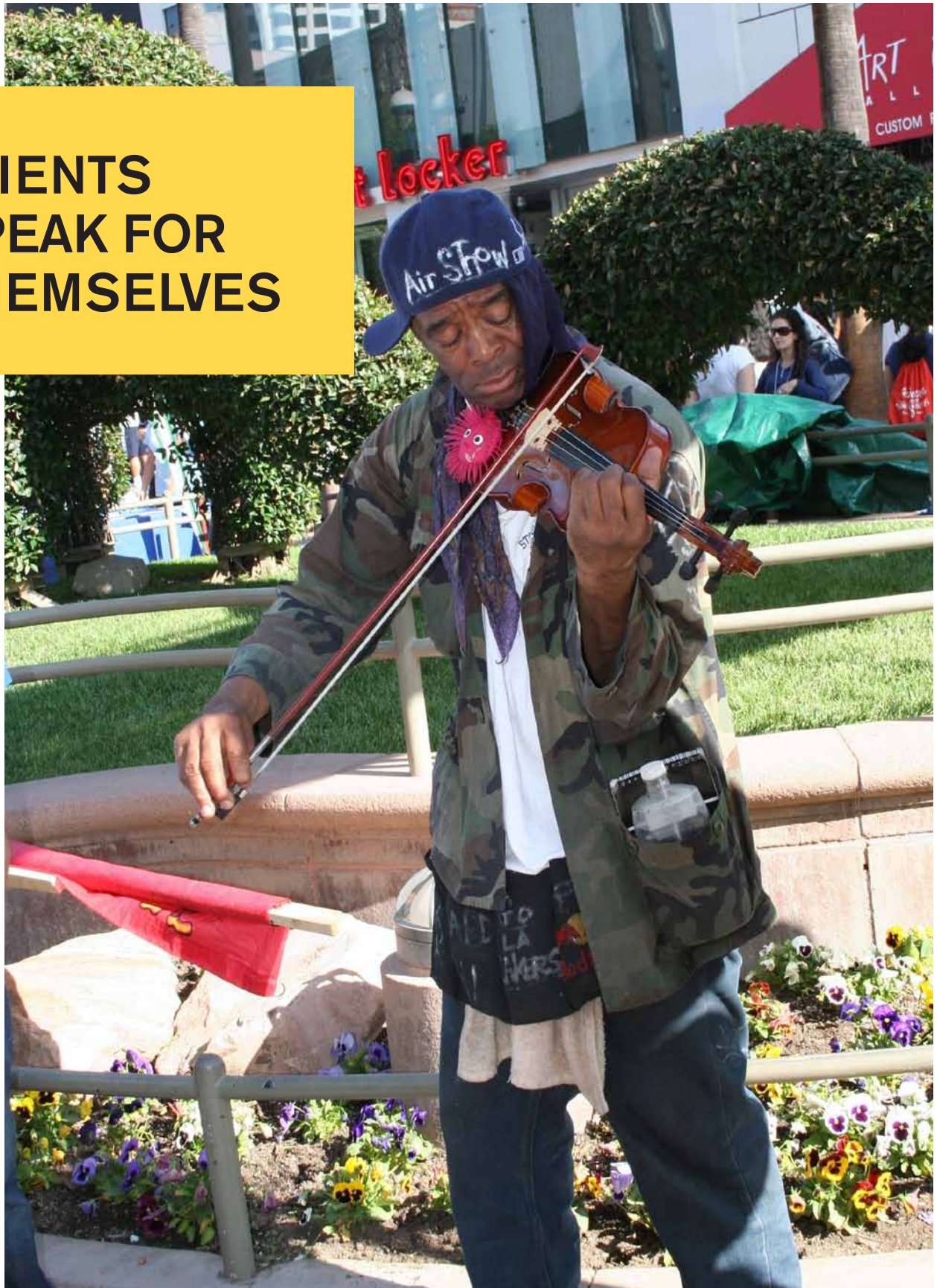


**CLIENTS
SPEAK FOR
THEMSELVES**



We've always witnessed our own abuse. And basically what happened in the early seventies is people started getting together and talking about what they had witnessed about themselves...And witnessing is almost like writing it in your mind so you could do something about it sometime.

Sally Zinman

Voiceless within the System

For much of the first half of the 20th century, most people who suffered from a serious mental disorder were forgotten souls, citizens without voices. The popular media, through films like "Psycho," perpetuated images of the mentally ill as people who could not think for themselves, who were potentially dangerous and always unpredictable. Many were expected to live out their lives in the locked wards of state hospitals. The principal modes of treatment were custodial care and behavioral control, through drastic, frightening, therapies, such as electroshock and insulin shock, which were often given repeatedly. Patients considered especially difficult were subjected to lobotomy, surgical separation of the frontal brain lobes, which left the individual docile, often childlike, but subject to seizures and other side effects.

The introduction of antipsychotic drugs in the early 1950s encouraged psychiatrists to rely on gentler therapies. But in most hospitals, staff still assumed that patients needed to be controlled. All aspects of their lives, including eating, sleeping, and socializing with others, were supervised, and they were rarely allowed a voice in their own treatment. Individuals with diagnoses of mental disorders felt they were treated like children.

Patients who were stabilized on the new medications could be released to live in the community. But few believed that they could lead independent lives. Housing and employment options were limited. Local communities, landlords and employers believed the stereotypes about violence and unpredictability and discriminated against anyone with a history of a mental disorder. Individuals without family resources found themselves living on the streets or in substandard housing, abandoned members of society. Those who were able to find work and a decent place to live nevertheless often felt marginalized by society, infantilized by their treatment, unseen and unheard.



Roots of the Mental Health Client Movement

Patients released from the hospitals, mental health clients as we will now call them, found their voices by talking to each other. They called meetings in each other's homes or in outdoor venues. Many resented what they saw as abusive treatment; others felt their civil rights had been violated; nearly all felt their real needs for help and treatment had not been met. The client movement gained strength in the counterculture era of the late 1960s and early 1970s, a time when radical activists challenged all types of authority and when the authority of medicine in particular – over women, people of color, prisoners, the disabled – was questioned. It acquired authority and leadership from a cadre of former patients who had the necessary resources and expertise. For example, Ted Chabasinski, who was hospitalized through much of his childhood, later earned degrees in law and psychology.

For the personal stories of Chabasinski and other survivors, see:

<http://www.mindfreedom.org/personal-stories/chabasinskited>

Sally Zinman, who taught English at Queens College before her treatment, was an effective speaker and writer. Radical psychiatrists and lawyers also provided support.

Finally, the client movement gained credence from the work of two iconoclasts within psychiatry: Richard D. Laing and Thomas Szasz.

R.D. Laing (1926-89), a Scottish psychiatrist, saw the medical model used in psychiatry as inappropriate, since diagnoses of mental and behavioral disorders were made not on the basis of any biological evidence, but on behavioral observations. He suggested an alternate view, that those diagnosed as “mentally ill” were trying to communicate real perceptions and concerns which they feared were inappropriate or forbidden, as a result of family conflict or other stressful experience; they lacked “ontological security,” the ability to integrate their internal and external perceptions. In works such as *The Divided Self* (1960), Laing suggested that mental “illness” might actually help a person to work through such conflicts and emerge as a whole and secure person.

<http://lainginstitut.ch>

Thomas Szasz (1920) is a Hungarian-born psychiatrist who has spent his active career in the US. In works such as *The Myth of Mental Illness* (1974), Szasz argued that the standard theories of psychiatry were socially constructed, that the label of “mental illness” was used to stigmatize and control behaviors seen as disturbing or troublesome to society. He analogized the treatment of the mentally ill to that of heretics, accused witches, and slaves in earlier eras. Like Laing, he questioned the accuracy of diagnoses based on subjective judgments.

A compelling writer, Szasz's own arguments are often based on subjectivity and labeling themselves, as when he wrote: “If there is no psychiatry, there can be no schizophrenics.” (*Schizophrenia: The Sacred Symbol of Psychiatry* Basic Books, 1976): 136.)

www.szasz.com

Although neither Laing nor Szasz were well accepted within psychiatry and disputed each other's arguments, their ideas appealed strongly to mental health clients who felt above all that their doctors, therapists, families, and caseworkers had not listened to them, but had perceived only the dehumanizing label of mental illness.

Building a Network

The small groups that had formed around the country – Sally Zinman formed a group in Florida, Judi Chamberlin in Boston, Leonard Frank and Wade Hudson in San Francisco – formed links with each other and national and state networks of ex-patients began to form. The anger and antiauthoritarianism of the groups were reflected in their names; some of those formed in California were CAPABLE (Citizens Against Psychiatric Abuse Bureaucratic Legal Entanglements); NAPA (Network Against Psychiatric Assault); STOMP (Stop the Torture of Mental Patients). More positive names included CAN (Client Advocacy Now) and TALLY (Take a Loving Look at Yourself). Others emphasized the drive for autonomy: the Insane Liberation Front was founded in Portland, Oregon, the Mental Patients Liberation Project in New York, and the Mental Patients Liberation Front in Boston. Groups often practiced acts of civil disobedience, including taking patients out of mental hospitals and chaining themselves to institutional gates. At one American Psychiatric Association meeting of the early 1970s, client activists linked arms and formed a human chain to bar the psychiatrists from their own meeting.

Major programmatic goals of the movement included ending involuntary commitment, forced treatment, patient restraints, seclusion, and electroshock treatment; and granting mental health patients a voice in their own treatment: “nothing about us without us.” In 1972, radical psychiatrist David Richman began publication of the movement's journal, Madness Network News; four years later, Richman was forced to resign as editor and was replaced by a former patient. The first Conference on Human Rights and Psychiatric Oppression was convened at the University of Detroit in 1973 and became an annual event. These conferences were largely unfunded and organized by clients themselves; often the whole first day was devoted to preparing the agenda.



Beginning in the late 1970s, the federal government made small grants available through the NIMH's Community Support Program to involve mental health “consumers” in policy and program planning. Clients who became involved in these initiatives were offered a role within the system, to give input into the development of better programs and services, including self-help services. In 1986, the PAIMI Act (Protection and Advocacy for Individuals with Mental Illness) created a formal advocacy program in each state, requiring that at least 50% of the Advisory Council members be current or former mental health clients or family members. The regulations were later amended to ensure that this representation included clients and not family members alone.

<http://mentalhealth.samhsa.gov/publications/allpubs/CMH97-5016/default.asp>

Several consumer leaders were now organizing more formally and finding ways to cooperate with state and local mental health systems and providers. The California Network of Mental Health Clients was founded in 1983 to coordinate the advocacy efforts of the many smaller groups throughout the state. Sally Zinman was the first coordinator of the Network and later served as Executive Director for ten crucial years from 1997 to 2007.

<http://www.californiaclients.org>

The Network's policy goals include:

- no expansion of forced or involuntary treatment
- improved regulation of board and care homes
- elimination of involuntary restraints and seclusion
- protection of patient rights and funding for rights advocates
- accessible voluntary services
- affordable housing
- work incentives and employment services
- promotion of client-run and peer-support programs
- elimination of stigma and discrimination

The Network also developed the concept of "client culture" which is now incorporated into the training of County mental health staff. It has not hesitated to make public statements in response to provider and government mental health plans and proposals.

1981 California Network's Response to the California Model

In 1984, the first Alternatives Conference presented workshops to teach clients to develop self-help groups, raise funds, participate in planning, and otherwise work within the system; these have become an annual tradition. The theme of the 2010 conference, organized by the National Empowerment Center, and funded through SAMHSA (the Federal Substance Abuse and Mental Health Services Administration) is "Promoting Wellness through Social Justice."

<http://www.power2u.org/alternatives2010/index.html>

The Alternatives Conferences, however also marked a split in the movement.

A number of clients, who call themselves psychiatric "survivors," have chosen to remain active and vocal, but generally refused to participate in system-supported projects.

The Well-Being Project

In 1986, the Prevention Office of the California Department of Mental Health planned to conduct a research survey to identify the needs of mental health clients, initially assuming the contract would be awarded to a university or other professional research group. Much to the surprise of some, the successful proposal was written by sociologist Jean Campbell and client activist Ron Schraiber, on behalf of the California Network of Mental Health Clients. Their study became the Well-Being Project. The Project surveyed 331 mental health clients, 53 family members and 150 professionals by mail, phone, and in face-to-face interviews. Much of the work, including the face-to-face interviewing, was conducted by trained clients; the summary report, *In Pursuit of Wellness*, was published in 1989, in conjunction with a video documentary, *People Say I'm Crazy*. Clients who participated in the Well-Being Project were clear and coherent about what they needed and wanted: "a decent home, a job, independence, a reasonable income, and good friends." Mental health clients, in fact, had the same needs and desires as everyone else.

Excerpt from *In Pursuit of Wellness*

As one stated:

Clients know what they need. They simply need to be asked. They are the experts and no professional can rise above those they serve. [quoted on page 17]

Clients who worked on and participated in the study also talked about the importance of helping each other:

We have to band together because this mental illness and homeless thing is not understood. We can help one another...I'm working for the betterment of myself. I think if I help other people get a better quality of life, it will eventually come to me, and I just feel good helping someone get off the street. [quoted on page 64]

Finally, clients testified in this study about the negative effects of dehumanization during treatment. Only 7% felt that their human rights had not been violated during their treatment; and 55% those who had experienced "forced" (involuntary) treatment stated that their fear of such coercion prevented them from seeking further help from the mental health care system. Clients repeatedly cited independence and human dignity as essential to quality of life.

Self-Help and Peer Support

The early movement protested angrily against several traditional forms of treatment, but what could be offered instead? As movement leaders began to consider what kinds of alternative services could be offered their client peers, many of whom lived lives of loneliness and fear, the concept of peer support and self-help was born. Several such

programs started as neighborhood storefronts, such as the Berkeley Drop-In Center opened by Sally Zinman in 1985. Self-help programs are organized and run by mental health clients in recovery to help others. At the very minimum, they offer the recovering client a place to go and people to talk to who have shared similar experiences. Programs have expanded however to offer education, job training, social activities, and other social support services crucial to individuals relearning how to live in the community.

Project Return clubs were the brainchild of psychology student Rhoda Zusman who founded the first groups in Buffalo, New York, in 1971, to help reintegrate clients released from state hospitals. The Los Angeles program was established in 1979, by the County Department of Mental Health, and taken over the following year by the National Mental Health Association (MHA).

1980 Project Return Newsletter

In 1992, the decision was made to put the entire network into the hands of mental health consumers and create Project Return: The Next Step. Bill Compton took a job with the new PR:TNS as regional aide in 1992, and in 1994, became Executive Director.

1994 Project Return Member Survey 1994 Project Return: The Next Step Brochure

Over the next decade, Compton expanded the network from 30 clubs to more than 100 and opened the Discovery Center in Antelope Valley, where clients can get life and work skills training, use a computer center and resource library. Other initiatives included the Friendship Line, a client-staffed help line; a program to train clients in preparing Advance Health Care Directives; Gifts for Giving, a holiday giving program; a special focus outreach on Spanish-speaking clients; and a Japanese-American consumer exchange.

2006 Report to DMH from PR:TNS

A Los Angeles-based organization, BACUP (Benefits Assistance Clients Urban Projects), was founded in 1986, with the primary goal of assisting clients to apply for SSI, Medicaid, Housing assistance, and other benefits. Under the direction of Andy Posner, BACUP operates a range of wellness and educational programs and brings clients together for informal socialization.

www.bacup.net

It's all about independence. That's all it is, it's all about independence.

(Andrew Posner Oral History Interview 2009)

Movement Stories

Some stories from California clients active in the client rights and self-help movements:

Bill Compton grew up in the Midwest and was a successful Los Angeles businessman when he developed late-onset schizophrenia at the age of 44, in 1989. Over the next few years, he lost his job, his home, and his insurance; was hospitalized several times, moved to a board-and-care, and finally lived on the streets for a period of time. About 1991, helped by some new medication, he joined Project Return, then a relatively small program, and became the most active member of his club. When PR was converted to Project Return: The Next Step, a consumer-run organization, Compton first took a job as regional aide in 1992, and in 1994, became Executive Director, expanding the network from 30 clubs to more than 100 over the next decade. He helped to increase client employment opportunities at Project Return and to introduce the Friendship Line, an after-hours service connecting mental health clients with peer support. Compton's dedication and managerial skills made him a leading figure in Los Angeles mental health in the early 2000s. In 2001, he was President of the California Network of Mental Health Clients, and he also served on the boards of Mental Health America, Protection and Advocacy, Inc, and Pacific Clinics. He died of cancer in August, 2007.



I can not be called a homeless person again...I am back in the real world! (From the LAC-DMH 40th Anniversary Book, 2000)

Pearl Ella Johnson was an abused child who became a ward of LA County and, as often occurs, was “lost in the system” after she became an adult. For 30 years, she was in and out of the California Rehabilitation Center, drug programs, and jails, often living on the streets when she was not “inside.” In 1990, she was sleeping in the 51st Street Park when an acquaintance encouraged her to visit the nearby Oasis House run by Mental Health America. There she met client advocate Gilbert Toliver and began to learn basic skills – cooking, cleaning, using a computer, and most importantly, to speak to others. Pearl Johnson became an administrator with Project Return: The Next Step, and, with the encouragement of Areta Crowell, gave testimony before the LAC Board of Supervisors and the Legislature. A vibrant and inspirational speaker, she traveled widely to tell her story and was beloved by the LA mental health community. She became a continuing care worker at DMH in 1994 and lived in her own home until her death in 2005.



To create independence, you have to create independent programs. That to create – to give people the opportunity to go back to work, it takes time and training, for anyone, whether it's through school or training programs. To see people advance in their lives, even if they can't go back to work, you need these additional ideas. You need these additional kind of programs, not to deny the clinical end, because that's important, but if you trap people only in the clinical side, then they are never going to get out on the other side.

(Andrew Posner Oral History Interview, 2009)



Andrew Posner grew up in California and struggled with mental illness and incorrect diagnoses throughout his youth. He was hospitalized several times and lived in a board-and-care home. After he found a therapist who could help, he arranged payment plans and worked at a series of manual labor jobs to pay for his own therapy. After he moved from the board and care to his own LA apartment, he suffered “culture shock” and called a local hotline; the counselor suggested he visit a nearby delicatessen just to be around people. He began thinking about starting a group called HOPE, Human Organization for Potential and Equality. Later, when he heard a speaker talk about self-help groups, “it was a great experience,” when he realized the philosophy behind such groups was exactly what he had imagined for HOPE. He worked for a while doing outreach at the Los Angeles VA, an experience that deeply touched him when he realized what many veterans had undergone and that they weren't getting the help they needed. In 1986, Posner became Executive Director of BACUP, Benefits Assistance Clients Urban Projects, a position he continues to hold in 2010. BACUP is a non-profit organization which works to empower mental health clients in recovery to become equal citizens in the community. In addition to help with benefits, BACUP provides many opportunities for informal socialization, training and education, and peer support; and its HOPE project provides outreach to the homeless.

[On membership in the California Network]:

There was a real great debate [about] who should we have [as] our membership, because some people said, “Okay, you have to have been hospitalized,” but we know some people that were never hospitalized for various reasons. They said you have to be on SSI, but some people never applied or were afraid to... We were afraid that neurotics would try to take over our psychotic organization [laughs]... I came up with a definition, it was something that people whose lives have been dramatically affected by psychiatric labeling or treatment.

(Ron Schraiber Oral History Interview, 2009)



Ron Schraiber grew up in California and experienced his initial “break” as a graduate student at UC Irvine, when he became very depressed. Subsequently, he was hospitalized

a number of times and lived on SSI payments in several different cities. He began reading Szasz' work, which appealed to him, and founded a client group which he named CAPABLE – Citizens Against Psychiatric Abuse and Bureaucratic Legal Entanglements. Later he worked as a client advocate in Contra Costa County. In 1983, he participated in the founding of the California Network of Mental Health Clients, and in 1986, co-wrote (with sociologist Jean Campbell) the research proposal for *The Well-Being Project*, a major survey of client needs conducted by the Network under contract from the State Department of Mental Health, and directed the Project through the publication of the final report, *In Pursuit of Wellness*, in 1989. Schraiber moved to Southern California in 1986, where he worked as a consumer advocate at LAMP on LA's Skid Row and at Metro State Hospital before joining the Los Angeles County Department of Mental Health as Director of Consumer Affairs in 1995. He was noted for his vigorous and articulate statements about mental health client rights at meetings and in public venues. As of 2010, he is Director of the Office of Policy and Research with DMH's Empowerment and Advocacy Division.

What I realize now and I did soon after was that though our immediate issue was this outpatient commitment and the threat to our independence and freedom, we really were educating the legislators and the community in the mental health system about us and our issues.

(Sally Zinman Oral History Interview, 2010)



Sally Zinman grew up on the East Coast and was hospitalized in Florida and in Pennsylvania under the care of an abusive psychiatrist who locked her in a cellar room and beat her. She won her own release by telling the psychiatrist what he wanted to hear – *I knew all that information. I just didn't believe it. So I did. I just lied.* – and then persuaded her family to let her live on a farm in Florida, near Boca Raton. There she advertised for others with similar experiences to meet with her and started the Mental Patients Rights Association in 1977. Zinman learned from a TV broadcast that there were other groups around the country; she was particularly attracted to NAPA and the California movement, made contacts and attended conferences there. In 1983, she made the decision to move to the Berkeley area, where she became the co-editor of *Madness Network News* and the co-founder and first coordinator of the California Network of Mental Health Clients, to coordinate advocacy and self-help groups throughout the state. In 1985, she opened the Berkeley Drop-In Center, to offer socialization, support groups, food services, information and referrals for mental health clients. The Center over time expanded its services to include benefits assistance, money management, housing, and job training. In 1997, Zinman became Executive Director of the California Network, now reorganized as a more formal organization to coordinate self-help and advocacy of clients throughout the state. After 10 years in that position, she “retired” but continues to be a voice and activist in the movement in 2010.

Client Advocacy Today

The Los Angeles County Department of Mental Health has actively promoted client involvement since the 1990s. The Mental Health Services Act of 2005 opened another channel for mental health clients to make their voices heard through the stakeholder process, and clients have been involved in the planning process at every step. Self-help groups like Project Return are active throughout the county, and the California Network of Mental Health Clients continues to be an advocate of patients' rights and participation in treatment, and listening to client voices. Stigma and discrimination still persist. Providers, policymakers, and community leaders must be alert and willing to listen to the voices of mental health clients, if they are to be heard.