

CHAPTER 1: Advocacy Overview

California has a legislatively-mandated patients' rights advocacy system made up of three components: (1) County Patients' Rights Advocates, (2) State Hospital Patients' Rights Advocates, and (3) the California Office of Patients' Rights. The county Patients' Rights Advocates are designated by the mental health director and may be employees or contractors of their respective counties. The staff of the California Office of Patients' Rights, including state hospital advocates, are employees of the agency providing advocacy services under contract with the California Department of State Hospitals. The Department of State Hospitals contracts for patients' rights services for state hospitals and, through an MOU with the Department of Health Care Services, manages the contract for county-related patients' rights services performed by the California Office of Patients' Rights.

Under this contract, the California Office of Patients' Rights (COPR) provides patients' rights advocacy and responds to patient complaints at the five state hospitals. Staff in COPR provide technical assistance and training for county advocates. They work to ensure that mental health laws, regulations, and policies on the rights of recipients of mental health services are observed in state hospitals and in licensed health and community care facilities. COPR also serves as a liaison between county patients' rights advocates and the State Department of Health Care Services.

Disability Rights California (DRC) is the private, nonprofit corporation designated by the Governor of California pursuant to state and federal law for the protection and advocacy of the rights of Californians with disabilities, including patients with psychiatric disabilities. The program that provides advocacy services to Californians with psychiatric disabilities is Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program. Other programs of DRC include units that address legislation, investigations of abuse and neglect, voting rights, peer and self-advocacy services, and advocacy services for individuals with developmental and other disabilities. Disability Rights California can be reached at (800) 776-5746 and their website is www.disabilityrightsca.org. A number of useful publications can be downloaded from this website.

In addition, Disability Rights California provides services funded by the Protection and Advocacy for Developmentally Disabled (PADD) federal grant, and holds a contract with the State Department of Developmental Services for the Office of Clients' Rights Advocacy (OCRA). OCRA provides clients' rights advocacy for

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people with developmental disabilities who are regional center consumers. Clients' rights advocates help people who have developmental disabilities and their families get the services they need. Such services can include representation in administrative hearings, training about their rights, and investigation into denial of rights in facilities. OCRA staff are employees of Disability Rights California.

The Office of Payee Review and Beneficiary Assistance (OPRABA) was created by the Strengthening Protections for Social Security Beneficiaries Act of 2018, a bi-partisan bill that was signed into law on April 13, 2018. OPRABA staff are employees of Disability Rights California, not SSA.

In addition to the federal and state programs, other advocacy programs and organizations have been developed to meet California's diverse population needs. These groups include representatives from the consumer, family member, and Patients' Rights Advocates organizations.

HISTORY

The following is a summary of the history of patients' rights advocacy in the United States and California. It not meant to cover all of many significant pieces of legislation and/or legal decisions, but rather to provide an overview of the changes that impact services for, and rights of persons with mental disabilities. It is written to provide you with sense of how advocacy evolved and to enhance your basic advocacy knowledge.

Mental health advocacy and the recognition of patients' rights were the result of increased public knowledge and numerous legal decisions. Providing institutional mental health treatment began to change in the late 1950's and early 1960's. Beginning in the nineteenth century, mental health treatment had been provided in large, centralized hospitals, isolating patients from their families and friends. Continuous concerns about the institution's recognition and enforcement of rights for the patients as well as concerns with safety problems, resulted in significant changes in treatment, including the development of community mental health options.

Beginning in the 1960's the courts began to take a more active role in defining and at times leading the development of mental health rights. First recognizing the legal rights of defendants, the judiciary began making a series of decisions based on the principle that loss of liberty is a grievous penalty for a person to pay in a democratic society. The ensuing legal decisions began to lay the foundation

for issues such as the right to treatment, the right to the least restrictive alternative to hospitalization and the right to refuse treatment.

In 1963 President Kennedy signed the Community Mental Health Center Act. Two years later the State of New York created the first mental health advocacy program known as the Mental Health Information Service (MHIS). The primary focus of this service was due process for individuals committed to mental institutions. Within two years many states were overhauling their commitment laws. Some states created more formalized advocacy systems to comply with changes in the law. Congress enacted the Mental Systems Act in 1980 that recommended that all states provide mental health advocacy services.

Motivated by the civil rights movement, former recipients of mental health services began to organize and protest the injustices and discrimination they experienced. In 1971 the first consumer or ex-psychiatric inmates group, the Mental Patients' Liberation Front of Massachusetts, was formed. Several years later, California's oldest and largest consumer organization, the Network Against Psychiatric Assault (NAPA) was established.

Today most states have a more formalized advocacy system. Many metropolitan areas have consumer or self-help groups as well as private advocacy organizations throughout the country. Advocates are engaged in a variety of activities, ranging from resolving patient complaints, to reforming service delivery problems and providing legislative testimony.

In California, the move to acknowledge patient's rights and establish an advocacy system began in 1969 with the implementation of the landmark Lanterman-Petris Short Act (LPS Act). It was co-authored by California State Assemblyman Frank Lanterman and California State Senators Nicholas C. Petris and Alan Short and can be found starting at Welfare and Institutions Code section 5000. The LPS Act was drafted in response to a 1966 legislative study which found that despite efforts to the contrary, large numbers of persons with mental disabilities remained in California's state hospitals for treatment.

Additional laws have been passed since the inception of LPS. In 1972 the Legislature adopted legislation recognizing that patients have certain rights including; the right to wear their own clothing, right to see visitors daily and the to refuse psychosurgery. Regulations adopted in 1976 require county mental health departments and state hospitals to provide advocacy services. These same regulations established procedures for notifying patients of their rights, complaint resolution and identified the good cause denial criteria.

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The legislature and the courts continued their involvement in establishing further rights regarding personal possessions, discrimination, informed consent, due process, notification of involuntary detention, certification review hearings, and the acknowledgement that persons with mental disabilities have "the same rights and responsibilities" possessed by other Californians.

The Department of State Hospitals and the Department of Health Care Services are the State agencies responsible for services to persons with mental disabilities, and for establishing policies on all patients' rights issues in California.

EXPRESSED VS. BEST INTEREST

Advocates represent client's interests as defined by the client, as long as those interests are consistent with statutory requirements and achievable within the advocate's resources. Advocates do not determine what is most "appropriate" for the client or in the client's "best interest." Rather, the Advocate should be responsible for advising the clients about their options, the implications of those options and assist the client to make an informed choice. This perspective is different from the traditional clinical "best interest" approach.

TYPES OF ADVOCACY

Individual advocacy - Historically, Patients' Rights Advocates' primary responsibility has been the investigation and resolution of individual problems. This can involve an explanation of legal rights and remedies, assistance in negotiating a solution to a problem, or representation of a client in a hearing or other dispute resolution processes. Additionally, advocates may be involved in representing clients in mental health administrative hearings. Advocates have also been involved in assisting clients with issues related to their hospitalization in the community mental health system.

Systemic Advocacy - Advocates provide continuous consultation and assistance to mental health facilities by (1) regularly monitoring mental health facilities for compliance with patients' rights law; (2) reviewing and commenting on policies and practices which affect recipients of mental health services; (3) providing recommendations and developing operational questions for the California Office of Patients' Rights and policy questions for the Department of State Hospitals and the Department of Health Care Services; (4) coordinating with other advocates for system reform; (5) analyzing state and federal legislation and regulatory developments; (6) educating and performing outreach to recipients of mental health services to increase clients' ability to advocate for themselves; (7) representing clients' interests in public forums; (8) interfacing with other

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advocacy, consumer, family groups, as well as with federal/state/county administrative or community organizations.

VALUE OF ADVOCACY

For the Patient - In addition to resolving issues, advocacy helps to give clients a measure of autonomy and dignity. By participating in the processes that affect their lives - making treatment decisions, negotiating with clinicians, establishing house rules in their residence or controlling their finances - clients grow in their independence, self-esteem and ability to work with others.

For the Mental Health Professional - Having an advocate work with a client means "an extra pair of hands" to resolve a client's issues. Because he/she is external to the system, an advocate can also help to improve communication, diffuse tensions and resolve conflicts when disagreements develop between a client and a service provider. Finally, a client whose self-respect and functioning is enhanced through resolving issues may become less dependent on traditional mental health resources.

For Mental Health Facilities - Because of their perspective, advocates can help to identify systemic issues that may be unknown or hidden, even from those working in the system. By participating in the development of policies and practices, advocates can help prevent future abuse and neglect. By articulating their clients' concerns, advocates contribute to ensuring that the mental health system is responsive and humane.

For the Community - Advocating for the rights and interests of their clients, advocacy helps increase public awareness and eliminates stigma. Advocates also can help generate public support for financial, medical and social progress in mental health treatment.

COUNTY ADVOCATES

Each county mental health director is required to appoint, or contract for the services of, one or more county Patients' Rights Advocates (Welfare and Institutions Code (WIC) Section 5520). The duties of county Patients' Rights Advocates include:

- Ensure that the 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, including the right to contact the

Advocate and the California Office of Patients' Rights (WIC Section 5520 [d]), (Title 9 California Code of Regulations (CCR) Section 863.2).

- Receive and investigate complaints from or concerning patients about violations or abuse of their rights (WIC Section 5520 [a], Title 9 CCR Section 863.2).
- Monitor mental health facilities, services and programs for compliance with patients' rights laws, regulations and policies (WIC Section 5520 [b], Title 9 CCR Section 863.2).
- Train 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 (WIC Section 5520 [c], Title 9 CCR Section 863.2).
- Advocate for patients and residents who are unable or afraid to register a complaint. (Title 9 CCR Section 863.2)
- Act as liaison between the advocacy program and the California Office of Patients' Rights. (Title 9 CCR Section 863.2)
- Many county Patients' Rights Advocates are also responsible for representing patients in certification review and/or capacity to give informed consent hearings.

STATE HOSPITAL ADVOCATES

There are five state hospitals in California that provide mental health treatment: Napa State Hospital in Napa County, Atascadero State Hospital in San Luis Obispo County, Metropolitan State Hospital in Los Angeles County, Coalinga State Hospital in Fresno County, and Patton State Hospital in San Bernardino County. Each hospital has a Patients' Rights Advocate who is employed by the designated contractor responsible for operating the California Office of Patients' Rights. Each state hospital advocate provides the same advocacy services as county Advocates, as well as representation capacity hearings.

CALIFORNIA OFFICE OF PATIENTS' RIGHTS (COPR)

The major statutory duties of the California Office of Patients' Rights are contained in WIC Section 5510, 5512, 5513, 5370.2, Title 9 CCR Section 864, and Title 9 CCR Section 868. Other responsibilities and duties are identified and defined in the contract with the Department of State Hospitals. Specifically, the duties of COPR include:

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- Ensure that the mental health laws, regulations and policies on the rights of recipients of mental services are observed in state hospitals and in licensed health and community care facilities (WIC Section 5510).
- Provide training, support and technical assistance to county and state hospital patient rights advocates. Training shall be directed at ensuring that all patients' rights advocates possess:
 - Knowledge of the service system, financial entitlements, and service rights of persons receiving mental health services. This knowledge shall include, but need not be limited to, knowledge of available treatment and service resources in order to ensure timely access to treatment and services.
 - Knowledge of patients' rights in institutional and community facilities.
 - Knowledge of civil commitment statutes and procedures.
 - Knowledge of state and federal laws and regulations affecting recipients of mental health services.
 - Ability to work effectively and respectfully with service recipients and providers, public administrators, community groups, and the judicial system.
 - Skill in interviewing and counseling service recipients, including giving information and appropriate referrals.
 - Ability to investigate and assess complaints and screen for legal problems.
 - Knowledge of administrative and judicial due process proceedings in order to provide representation at administrative hearings and to assist in judicial hearings when necessary to carry out the intent of WIC Section 5522 regarding cooperation between advocates and legal representatives.
 - Knowledge of, and commitment to, advocacy ethics and principles. in patients' statutory and service rights; civil commitment statutes and procedures; other state and federal laws affecting persons identified as mentally ill; and, skills and knowledge in providing advocacy and investigative services (WIC Section 5512).
 - Serve as liaison between county Patients' Rights Advocates and the Department of Health Care Services (WIC Section 5513).

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- Respond to patients' rights complaints referred to the California Office of Patient's Rights by local mental health directors or the Department of State Hospitals, as part of the complaint procedure required by regulation (Title 9 CCR Sections 864, 885).
- Conduct annual reviews of local Patients' Rights advocacy programs, with the assistance of the county Patients' Rights Advocates (Title 9 CCR Section 868).
- Receive and maintain quarterly reports of denial of patients' rights from mental health facilities submitted in accordance with Title 9 CCR Section 866.
- Analyze and make recommendations regarding legislation on patients' rights.
- Ensure that services are client-driven by consulting with statewide organizations of mental health patients' rights advocate, clients of mental health services, family members of persons with mental disabilities, county mental health directors and the Department of Health Care Services.
- Develop quality assurance service goals and measurable outcomes to improve the quality of California's patients' right program.

DEPARTMENT OF STATE HOSPITALS AND DEPARTMENT OF HEALTH CARE SERVICES

In 2012, California's mental health system underwent a major reorganization. The duties related to patients' rights formerly held by the Department of Mental Health are now divided between the Department of State Hospitals and the Department of Health Care Services. These duties include upholding the rights of persons with mental disabilities and ensuring that mental health laws, regulations and policies on the rights of recipients of mental health services are observed and protected in state hospitals and in licensed health and community care facilities.

The Department of State Hospitals retains authority for establishing all statewide patients' rights policies and procedures in the state hospitals. The Department of Health Care Services retains authority for policy related to local or county mental health patients' rights.

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