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Health Advocacy Project

Protection and Advocacy, Inc. announces this three year program of comprehensive services for persons with mental disabilities who reside in community care (board and care) facilities. The project is intended to serve as a pilot project, initiated first in San Diego County and readied for statewide replication upon completion. These services are designed to promote and protect the health, quality of life, and independence for this population of under served individuals. Program design and implementation is based upon the collaborative participation of multiple community based organizations, consumer groups, family members, individual advocates, and San Diego County Mental Health..

BACKGROUND

Prior to 1969, the majority of persons with chronic mental disabilities lived, and were cared for, in large State Hospitals. Beginning in 1969, California began recognizing the right of individuals to live in the least restrictive, most appropriate settings, and to receive services that promote the potential for persons to function independently (See Welfare and Institutions Code, Section 5000, et seq.). In doing so, California began shifting to a community-based system of care from the State Hospital based system. As a result, thousands of individuals with mental disabilities were discharged from State Hospitals, with a large percentage being placed into Community Care Facilities, otherwise known as board and care homes. (According to a March, 2000 publication of the Community Residential Care Association of California, "there are about 28,000 mental health residents in some 2,700 homes in California." In San Diego County there are an estimated 200 facilities and approximately 3,000 residents.)

The regulatory requirements that established board and care homes called for the provision of safe, high quality, supervised living environments, and the services necessary to meet the clients' identified specific needs. (See Title 22, CCR, commencing with section 8000). Consistent with the rights identified above, board

and care homes were intended to play an important role in protecting the health of residents and in assisting individuals to experience continued improvement in their health, so they could ultimately move into more independent living arrangements.

Consequently, to protect and improve the health of residents, specific requirements were enacted to assure that individuals, based on their healthcare needs and status, were appropriately placed in facilities capable of meeting their needs. Furthermore, standards were set to assure continuity of care and on-going access to care. For example, prior to accepting a person for admission, a properly qualified medical/clinical professional must complete (among other things) a client 1) medical assessment, 2) functional capabilities assessment, 3) mental health assessment, and 4) needs and services plan. (see Title 22, CCR, Section 80069, et seq.)

Systemic reforms that have occurred in the delivery of health and mental health care services, particularly with the advent of Managed Care in the '80's and '90's, have changed the role of board and care homes. These reforms have placed pressure on counties and private hospitals to reduce the use of costly in-patient services. Consequently, the length of time patients remain hospitalized has been substantially reduced. In turn, this has placed pressure on hospital social workers to locate placements for patients being discharged from acute hospitals. With a lack of alternatives, board and care homes are therefore being relied upon as an important resource for placing these patients.

- *Resident Health and Access to Care at Risk* -

Due to the pressure to discharge patients, placements from acute hospitals are frequently made on short notice. Hospital social workers report that they are often unaware of the discharge and health service planning requirements discussed above, and/or it is often impossible for them to fully comply with the requirements on such short notice. Our research on the issue, including a review of a number of facility records, confirms that report. Consequently, persons with mental disabilities are being admitted to community care facilities without proper hospital discharge planning, without complete medical/clinical assessments, and without proper service planning. As a result, the health and safety of the residents in board and care facilities is often at risk.

Further difficulties in accessing health care occur after a person has been admitted to a facility. Specifically, whenever a resident is in need of healthcare services, particularly non-routine services, the standard of practice is for the facility operator

to go through the case-manager or conservator to make the necessary arrangements. This often results in delays, or even failures to access care, due to the case-manager or conservator being unavailable as a result of a heavy case load.

- Resident Health, Safety & Well Being at Risk -

In addition to the above pre-admission requirements, provisions establishing personal rights and a process for residents to make complaints to State Licensing were enacted. (See Title 22, CCR, Sections 80072, 85072) Aimed at preserving the quality of life and services for residents, these provisions were designed to serve as a vehicle for protecting the rights of clients, addressing problems regarding services and the condition of facilities, and protecting residents from abuse, neglect and other potentially harmful situations. Surprisingly, despite the fact that there are over 2,500 facilities, serving nearly 30,000 mentally disabled clients (discussed below), routine monitoring of facilities for compliance with the law is not a requirement of State Licensing. Therefore, licensing personnel are dependent upon residents making complaints to carry out their responsibilities.

However, a consistent message we received from clients across the state is that they are extremely reluctant to file complaints for fear of being "kicked out" in retaliation for complaining. This fear cannot be overstated. Residents we spoke with told us that they knew there was a lack of residential placements in the community and they did not want to jeopardize their own placement by filing a complaint. Several feared being involuntarily committed to a hospital should they complain. Consequently, State Licensing's ability to enforce regulatory client protections, arguably inadequate to begin with, is diminished by these circumstances. Clients are being placed at risk of harm as a result.

- Residents' Right to Community Innovation Denied -

Finally, to give residents the opportunity "to make recommendations to improve the quality of daily living in the facility, and to negotiate to protect residents' rights with facility administrators," regulations were established calling for the creation of Resident Councils. (Title 22, CCR, Section 85080) Resident Councils are required in homes with more than six residents, when requested by a majority of those residents. They have regulatory standing and protection. Part of every council meeting is required to take place without the presence of any facility personnel.

Any opportunity for board and care residents to "have a greater influence on improving conditions that directly effect their health and well being," is of great importance. Yet, our research and experience tells us that functional Resident Councils are extremely rare, or may not exist. Most commonly, larger homes have what are called "house meetings." These meetings are usually run by facility staff and fall short of providing residents with opportunities for meaningful input. In many other homes, residents simply remain unaware of their right to request and have a Resident Council.

- Multicultural Population -

State and county data is available that indicates community care facilities have a higher proportion of persons of color than is reflected in the state population that is receiving mental health services. Furthermore, although we were unable to locate or obtain statistical information, facility ownership and operation by members of ethnic minority groups is accepted as common. This, in combination with the ethnic composition of residents, magnifies the importance of cultural awareness and sensitivity. Cultural competence training and education will be integrated permanently into the curriculum of all service activities of this project.

SERVICE ACTIVITIES

To address the issues touched upon above we will be conducting the following service activities:

1. In collaboration with local Board and Care facilities, we will pilot the use of a Health Advocate in a total of four board and care facilities. Specifically, each Health Advocate will:

   a) Assist the residents in establishing and maintaining an active Residents Council, consistent with regulatory requirements.

   b) Assist the owner/operators in maintaining compliance with regulatory requirements, including resident needs and services plans, medical assessments, etc.

   c) Train/Assist/Facilitate residents in accessing health services, mental health treatment and/or other services.

2. In collaboration with the San Diego Clubhouse Coalition, the following services will be provided at consumer run Clubhouse programs in San Diego County:

    a) A weekly access to healthcare training program for board and care residents, specifically focusing on techniques for maximizing access and assuring follow-up care.

    b) Opportunities for Board and Care residents to discuss issues in a safe, neutral environment.

    c) Other agreed upon consumer self-help activities consistent with the values, goals and objectives of the project.

3. In cooperation with the local office of Community Care Licensing, and local regional hospitals, we have identified existing, mandatory training programs for facility owners/operators and will be providing on-going training programs as part of their curriculum.

4. In coordination with the San Diego Alliance for the Mentally Ill (AMI), we will be implementing an on-going education program for consumers, families, and significant others. Specifically, we will:

    a) Conduct semi-annual education programs for each of the four regional chapters of AMI regarding access to healthcare, rights, and services for board and care residents.

    b) Develop training curriculum to be incorporated into the training program for consumers known as "Peer to Peer."

5. Work actively with the San Diego chapter of the California Coalition for Mental Health, and other interest groups in maintaining a community-wide focus on the use of Board and Care facilities for persons with mental disabilities.

Health Advocacy Project Web Site List

Community Care Licensing – see http://ccld.ca.gov/default.htm

Medical Care Statistics – see http://www.dhs.ca.gov/mcss

National Center for Health Statistics – see http://www.cdc.gov/nchs/

HHS – Office of Disease Prevention and Health Promotion – see
http://www.healthypeople.gov

California Department of Manage Health Care – see http://www.hmohelp.ca.gov

Foundation for Taxpayer and Consumer Rights – see
http://www.calpatientguide.org

Agency for Healthcare Research and Quality – see http://www.ahrq.gov

Medi-Cal Policy Institute – California Healthcare Foundation – see
http://www.medi-cal.org