor definitions could be re-examined. This needs to include the exclusion of people who sought services and did not get any.
- Comment that the advocacy piece in the tool kit was too short.
- Comment that the tool kit was more services focused than advocacy focused. There is a need to ask: Are cultural differences included in consumer identity? There is a need to explore the issues of general identity of consumers regarding a specific role in an organization. Comment on the need to distinguish between consumers working in an organization and consumers currently receiving services. MHSOAC Staff commented that on page 4 it states that a consumer-operated service is controlled by the persons who use the service. Sally Zinman commented that the concept is the people who use the services help run the service in a non-hierarchical way.

### **Public Comment**

- Comment that consumers who receive services should have input into services provided. Need to have consumers on a grievance committee. When people leave services, consumers could control the next support process.
- Concern expressed about splitting the role of a peer specialist. This discussion of the peer role is about the family. You can't split up the

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- family, adults versus children. The tool kit can help define the peer role and advocate for children.
- Comment that the Department of Mental Health (DMH) assured evaluation with outcome based theory and they have not been following through. Consumers have a unique viewpoint and need to be at the table. With the Affordable Care Act, there will be a management board and consumers will not be at the table. There is a need to have support for each age group. A study of emergency rooms was done in San Diego where peer counselors go to older adult inpatients and escort them to their first psychiatric appointment.
  - Question asked that for the purposes of funding and guidance, is there a category for a for-profit business model? Comments made regarding an on-line, peer support, service. This service is outside of any agency-- wholly peer originated and staffed. Examples of several peer-run programs were named, including "Recovery International" and "Power to Change." Question asked whether corporate organization makes a difference to funding.
  - Comment made that people with psychiatric difficulties do recover and peer support is not replaceable. Consumer-operated organizations should have 75% consumers in their governance with 25% made up of psychiatrists and psychologists. On page 2 of the tool kit, shared decision making is left out. Concern expressed with over-diagnosis and treatment. Consumers should be seen by a peer advocate first before seeing a psychiatrist.
  - Kathleen Derby of NAMI California commented that this discussion is on funding and what qualifies for funding. She noted that NAMI is a combined consumer and family organization. She asked: How do we know who is a consumer? Is it legal to ask? Ms. Derby commented that family members are consumers in their own right and segregation of consumers and family members is not productive.
  - Comment that there will be a client congress in Los Angeles soon and Katherine Bond is working on this project.
  - Comment that there is a need for an evaluation component and a strong advocacy component in the guidance document. NAMI has supported peer self help. In NAMI "Family to Family," the greatest tragedy is when a family member is blamed for a family member's illness. It is better for consumers to take over consumer-run organizations. It is important to note that family members have a pass to get out of a locked facility. This issue is about autonomy for consumers.
  - Comment that everyone who has an interest should develop their own document: children, TAY, adults, and older adults. Pat Deegan's book, "Common Ground", should be referenced for this project.
  - Chair Vega thanked the participants and stated that for next steps he and Commissioner Nelson will consult with staff to determine a course of action and will discuss this at the next committee meeting on August 15, 2012.

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**Adjournment**

Meeting adjourned at 4:00 pm.