SPEAKER NOTES

Advocacy and Patients' Rights: Assistance with Treatment and Financial Support for the Mentally Ill

Summarized by Thomas T. Thomas

People with mental illness are particularly vulnerable in our society. Their illness often prevents them from being self-supporting or even representing themselves to the institutions and government agencies that provide for their care and financial support. **Dan Jordan,** who is Director of the Patients' Rights Advocacy Office in Oakland and on the staff of Mental Health Advocates, also in Oakland, spoke at our September 22 meeting and offered advice about the financial and other aids available.

DAN JORDAN

"I came to Mental Health Advocates in 1978," Jordan said. "That was right after the Federal government ended its program called Aid to the Totally Disabled [ATD], which provided help for people with mental illness through assignment of a county worker. That program was replaced by financial support under the Social Security Administration, and consumers lost the personal assistance that had been provided under the old program. So Mental Health Associates was created in 1975 to help people get through the different bureaucracies."

Personal advocacy is a good deal, he said, because it saves the client suffering and it saves the government the expense of having people inappropriately hospitalized. The advocate works with the client one-on-one to help them in a variety of ways. The only requirement is that the client has to want this help. It doesn't matter if the person doesn't know what services and support are available, or even does not know exactly what he or she needs. The services of the Patients' Rights Advocacy Office are free to the client, because they are mandated and funded by Alameda County. The services are confidential. And if the client chooses to appoint the advocate as his or her representative with the various government organizations—authorized to fill out forms, make phone calls, and speak in the person's express interest—he or she does not give up any rights under the law.

"The difference between counseling and advocacy," Jordan said, "is that if you get evicted, the counselor will ask you how you feel about it. The advocate will ask you about the conditions of the eviction and help you enforce your rights."

The advocate can also secure financial support for the client from state General Assistance and get a referral for emergency food and shelter. Most commonly, the advocate helps file the applications for Federal assistance—Social Security Disability Insurance (SSDI), in which the benefits are based on a prior work history, and Supplemental Security Income [SSI], which is needs based and provides access to treatment and medications under Medi-Cal—and takes the client through the almost inevitable processes of rejection, reconsideration, and hearings on appeal.

"The mentally ill patient is like a square peg in the round hole of the government's programs," Jordan said, "and we help make the hole square for them." The advocate is neither a clinician nor a lawyer, but someone who understands the system and the client's rights and can speak on his or her behalf.

The Federal government defines a person as disabled if he or she has been disabled for six months, the disability will last another six months, and he or she is unable to do any work that is available in the economy. The person may apply for SSDI or SSI before the first six months have passed. Because the government is quick to reject applications under this standard, or later to send letters demanding reimbursement for overpayment on benefits that have already been granted, the advocate helps the client deal with these issues and exhaust the appeals process.

Often the client may suffer from a combination of disabilities that keep him or her from working. For example, Jordan described one man who had bipolar syndrome and asthma. Neither one is disabling in itself, but the man took Prednizone for the asthma, and this medication has an elevating effect that triggered his manic phase. The combination was considered disabling.

SSI, whose benefits are based on the client's financial situation, has a regulation that a person may not have more than $2000 in the bank. The advocate can advise the client stay under this limit by keeping the balance at just $1999. The program also has a $2000 limit on the amount of stocks, bonds, and other assets a recipient may own. When a woman admitted on her application that she had three gold coins as an inheritance from her grandmother, the advocate advised her to get them appraised as if she planned to sell them, and this produced a lower valuation that stayed under the limit.

SSI limits the value of a client's car to $4500 but waives this limitation if the vehicle is used for medical purposes—which includes doctor visits or picking up prescriptions—at least four times a year. The advocate advises the client on how to use the car in order to stay within the regulations.

Under SSI, a client may own a house only if it is his or her primary residence. But if the client has to go into an assisted living situation, the advocate can work to keep the house intact. Similarly, the government deducts from the monthly benefit for "in kind" services such as food and housing. In one case, SSI wanted to deduct $35 per week because a young man's mother gave him casseroles. The advocate advises parents to charge a nominal rent and service fees that will help qualify the beneficiary for reimbursement under SSI.

If a client receives an overpayment letter from SSI, it can be waived under two conditions. The first is that the client cannot afford to pay the amount. The second is that the client was not at fault for causing the overage—that is, did not conceal facts or fail to report earnings or sources of income.

One case that Jordan described was based on the fact that the SSDI and SSI programs are considered too complicated for any single worker in the Social Security Administration to understand. A client was facing an overpayment of $10,000 and asked which of the programs he was on, because he had a combination of benefits. One administrator told him one thing, another told him something else. The advocate found in the man's file a letter stating that it is not SSA policy to dispute what another administrator has said. Since the man had asked an honest question, the advocate used that letter to convince the hearing judge to waive the overpayment.

Since SSDI and SSI are Federal programs, Jordan said, the client is not required to go into the office nearest home but can use any office that feels comfortable. The client can also apply for benefits over the phone.

Mental Health Advocates has a drop-in office that's open 9 a.m. to 5 p.m. at 1801 Adeline Street in Oakland. The phone number for people in Oakland and northern Alameda County is (510) 835-5532.

The other organization Jordan is associated with, Patients' Rights Advocates, is located at 954 60th Street, Suite 10, in Oakland with office hours 9 a.m. to 5 p.m., a toll-free number (1-800-734-2504), and a message tape for after hours. "Patients' Rights never takes a holiday," Jordan said, noting that while the government offices are all closed for the Monday holidays during the year, his staff will always come out to the hospital to help the client.

Patients' Rights has seven people on staff—well above the country mandate of one advocate for 500,000 residents—and yet consumes less than 1% of the Alameda County mental health budget.

The organization has four functions:

Educate consumers, facility staffs, board-and-care operators, and others on available programs and the client's rights under them.

Monitor facilities and make sure they follow the law. For example, if a person is held in restraint, is there a staff member doing one-on-one observation all the time? This is the new standard, replacing the old 15-minute check.

Investigate complaints from consumers. For example, one man called to say that the staff at a facility had "cut off his arms." Rather than treat the complaint as delusional, the advocate found that the man had received a change in his medication that caused a dystonic reaction—a tightening of the neck and shoulder muscles—and this was his only way of describing it.

Represent clients at certification review and probable cause hearings. A patient who is considered a danger to self or others or "gravely disabled" (i.e., unable to provide for his or her own food, shelter, and clothing because of mental illness) may be placed under an involuntary hold for 72 hours on Welfare and Institutions Code 5150. At the end of this period, the patient may be discharged, enter voluntary hospitalization, or be placed under a 14-day hold on W&I Code 5250. The latter requires a certification hearing at which the patients' rights advocate works in the client's express interest to establish what he or she wants. The standard for such a hearing is "probable cause," which means that the judge weighs the evidence and may grant a continuing hold if a majority (51%) of it supports this course.

In Alameda County, about a third of the people held on Code 5150 go on to a 14-day hold—which is high, compared to the national average. And then 7 to 10% of those held on Code 5250 require a capacity hearing.

A capacity hearing occurs when a client refuses medication. Until 1951, anyone under involuntary hold could be medicated against his or her will. Now the patient has a right to refuse medication unless it's an emergency—that is, the patient is violent and about to hurt someone or him- or herself. The capacity hearing tests whether the patient is (1) aware of his or her situation, (2) has had the medication's benefits and effects described by the doctor and is able to weigh that information, and (3) is able to make a rational decision. The patients' rights advocate helps the client understand this process and demonstrate his or her competence to make this decision.

Under California Assembly Bill 1424, which is now the law, the family may also have input to this process, addressing such issues as treatment history, functional ability, current medications, allergies, and other things the doctor should know. Under the law, the doctors and staff of the facility must consider this information in making their treatment decisions.

Q. What happens if the patient is not coherent?

A. If the patient is talking "delusional material" or is "firmly ambivalent"—that is, doesn't know what he or she wants—or simply refuses to communicate, then the advocate can ask for a continuance. Because of the 72-hour hold duration, these hearings are held every other day, usually on Monday, Wednesday, and Friday, and the hearing officer can grant one continuance. After that, the advocate can state that he or she was unable to establish an advocate-client relationship. Sometimes, too, it can be useful for the hearing officer to experience the patient's incoherence or delusions.

Q. My wife and I are elderly and have our son covered under our private health insurance. When we go on Social Security and are covered under Medicare, what benefits will he get?

A. If his illness was diagnosed before the age of 22 and he has never been self-supporting, he will receive one-half of the amount of your Social Security coverage without having to wait until he's 65. He will be eligible for Medicare after the two-year waiting period, and there's no way to shorten that.

Q. My brother is disabled because he cannot work, but he won't admit he has a mental illness. Do you need this diagnosis to get benefits?

A. You should put on the application form whatever reason applies, then during the reconsideration and appeals process do a psychiatric or vocational evaluation or a consultative examination. The first step, however, is to file the application.

Q. If a person is homeless and doesn't have an address, can he still get benefits?

A. You can use a mail drop or convenience address for the application. The SSI benefit is based on the person's living situation, so the monthly amount will be less if there are no housing costs to support.

Q. Under AB 1424, is there any common form the medical facilities use to take family input?

A. Alameda County is trying to develop such a form, with areas for the psychiatric history, what conditions escalate the illness, medications, and so on. The development process is soliciting input from family members and dealing with issues of acceptance by consumer groups.