

Patients' Rights Advocacy in California: Analysis and Recommendations



California Behavioral Health Planning Council

Patients' Rights Committee

April 2023

The California Behavioral 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 review and report on the public behavioral health system; participate in statewide planning; and to advise the Legislature on priority issues.

CBHPC Patients' Rights Committee

Chairperson: Daphne Shaw

Chair-Elect: Mike Phillips

Members: Richard Krzyzanowski, Catherine Moore, Darlene Prettyman, Walter Shwe, Susan Wilson

Committee Staff: Justin Boese

Welfare and Institutions Code § 5772

The California Behavioral Health Planning Council shall have the powers and authority necessary to carry out the duties imposed upon it by this chapter, including, but not limited to, the following:

- a) To advocate for effective, quality mental health programs;
- b) To review, assess, and make recommendations regarding all components of California's mental health system, and to report as necessary to the Legislature, the State Department of Health Care Services, local boards, and local programs.
- c) To advise the Legislature, the State Department of Health Care Services, and county boards on mental health issues and the policies and priorities that this state should be pursuing in developing its mental health system.
- d) To assess periodically the effect of realignment of mental health services and any other important changes in the state's mental health system, and to report its findings to the Legislature, the State Department of Health Care Services, local programs, and local boards, as appropriate.

Welfare and Institutions Code § 5514

There shall be a five-person Patients' Rights Committee formed through the California Mental Health Planning Council. This committee, supplemented by two ad hoc members appointed by the chairperson of the committee, shall advise the Director of Health Care Services and the Director of State Hospitals regarding department policies and practices that affect patients' rights. 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 the Director of State Hospitals concerning the adequacy of each plan or performance contract in protecting patients' rights. The ad hoc members of the committee shall be persons with substantial experience in establishing and providing independent advocacy services to recipients of mental health services.

Introduction

The Patients' Rights Committee (PRC) of the California Behavioral Health Planning Council (CBHPC) is mandated in state law to advise the Departments of Health Care Services and State Hospitals regarding policies and practices that affect patients' rights. The PRC also monitors, reviews, evaluates, and makes recommendations for the protection and upholding of patients' rights to receive effective, timely, and humane treatment in the public mental health system of California. Starting in 2017, the committee has focused on evaluating the system of patients' rights advocacy in California and increasing the effectiveness of patients' rights advocates (PRAs) who provide vital services in securing the rights of mental health patients throughout the state. This has included outreach to patients' rights advocates and organizations, survey engagement and analysis, written reports and recommendations, legislative advocacy, and more.

While the PRC is proud of this work and the improvements that have been made to the system, there is still much to be done. Patients' Rights Advocates are a crucial safeguard within our mental health system, and they continue to face significant challenges to the successful completion of their duties on top of the steadily increasing complexity of their responsibilities. A number of the issues the committee identified early on in these efforts persist to this day, and new concerns have emerged in recent years as well. The purpose of this report is to provide a brief overview of the duties of patients' rights advocates, summarize the PRC's work regarding patients' rights advocacy from 2017 to 2022, identify some of the current issues in this field, and provide recommendations for addressing these issues.

Background

What Are Patients' Rights?

California law, including the Lanterman-Petris-Short Act and other laws, state that clients and consumers of mental health services all have certain rights, even when receiving treatment involuntarily. According to WIC Section 5325.1, "persons with mental illness have the same legal rights and responsibilities guaranteed to all other persons by the Federal Constitution and laws and the Constitution and laws of the State of California unless specifically limited by federal or state law or regulations."

Within the LPS system these rights are split into those that can never be denied, and those that can be denied if there is "good cause."

The list of **non-deniable** rights includes, but is not limited to:

- A right to treatment services which promote the potential of the person to function independently. Treatment should be provided in ways that are least restrictive of the personal liberty of the individual.
- A right to dignity, privacy, and humane care.
- A right to be free from harm, including unnecessary or excessive physical restraint, isolation, medication, abuse, or neglect. Medication shall not be used as punishment, for the convenience of staff, as a substitute for program, or in quantities that interfere with the treatment program.
- A right to prompt medical care and treatment.
- A right to religious freedom and practice.
- A right to participate in appropriate programs of publicly supported education.
- A right to social interaction and participation in community activities.
- A right to physical exercise and recreational opportunities.
- A right to be free from hazardous procedures.
- The right to refuse psychosurgery (brain surgery).
- The right to see and receive the services of a patient advocate who has no direct or indirect clinical or administrative responsibility for the person receiving mental health services.

Psychiatric facilities must also uphold the following rights, which can only be denied by establishing “good cause.” Good cause can be established when allowing that right to be exercised would cause injury to the individual, a serious infringement on the right of others, or serious damage to the facility. Even when a right is denied with good cause, it must be denied in the least restrictive way possible.

- The right to wear one’s own clothing.
- The right to keep and use one’s own personal possessions, including toilet articles, in a place accessible to the individual.
- The right to keep and spend a reasonable sum of one’s own money for canteen expenses and small purchases.
- The right to have access to individual storage space for one’s own use.
- The right to see visitors each day.
- The right to have reasonable access to a telephone, to make and receive confidential calls, or to have calls made for you.
- To mail and receive unopened correspondence.
- The right to have ready access to letter-writing materials, including stamps.
- Other rights, as specified by regulation.

County Mental Health Patients' Rights Advocates

California first moved to establish patients' rights and the right to advocacy began in 1969 with the implementation of the Lanterman-Petris-Short (LPS) Act, the intent of which was to replace the "warehousing" of individuals with mental health disabilities and increase community based treatment services so patients would be treated in the least restrictive manner.¹ In 1972, the California Legislature established that mental health patients have rights such as seeing visitors, refusing psychosurgery, and wearing their own clothing. After it was found that compliance with patients' rights laws was inconsistent in institutional settings, the California legislature mandated the establishment of the State Patients' Rights Office in 1974², but this still lacked the capacity to properly respond to individual complaints of patients in state hospitals and other mental health facilities. This was addressed in 1976 when new regulations required county mental health departments and state hospitals to provide advocacy services to patients and specified responsibilities for these newly created "Title 9 County Patients' Rights Advocates."³

The initial responsibilities for PRAs included:

- Insuring that patients are notified of their statutory rights.
- Receiving and investigating patient complaints.
- Advocating on behalf of patients whose rights had been violated.
- Monitoring facilities for compliance with patients' rights laws.
- Providing training and education to mental health providers regarding patients' rights.

These duties already necessitated an ambitious workload, but additional responsibilities have been added by further legislation and judicial decisions, including:

- Providing patient representation in certification review hearings and capacity hearings.
- Representing minors in independent clinical reviews.

Furthermore, 1991 "realignment" has increased the number of patients that county PRAs are responsible for serving, as well as the types of facilities and programs they are responsible for overseeing.

¹ California Welfare & Institutions Code § 5001(a); California Welfare & Institutions Code § 5325.1(a)

² California Welfare & Institutions Code § 5370.2

³ California Welfare & Institutions Code § 5520

CBHPC Patients' Rights Committee – 2017-2023

PRA Survey and White Paper (2017)

In 2017, the Patients' Rights Committee collaborated with the California Association of Mental Health Patients' Rights Advocates (CAMHPRA) to conduct a survey of PRAs and publish a report highlighting the issues identified. The primary findings of the paper were organized into three categories, and recommendations were developed for each category.

Staffing and Funding: A majority of survey respondents reported that their county did not have enough PRAs to adequately service the patients in their communities. In some cases, PRAs were only hired on a part time basis and identified a need for more hours to fulfill their duties. This staffing issue is also indicative of a lack of adequate funding for patients' rights programs.

Initial Recommendations:

- Establish a minimum level of staffing for patients' rights advocacy services in all counties.
- Seek legislation requiring specific ratios for PRAs based on the number of acute mental health beds and county population, as well as other factors.

Education and Training: Survey respondents identified issues with the quality or amount of training that they received, and a strong majority said they supported legislation to mandate specific training requirements for PRAs.

Initial Recommendations:

- Mandated and standardized training requirements for all PRAs.
- County reimbursement for all training costs.
- Expansion of the California Office of Patients' Rights (COPR) contract for increased support and technical assistance to county patients' rights programs.

Fear of Employment Retaliation: A subset of survey respondents expressed that concern over employment retaliation affected how strongly they advocated against practices and policies that they believe violate clients' rights. This is a significant issue because while PRAs work for the counties or are contracted by them, they are required to receive and investigate complaints against county mental health facilities. While county employees were covered by existing whistleblower protections, contracted PRAs were not – and a significant portion of county PRAs are independent contractors or employees of contracted organizations.

Initial Recommendations:

- Legislation providing whistleblower protections for county contractors.

Legislative Advocacy (2018-2019)

Following the release of the 2017 white paper, the Patients' Rights Committee continued to collaborate with CAMHPRA to enact some of the recommendations of the report. The two groups worked with then Assemblymember Susan Eggman on two pieces of legislation focused on the training and retaliation issues and supported the bills as co-sponsors.

Assembly Bill 2316, signed in 2018, established mandated training of newly hired PRAs via an online training program. The online training materials are provided by COPR, and the PRC receives verification of the completion of this training for each participating PRA.

Assembly Bill 333, signed in 2019, provides whistleblower protections against employment retaliation for patients' rights advocates who are county contractors.

Survey of Local Behavioral Health Boards/Commissions (2020-2021)

In late 2019, the PRC decided to conduct a survey of Local Behavioral Health Boards and Commissions to see how familiar the boards/commissions were with the duties and responsibilities of county mental health patients' rights advocates. By this point, the PRC was exploring the issue of patients' rights advocacy in county jails, as discussions with groups like COPR, Disability Rights California (DRC), and the ACLU of San Diego had raised concerns about patients' rights violations and inadequate advocacy services in this setting. Because of this, a few questions specifically asking about how familiar the boards/commissions were with those duties in particular were added to the survey.

This survey was sent out in 2020, and the analysis report was published in 2021. Findings of note from this survey include:

- Around 70% of the responding boards said their members were somewhat or very familiar with the roles and duties of PRAs in general. However, less than 40% were familiar with patients' rights advocacy work in county jails.
- About half of the responding boards/commissions said that PRAs in their county attend local behavioral health board/commission meetings.
- A large majority (78%) indicated that they do not regularly receive reports on patient's rights activities or violations that occur in their county.
- When asked if PRAs in their county have access to county jail facilities, inmates, and inmate records, less than 3% answered "Yes, full access." About 27% responded "Yes, but only partial or limited access"; 7% answered "No"; and 63% answered "Unknown."

The results of this survey highlighted that knowledge of patients' rights advocates and their work varied greatly among the local behavioral health boards/commissions. Furthermore, knowledge of PRA work in county jails was lacking in particular. The

report concluded with a goal to engage in further conversations about these topics to increase awareness of the role and duties of PRAs and the challenges impeding their work. The hope is that this will garner more support for the work of PRAs to better protect the rights of mental health patients throughout the state.

Survey of County PRAs on Advocacy in County Jails (2021-2022)

The Patients' Rights Committee followed up the 2020 survey with another survey in 2021. This survey was once again directed at patients' rights advocates, this time focusing on their work in county jail facilities. The survey was distributed with the help of CAMHPRA and COPR. Findings of note from this survey, which was published in 2022, include:

- Close to 40% of PRA teams that responded said that their team/office was unable to provide patients' rights advocacy services in local county jail facilities.
- When asked to identify what challenges they face in regard to providing advocacy services in jails from a list, 35% marked "inadequate access to inmates" and 28% cited "lack of access to jail facilities."
- Respondents also identified a variety of other issues in written comments. These included confusion over the specific authority and duties of PRAs in county jails, difficulty communicating with clients in jails, and difficulty establishing connections with county jail staff.

These survey responses confirmed that there are significant challenges for some patients' rights offices when it comes to serving patients receiving mental health services in county jails. They also provided some insight on specific barriers that can be investigated and addressed.

Current Issues

Inadequate PRA Staffing

One of the core issues identified in the PRCs 2017 survey and white paper was the lack of adequate PRA staffing in the absence of an official staffing ratio. A more detailed history of this issue can be found in that report, available on the CBHPC Patients' Rights Committee web page, but the main points are summarized below.

Despite the establishment of Title 9 patients' rights advocates in state law, regulations never set any staffing requirements to assure that advocacy services were adequate to fulfill the regulatory responsibilities of PRAs, nor were state funds allocated to the hiring of county PRAs. However, local site reviews conducted at the time these regulations were created found a direct relationship between compliance with patients' rights laws

and the staffing level of county patients' rights advocates. As early as 1980, recommendations have been made for a staffing ratio: a ratio of 1:500,000 (1 full time equivalent per 500,000 county population) was recommended by the State Patients' Rights Office and the State Director of Mental Health. Notably, this ratio was suggested before the most significant expansions of PRA duties, such as certification review and capacity hearings.

In 1987, the Report of the Task Force on County Patient's Rights Advocate Staffing Ratio found that:

- Most patient's rights advocacy programs did not have adequate staff to provide regular services in mental health facilities other than acute facilities.
- Programs were not able to adequately serve special client populations such as ethnic/racial minorities, minors, homeless patients, and more.
- Few programs had adequate time to provide trainings for providers and clients.
- The duties of PRAs and number of complaints received had significantly increased in recent years.

The report concluded that the demand for patients' rights advocacy services are impacted by a number of factors, including geographic and demographic characteristics of a county, the number, size, location and nature of facilities, and the rate of involuntary detentions and review hearings. The report recommended a minimum ratio of 1:300,000 to complete basic statutory duties, though it acknowledged that this minimum would not be adequate to serve specialized client populations or regular monitoring of psychiatric facilities. Despite this report, no formal staffing ratio was established by law.

Since then, a number of other recommendations for a revised ratio or an evaluation of adequate staffing have been made: by the Director of the California Department of Mental Health in 1992; by CAMHPRA in 2000; and by COPR in 2007 and 2011. The 2017 PRC survey and white paper confirmed that PRA staffing continues to be deficient in many counties, as inadequate staffing was cited as a problem by over half of the participating patients' rights offices. Recognition of this issue has been consistent and repetitive, yet there has been no progress on establishing a *required* minimum staffing ratio or meaningfully addressing staffing shortages at the state level.

Training and Technical Assistance

State law requires the Department of State Hospitals, in agreement with the Department of Health Care Services, to contract with a single nonprofit entity to provide investigative and advocacy services to State Hospital patients as well as technical assistance to county PRAs. The California Office of Patients' Rights, a Disability Rights California unit, holds this contract and is responsible for the training and technical assistance for county patients' rights programs. While COPR admirably performs their duties regarding PRA training, including through the annual Patients' Rights Advocacy Training (PRAT)

conference and the online training resources mandated by AB 333, their ability to provide education and technical assistance to county PRAs is highly limited by their current contract.

Currently, COPR only receives enough funding through this contract for **one** patients' rights specialist to support county PRAs. This is inadequate given that this person is responsible for supporting PRA offices throughout the entire state. Both the PRC's surveys and in-person discussions with advocates indicate that county PRAs need far more technical assistance than they are currently receiving to support the sheer variety and complexity of their administrative and statutory duties.

Patients' Rights in County Jails

The PRC has identified patients' rights in county jails as an area of importance and interest in the past several years after hearing about issues in these settings from multiple sources. This includes conversations with and presentations from county patients' rights advocacy teams, Disability Rights California, and the ACLU of San Diego. Not only are patients in county jails particularly vulnerable, but patients' rights violations in these settings can have dire consequences for a patient's safety and well-being, as the PRC has heard from organizations in counties where such violations are rampant. All too often the only recourse for inmates facing inadequate or inhumane treatment are lawsuits by organizations like DRC.

The surveys the committee conducted in 2020 and 2021 further confirmed that this topic is directly relevant to the work of patients' rights advocates. Patients' Rights Advocates are a vital safeguard and watchdog for ensuring the rights of all mental health patients, including those in county jails, but there are significant obstacles that limit the ability of PRAs to conduct their mandated duties in jail settings.

Challenges that the committee has identified include:

- Inadequate knowledge on the part of some PRAs regarding their duties and responsibilities in county jails, and how to interpret and apply patients' rights laws to these settings.
 - This lack of awareness also extends to mental health boards/commissions, county behavioral health departments and county jail staff, contributing to decreased accessibility and accountability.
- Difficulty accessing county jail facilities, inmates, and inmate records. This includes not just physical access to inmates, but also access via phone calls or written communication. The County Sheriff's Office controls PRA access to their facilities, so the degree to which PRAs can operate in county jails is dependent on their awareness and accommodation of advocate duties.
- To some degree, a lack of staff or adequate time to conduct advocacy work in county jails can also present an issue to advocacy offices.

Conclusions and Recommendations

This report summarizes and builds on years of committee activity, including outreach, research, evaluation and advocacy. Based on this work, the committee presents the following four recommendations to policy makers, advocates, and stakeholders in California:

Recommendation 1: Establishment of a Formal PRA Staffing Requirement

The issue of establishing adequate levels of county mental health patients' rights advocate staffing is still at the forefront of this committee's concerns. With their current levels of staffing, many advocacy teams and independent PRAs struggle to serve the number of mental health patients in their given counties, monitor county facilities, and perform training and educational duties.

The CBHPC Patients' Rights Committee continues to recommend the establishment of a minimum level of staffing for patients' rights advocacy services in all counties, with sufficient resources and supports for PRAs to perform both administrative and statutory duties. A staffing ratio or rate should be based on factors such as the county population, geographic size, specific populations, type and number of facilities, county jail populations, and other relevant factors.

Recommendation 2: Expansion of the COPR Contract

While the PRC is confident in the commitment that the California Office of Patients' Rights demonstrates in fulfilling their contracted duties to the best of their ability, the committee strongly believes that the current contract is insufficient in regards to staffing for county-level and statewide support and training for patients' rights advocates. It is clear that the demand for both education and technical assistance is very high, particularly due to the increase in mental health legislation and evolving job complexity that impact PRAs.

The CBHPC Patients' Rights Committee recommends the expansion of the California Office of Patients' Rights contract to allow for increased training, support and technical assistance for county patients' rights advocates. Specifically, funding should be provided for more than the singular full-time position dedicated to supporting county PRAs and their activities.

Recommendation 3: PRA Access to County Jails Facilities and Records to Serve Mental Health Patients

Because of the increasingly high rates of incarceration for people with mental illness, jails have become the biggest de-facto mental health facilities in California. Given this prevalence along with the increased dangers for people with mental illness in jails, patients' rights advocates are an essential safeguard to the rights of inmates who are receiving mental health treatment, yet many PRAs face significant obstacles in accessing county jail facilities to conduct their duties.

The CBHPC Patients' Rights Committee recommends that adequate and ready access to county jail facilities, inmates, and inmate records be assured to all PRAs so that they can properly serve mental health patients who are incarcerated in county jails.

Furthermore, the PRC recommends for the authority of PRAs to conduct their mandated duties in county jails to be clarified in California state law to remedy any ambiguity regarding this aspect of their duties.

Recommendation 4: Establishment of Civilian Oversight of County Sheriffs in all California Counties

Due to aforementioned concerns, including high rates of incarceration for people with mental illness and incidences of inadequate services and inhumane treatment in California jails which have necessitated lawsuits by civil rights groups on behalf of inmates, the PRC promotes the use of civilian oversight of county sheriff departments as a best practice.

The CBHPC Patients' Rights Committee recommends the establishment of a civilian oversight board and/or an inspector general, as authorized in AB 1185 (2020), in every county in California, in order to monitor the activities of the County Sheriff and ensure the proper treatment of all county jail inmates.

Appendix: Patients' Rights Advocacy Information and Resources

Duties and Authority of Patients' Rights Advocates

The duties and authority of California county mental health patients' rights advocates are outlined in Welfare & Institutions Code §5200 and California Code of Regulations §863.2, and include but are not limited to:

- To ensure that information about patients' rights is posted in all facilities providing mental health services, and that all incoming clients and recipients of mental health services in all licensed health and community care facilities are informed of their rights.
- To receive and investigate complaints from or concerning patients about violations or abuse of their rights.
- To monitor mental health facilities, services, and programs for compliance with patients' rights laws, regulations, and policies.
- To train and educate mental health providers about patients' rights, laws, regulations, and policies and act as a consultant to staff in mental health facilities in the area of patients' rights.
- To advocate for patients and residents who are unable or afraid to register a complaint.
- To act as liaison between the advocacy program and the California Office of Patients' Rights.
- Many county Patients' Rights Advocates are also responsible for representing patients in certification review and/or capacity to give informed consent hearings.

Advocacy in County Jails

County jail facilities that provide mental health services fall under the definition of "mental health facilities." Thus, the authority of PRAs extends to **any inmates receiving mental health treatment in jails**, and county PRAs have a right of access to jail facilities, jail inmates, inmate records, and jail employees providing mental health services.

Other Resources:

California Office of Patients' Rights (COPR): <https://www.disabilityrightsca.org/what-we-do/programs/california-office-of-patients-rights-copr>

California Association of Mental Health Patients' Rights Advocates:
<https://www.camhpra.com>