California Mental Health Planning Council

Patients' Rights Committee

October 19, 2016

Lake Natoma Inn, Placer Room

702 Gold Lake Drive Folsom, CA 95630

11:00 a.m. to 12:30 p.m.

Time	Topic	Presenter or Facilitator	Tab
11:00 a.m.	Welcome and Introductions	Daphne Shaw, Chair	
11:05	Agenda Review	Daphne Shaw, Chair	
11:10	Review and approve June 2016 meeting minutes	Daphne Shaw, Chair	A
11:15	Discuss Issue of Ratio of Patients' Rights Advocates, training requirements, and update on Humboldt Co. investigation. Report out from 8/24 CAMHPRA meeting.	Samuel Jain, Mental Health Advocacy Project Daphne Shaw, Chair All	B
12:00	Review Projects on Work Plan and revise as necessary	All	C
12:10	Review PRA Survey draft	All	D
12:20	Plan for Next Meeting/Report Out	All	
12:30	Public Comment/Adjourn		

The scheduled times on the agenda are estimates and subject to change.

Committee Members:

Co-Chairs:	**Daphne Shaw**	**Cindy Claflin**
Members:	Adam Nelson, MD	Walter Shwe
	Carmen Lee	Richard Krzyzanowski
Staff:	Tom Orrock	Jane Adcock, EO

If reasonable accommodations are required, please contact the CMHPC office at (916) 552-9560 not less than 5 working days prior to the meeting date.

_____ **INFORMATION** **TAB SECTION** **A**

__X___ **ACTION REQUIRED:** **DATE OF MEETING** 10/19/16
Approve Minutes

MATERIAL PREPARED BY: Orrock **DATE MATERIAL PREPARED** 9/1/16

AGENDA ITEM:	Approval of PRC Committee Meeting Minutes
ENCLOSURES:	• Minutes of PRC Meetings on June 16, 2016
OTHER MATERIAL RELATED TO ITEM:	None

ISSUE:

Patients' Rights Committee review and approval of minutes from June 2016 Quarterly meeting in Ontario, CA.

Patient's Rights Committee

Meeting Highlights
June 15, 2016
700 North Haven Avenue, Ontario, CA

Committee Members present:

Daphne Shaw, Chair Walter Shwe
Carmen Lee

Staff present:

Tom Orrock, Jane Adcock

Others present:

Beryl Nielsen, Napa County
Maya Petties, CMHPC, Patton State Hospital
Darlene Prettyman, CMHPC
Jim Preis, Mental Health Advocacy Services
May Farr, San Bernardino County

Welcome and Introductions:

Daphne Shaw welcomed all committee members and guests. Daphne took role and noted that we would not be able to approve the minutes as the committee did not have a quorum.

Discussion of Patients' Rights Advocates Ratio:

Daphne introduced Jim P. to the committee and pointed out the enclosures in the packet. Daphne pointed out that we haven't made progress since 1981 in regards to ratios. Jim stated that he was not prepared to recommend a particular ratio. Jim's organization focuses mostly on those placed outside of the hospital but began with work at Metro State Hospital. In the early 80s patients' rights advocacy really began with inclusion of language in WIC.

Jim stated that we are now creating a bridge between CAMHPRA and the CMHPC PRC. There are so many diverse county systems and sizes so a ratio is difficult to identify. How do ratios impact across the state given the different county set ups. Everything in San Francisco is on top of each other and in San Bernardino county things are very spread out. That creates significant issues for ratios. Daphne pointed out that we also have IMDs in some counties and not in others. Surrounding counties place individuals in IMDs so that has to be taken into account as well. When Title 9 regs were being developed, they put a 1:500,000 ratio in place. Regardless of whether this was right or not the kinds of services and locations of MH services has expanded since then. We went from a medical model to a recovery model so this changed where services were being performed. This has forced the question, "what is the role of an advocate?" Several court decisions over the last 35 years. Doe vs Gallino looked at the constitutionality of the LPS Act and stated that it was not appropriate and there was not enough due process. A judicial review occurred only if they asked for it. This was not fair to the client as they were

often highly medicated or at the height of their psychosis. This created the need for patients' rights advocates. There are more advocates today then there were in 1981 but they're all out there driving from hospital to hospital taking part in commitment hearings. What about all of the other things they did in 1981 i.e. ensuring appropriate discharges, wishes of the clients regarding care, general advocacy that would further the clients best interest.

What is the role of the PRA in the mental health system? The PRA is set apart from other providers in that they are there as the spokesperson for the client. They aren't clinicians. They are the voice for the client in the system. That's a unique role. The client may be wrong but the advocate still helps the client voice their desire. What is the value of that? In the legal field there is a whole academic theory called "therapeutic jurisprudence". Having an opportunity to hear the needs or desires of a client whether it leads to a desired outcome can be seen as therapeutic.

The second big case which set precedence is Reese vs St. Mary's Medical Center. It found that just because you are hospitalized does not mean you can't make decisions about medication. If you want to medicate a patient you need to now have a capacity hearing. In response to this they created Reese Hearings. Advocates take part in these hearing to be the voice of the patient. Before this Patients had no say in their own treatment. Reese says that you need to get informed consent from the patient.

Jim feels that giving a patient a voice is more important than ever. There are several opportunities for advocacy in the community as well as in hospitals. The things that are seen as mandatory receive the most attention. There is no accountability regarding a complaint about treatment in a community care facility. What is the role of the advocate in relation to CCL? How robust is the grievance process. Nobody is providing oversight to grievances.

Darlene stated that her PRA comes to the MH Board meetings (Tulare). This may be something that we recommend to the county MH boards. How do we encourage patients to speak for themselves? What should the role of peers be in advocacy? Peers do Title 9 advocacy but it remains unclear about how this advocacy is done. How do peers fit into any type of formula that we develop?

Maya P. stated that in Patton advocates have moved from dealing with grievances to helping in Reese hearings. Someone who is denied grounds privileges doesn't have the resources for advocacy that they used to have. The advocacy lines are not staffed or responded to most times.

Internal advocates have an opportunity to be part of the whole team. At its worst the advocate could be stifled by a Director who says 'hey you work for me". External contracts can be terminated which also creates a tension for advocates. Jim stated that the best scenario is to have the advocate work internally in an advocacy role only. To eliminate role confusion. You can't be a nurse practitioner and an advocate.

Daphne is happy to have CAMHPRA on board. She is hopeful that we may be able to obtain more information about the subject. Jim stated that we might not want to get counties to do something but

instead get them to want to do something. Think about hearings as part of the therapeutic process and not just an adversarial process. The main thing about advocacy is listening. Listening to someone is providing a very important therapeutic approach. Could peers serve as those who hear the everyday complaints and provide that therapeutic advocacy? Professionalized advocacy has not been widely accepted by CAMHPRA. They don't want advocates to be seen as certified professionals. ???

Walter pointed out that some advocates serve patients to navigate the system and help clients get the services they need. This is an additional role of an advocate. Jim asked if this was advocacy or what the whole MH team ought to be doing.

A question from the audience was asked about advocacy in situations when a family is trying to get treatment for an adult relative who is refusing treatment. Jim stated that there should always be a family advocate as well as a patient advocate. The advocate is the express voice of the patient. They can't be the mediator between family and patient.

Jane A asked if there is confusion about who handles grievances. Is there a way that it is made more of a seamless process? Jim stated that this was a good point and that a goal could be to establish better procedures for grievances and complaints. They are trying to reconcile this and have one grievance process. It seems that MH directors should have some standards in regards to the location on the website where they can find grievance procedures. Walter agrees that uniformity between MHSA and Medi-cal is the way to go so as to avoid confusion.

How do we get counties on board to want to do therapeutic jurisprudence? Jim stated that directors will fight against requirements so it has to be done in a way that is suggestive of best practice. Counties are not able to provide everything that a patient wants. There are mandates that make it difficult to do anything about some of the needs expressed by patients. So there is tension created when advocates ask for things that are not easily provided by a county.

Data needs to be collected through a survey process to ask advocates about their functions. We will continue to work with Samuel Jains to continue the discussion about proper representation for patients.

Jane asked if we might want to interact with a DHCS representative at our October meeting so that we can address our role to advise DHCS about these issues.

Discuss/Review Projects on Work Plan:

The letters were sent out. Daphne asked the San Joaquin County MH Board if the letter was received. She was told that they didn't receive anything. The letter was sent to the director c/o the MH Board chair. It may be a better idea to send information to the liaison to the MH Board. Maybe we could get something included in the training for new MH Board members that CIBHS does.
We will continue to work with CAMHPRA and the task force. There is nothing in our work plan about State Hospitals but Daphne felt we needed to stay focused on the current subject of patient rights advocacy ratios.

Public comment:

No public comment

Meeting adjourned at 12:22 pm

___X__ **INFORMATION** **TAB SECTION** **B**

_____ **ACTION REQUIRED** **DATE OF MEETING** **10/19/16**

MATERIAL PREPARED BY: Orrock **DATE MATERIAL PREPARED** 09/06/16

AGENDA ITEM:	Discussion with Samuel Jain, CAMHPRA. Review of correspondence sent to DHCS and Humboldt Co BH Board Chair. Report out from 8/24 CAMHPRA meeting.
ENCLOSURES:	1) Letter to DHCS, Baylor 2) Letter to Linda Atkins 3) CAMHPRA letter to COPR
OTHER MATERIAL RELATED TO ITEM:	

ISSUE: These letters (1,2) were sent in response to a concern from CAMHPRA regarding the advocacy services in Humboldt County. There was a request for investigation from Humboldt County to the COPR (letter 3). The CMHPC letter supports CAMHPRAs desire for an investigation.

The second letter was sent to Linda Atkins who is the new BH Board Chair. The letter provides a summary of the request for investigation and CMHPC's support for the investigation.

California Mental Health Planning Council

CHAIRPERSON
Josephine Black

EXECUTIVE OFFICER
Jane Adcock

July 12, 2016

Karen Baylor, Ph.D.
Deputy Director, Mental Health and Substance Use Disorder Services
California Department of Health Care Services
1501 Capitol Avenue
Sacramento, CA 95899-7413

Dear Dr. Baylor,

Recently, the California Mental Health Planning Council (CMHPC) was informed by Samuel Jain, President of the California Association of Mental Health Patients' Rights Advocates (CAMHPRA), of a situation in Humboldt County regarding the contracts of the two Patients' Rights Advocates. Additionally, Mr. Jain stated a request has been made by CAMHPRA to Michele Mudgett, Director of the California Office of Patients' Rights (COPR), to investigate the non-renewal of patients' rights contracts in Humboldt County. (See Enclosure)

In his letter, Mr. Jain explains that Humboldt County's two patients' rights advocates received notice informing them that their contracts would not be renewed. According to Mr. Jain, this action came a few months after some ongoing contentious advocacy regarding patients' rights violations in the county's Crisis Stabilization Unit (CSU). The letter asserts that CSU staff received a memo which forbid them from speaking with the advocates without a release of information. Mr. Jain is concerned that the advocates may have been obstructed from carrying out their duties as patients' rights advocates. The letter also shares concerns that Humboldt County's decision to not renew the advocacy contract may have been retaliation against the advocates following their investigation of the CSU.

- **Advocacy**
- **Evaluation**
- **Inclusion**

As you know, the CMHPC has a Patients' Rights Committee who has responsibilities, in statute, to review the advocacy and patients' rights components of each county mental health plan or performance contract and advise the Director of Health Care Services concerning the adequacy of each plan or performance contract. Mr. Jain's letter causes concern and it is our hope that this matter is investigated. The CMHPC supports CAMHPRA's request that an investigation be conducted regarding the situation in Humboldt County. The CMHPC requests that DHCS direct the COPR to inform the CMHPC of the outcome of its investigation.

Sincerely,

Josephine Black, Chairperson
California Mental Health Planning Council

Daphne Shaw, Chairperson
CMHPC Patients' Rights Committee

MS 2706
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Sacramento, CA 95899-7413
916.323.4501
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Enclosure

July 19, 2016

Linda Atkins, Chairperson
Humboldt County Behavioral Health Board
1711 3rd St
Eureka, CA 95501

Dear Chairperson Atkins

The Patients' Rights Committee of the California Mental Health Planning Council (CMHPC) has responsibilities in statute to both review county patients' rights plans and advise the California Department of Health Care Services regarding its policies and practices pertaining to patients' rights. The Council was recently copied on a letter regarding the Patients' Rights Advocates in Humboldt County. In the letter to the California Office of Patients' Rights (COPR), Samuel Jain, President of the California Association of Mental Health Patients' Rights Advocates (CAMHPRA) stated that the contracts of the only two Patients' Rights Advocates were not renewed. Mr. Jain made a request to Michelle Mudgett, Director of COPR, to investigate the non-renewal of the patients' rights contracts as well as other potential patients' rights violations. (See Enclosure)

In his letter to COPR, Mr. Jain states that the non-renewal decision came a few months after some ongoing contentious advocacy regarding patients' rights violations in the county's Crisis Stabilization Unit (CSU). The letter asserts that CSU staff received a memo which forbid them from speaking with the advocates without a release of information. If true, this could be considered a violation of Welfare and Institutions Code 5530. Mr. Jain is concerned that the advocates may have been obstructed from carrying out their duties as patients' rights advocates. The letter also shares concerns that Humboldt County's decision to not renew the advocacy contract may have been retaliation against the advocates following their investigation of the CSU.

The CMHPC and the California Association of Local Behavioral Health Boards and Commissions have an excellent working relationship. We want to ensure that you are made aware of what we know so far as it pertains to this situation in Humboldt county. We have written a letter to Karen Baylor, DHCS Deputy Director of Mental Health, indicating our support for an investigation and a request to be made aware of the findings. We look forward to working with you as this matter is addressed.

Thank you for your service to the Behavioral Health Board in Humboldt county.

Sincerely,

Josephine Black, Chairperson
California Mental Health Planning Council

Daphne Shaw, Chairperson
CMHPC Patients' Rights Committee

Enclosure

C . A . M . H . P . R . A

California Association of Mental Health Patients' Rights Advocates

July 7, 2016

Michele Mudgett
Director – COPR
Disability Rights California
1831 K St.
Sacramento, CA 95811

Re: Non-renewal of Humboldt County PRA contracts

Dear Ms. Mudgett:

I am writing on behalf of the California Association of Mental Health Patients' Rights Advocates (CAMHPRA) to request that the California Office of Patients' Rights (COPR) investigate the non-renewal of patients' rights contracts in Humboldt County.

CAMHPRA is a statewide organization composed of county patients' rights advocates mandated by state law (Calif. Welf. & Inst. Code § 5520), private and public interest attorneys, consumers of mental health services, and representatives from other advocacy organizations. CAMHPRA is dedicated to protecting and advancing the legal rights and treatment interests of individuals with mental health disabilities.

CAMHPRA has learned that the only two patients' rights advocates in Humboldt County, Stephen Infantino and Nicole Garito, recently received notices of non-renewal approximately a week before their contract was set to expire. The two advocates have been in their roles for seven years and one and a half years, respectively. The notice of non-renewal did not state a cause and was in the context of a communication blackout between the advocates and Humboldt County's interim behavioral health director. All requests for dialogue from the advocates were ignored by the interim director and there was no attempt by the interim director to open the contract for re-negotiation.

The notice of non-renewal was received a few months after contentious advocacy regarding serious patients' rights violations of minors in a county-operated Crisis Stabilization Unit (CSU). Following the advocates' investigation and advocacy in accordance with Calif. Welf. & Inst. Code § 5520, the CSU's administration sent out a memo forbidding staff from speaking with advocates without a written release of information, in violation of state law. Calif. Welf. & Inst. Code §§ 5522, 5550(b); 9

152 N. Third St., 3rd Floor, San Jose, CA 95112 Phone: (408) 280-2450 FAX: (408) 250-1158

C.C.R. § 863.2. Upon confrontation of CSU administrative staff by the advocates, the interim behavioral health director was brought in by CSU staff and personally questioned the role and activities of the advocates. The context and manner in which the advocates in Humboldt County were let go after years of service raises serious concerns about retaliation and the ability of Title 9 advocates throughout the state to conduct the statutory requirements of their positions without fear of losing their jobs.

CAMHPRA formally requests COPR investigate the above situation and pursue all appropriate legal remedies available. Please contact CAMHPRA president, Samuel Jain, at (408) 280-2450 or samuel.jain@lawfoundation.org if you have any questions or would like to discuss CAMHPRA's concerns in more detail.

Sincerely,

Samuel Jain
CAMHPRA President

cc: Karen Baylor, Ph.D.
Deputy Director, Mental Health & Substance Use Disorder Services
California Department of Health Care Services
1501 Capitol Avenue, MS 4000
P.O. Box 997413
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Daphne Shaw
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X____ INFORMATION **TAB SECTION C**

_____ ACTION REQUIRED **DATE OF MEETING** 10/19/16

MATERIAL PREPARED BY: Orrock **DATE MATERIAL PREPARED** 09/05/16

AGENDA ITEM:	Review and Discuss projects on the Work Plan
ENCLOSURES:	PRC 2016 Work Plan
OTHER MATERIAL RELATED TO ITEM:	

ISSUE:

The Work Plan will be discussed in order to evaluate what has been accomplished to this date and to discuss future projects of the PRC.

The PRC Committee may wish to re-visit the MHP grievance process or the 2016 Survey of PRAs and add a project or projects related to that to the Work Plan.

California Mental Health Planning Council
Patients' Rights Committee

Work Plan 2016

Mandate: ***WIC 5514*** *…The committee shall also review the advocacy and patients' rights components of each county mental health plan or performance contract and advise the Director of Health care Services and Director of State Hospitals concerning the adequacy of each plan or contract in protecting patients' rights. …"*

Goal #1	**Measure of Success**	**Targeted Audience**
Measure each County's compliance with WIC 5520 (a)-(e)	Issuing Statewide Report	Directors of Health Care Services and State Hospitals

Objectives	**Action Steps**	**Data/Evaluation**	**Timeline**	**Leads**
• Gather Data • Compile Responses • Evaluate Results • Develop and Disseminate Report	• Survey the Counties/MHBs • Collect PRAT Questionnaires • Secure Input from NAMI • Send Letter to County MH Directors • Send Surveys to Local MH Boards/Commissions • Compile/Analyze/Evaluate all Input • Draft Statewide Report • Submit report to DHCS	Review survey data from PRAs, Counties Explore data from Medi-Cal Compliance Reviews Review annual report from Disability Rights CA	• **November 2013**: County surveys released •**? 2013**: Survey of Mental Health Boards • **March 2014**: Participated in Patient Rights' Advocate training and solicited attendee input • **November 2014**: Letters sent to County MH Directors • **February 2015**: Follow up PRA survey at PRAT conference and online **COMPLETED Jan. 2016** **-June 2016**	Michael Gardner Laura Leonelli Tom Orrock

California Mental Health Planning Council
Patients' Rights Committee

Goal	**Measure of Success**	**Targeted Audience**
Increase Number of PRAs in CA	Decrease the ratio of PRAs to general population	DHCS County MH Departments

Objectives	**Action Steps**	**Data/Evaluation**	**Timeline**	**Leads**
Establish what is current ratio Seek basis/rationale for current ratios Issue report ? Letter to DHCS ? Seek legislation ?	Query DRC, CAMHPRA and County PRAs for info Search for studies, reports, articles which include rationale for current PRA staffing ratios.	Chair to attend CAMHPRA meeting to query about ratios. Review Task Force on County PRA report. Review "A Model for CA Comm. MH Programs" report	May, 2016 June 2016	Tom Orrock

California Mental Health Planning Council
Patients' Rights Committee

Goal	Measure of Success	Target Audience
Encourage discussion at the county MH Com/Board level about the duties of Patients' Rights Advocates.	Letter distributed to each MHP which encourages the Com/Board to place the issue on their meeting agenda.	Local MH Com/Boards

Objectives	Action Steps	Data/Evaluation	Timeline	Leads
Gather information regarding the duties of PRAs in WIC.	Review WIC in areas which discuss the specific responsibilities of the local PRA		January, 2016	CMHPC staff
Discuss the contents of a letter to be sent to local Com/Board.	PRC Committee to discuss at the January CMHPC quarterly meeting		January, 2016	Daphne Shaw
Draft letter to all Local MH Com/Boards	Chair and EO meet to discuss and draft a letter.		April, 2016	
Send letter to all Com/Board Presidents	Print and send paper letter to Com/Board Presidents through the County Behavioral Health Director's Office.		May, 2016 **COMPLETED May, 2015**	Tom Orrock

_____ **INFORMATION** **TAB SECTION** **D**

_X___ **ACTION REQUIRED** **DATE OF MEETING** 10/19/16

MATERIAL PREPARED BY: Orrock **DATE MATERIAL PREPARED** 09/12/16

AGENDA ITEM:	Review and Discuss PRA Survey Draft
ENCLOSURES:	PRA Draft Survey
OTHER MATERIAL RELATED TO ITEM:	

ISSUE:

The PRC has expressed interest in surveying Patients' Rights Advocates around the state on a number of issues that pertain to the work of the PRC. In order to better advise DHCS and DSH regarding the current policies around advocacy, a survey should be created and dispersed to all PRAs.

This agenda item will allow for committee members to review the draft survey, remove or add items, and provide feedback to CMHPC staff on revisions necessary prior to sending out.

2016 Survey of County Patients' Rights Advocates

Name of County: _____

How long have you been serving as a Patients' Rights Advocate? _____years _____months

# of Full Time Equivalent(FTE) Patients' Rights Advocates (PRAs) in your county: _____

To the best of your ability, please provide a breakdown, in percentages of time spent, on specific advocacy activities: **Totals should equal 100%**

%	Receiving and investigating complaints from recipients of mental health services
%	Monitoring facilities for compliance
%	Providing training and education about MH law and patients' rights to providers
%	Ensuring that all recipients of MH services in licensed facilities are advised of rights
%	Provide advocacy in certification hearings
%	Exchanging information with providers, family members, and recipients

If there are other types of advocacy services provided by your county PRAs which are not listed above, please describe:

_____

Does your county provide training to Patients' Rights Advocates which prepares and equips them to carry out their duties?

	YES
	NO

If yes, who provides the training? _____

If yes, in what form is this training provided?

	Webinar
	In-person conference
	Written material
	Informal discussion with other advocates
	Informal discussion with County Behavioral Health representatives
	Other

DRAFT

On a scale from 1-5, how effective are the advocacy services in your county? (check one)

1 (poor)	2	3	4	5 (great)

Specifically, what is needed for more effective advocacy in your county?

_____

_____

In the past year, have you attended a Behavioral Health Board/Commission meeting?

	YES
	NO

If yes, were you invited to attend or did you attend on your own?

	Invited
	Attended on my own

If yes, did you present information about advocacy services to the BH Board at the meeting?

	YES
	NO

What is your procedure for resolving a conflict between yourself and the mental health facility or the office of the County Behavioral Director?

_____

_____

_____

DRAFT

The staff in the licensed health and community care facilities supports my work as an advocate:

	Strongly Agree
	Agree
	Somewhat Agree
	Disagree
	Strongly Disagree

The County Behavioral Health department representative(s) supports my work as an advocate:

	Strongly Agree
	Agree
	Somewhat Agree
	Disagree
	Strongly Disagree

Are there enough advocates in your county to provide all necessary advocacy services? To answer this question please check the best response.

	Too many advocates
	Adequate number of advocates
	Shortage of advocates
	Severe shortage of advocates

If you believe that more advocates are needed in your county, please check the services that need more attention from advocates.

	Receiving and investigating complaints from recipients of mental health services
	Monitoring facilities for compliance
	Providing training and education about MH law and patients' rights to providers
	Ensuring that all recipients of MH services in licensed facilities are advised of rights
	Provide advocacy in certification hearings
	Exchanging information with providers, family members, and recipients

DRAFT