CALIFORNIA NETWORK
OF MENTAL HEALTH CLIENTS

# Cal Net Gazette

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MARCH 2001

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## Client Spirits Bolstered by Little Hoover Commission's Report

On January 30, clients attended the Joint Informational Hearing of the Assembly Health Subcommittee on Mental Health and Senate Select Committee on Developmental Disabilities and Mental Health.

Almost 50 clients from around the state came to attend the hearing- Mendocino County to Los Angeles County. Ed Ellis from Project Return, the Next Step (Los Angeles County) told a revealing story of what happened to him on his twenty first birthday. He was feeling in need of mental health care, really feeling bad. His Mother took him to the hospital. He had to sleep in the hallway that night. When the Doctor finally did see him the next morning, the Doctor said he could not admit Ed. The Doctor said Ed wasn't severely sick enough to be admitted.

The only way he could be admitted the Doctor said was if, for example, he cut himself. As the Doctor said this, he looked over to some paper clips in the room. Because Ed really did want to go into the hospital and get help, he picked up the paper clips and started cutting himself. Ed was then admitted into the hospital.

## No Reliable Data on Involuntary Treatment Being Effective Says RAND Study

Major findings include: The data is inconclusive on whether involuntary outpatient commitment works. The study did find abundant evidence that alternative voluntary community-based mental health treatments do work. The RAND Study of Involuntary Commitment further found that "a significant percentage of people with mental illness who need services aren't getting them, and those who do get very few." Copies of the Study are available for $15 from the Senate Office of Research at 916-445-1727.

*"In our culture, only people deemed worthless are mass buried. Every single one of these lives has worth." — Carole Ford, discussing the Historical Cemetery Project at a CNMHC Board Meeting. Read more about this project on page 7.*

## Hoover Commission Calls for Full Services

"Mental health care means more than medication and emergency services. Adequate care may require housing, counseling, substance abuse treatment, vocational rehabilitation and independent living skills training."

"Rather, in most communities, care is rationed to those with severe mental illness. Even then, the system seldom recognizes that some clients need a home, others need a job and all need respect—in addition to medication."

"We do not tell cancer patients to come back if and when their disease has metastasized."

"In many cases, mental health treatment is limited to medication, when what is really needed is help with housing, substance abuse, and other problems."

# The Scope of California's Problem

**Numbers from the Little Hoover Commission Report:**

- California has over 500,000 mental health clients in need of substance abuse treatment, but treatment services do not begin to meet the need.
- Over 75,000 clients need some form of housing assistance.
- The majority of people with serious mental illness are capable of working with support, but 80 to 90 percent are unemployed.
- Over 95% of the Dept. of Mental Health's staff is dedicated to operating institutions.

**The Hoover Commission Addressed LPS Reform:**

"The Commission believes that adequate information has not been developed to fully assess the need for LPS reform. Involuntary treatment laws may need to be reformed. But involuntary treatment should be understood as the last and final resort in a continuum of care that prioritizes voluntary treatment. The Commission believes the debate over LPS reform should be guided by the following analyses:

- An assessment of how the current LPS law is administered across counties. Are due process requirements adequate and involuntary treatment decisions consistent across the state?
- An assessment of how improved access to voluntary treatment could diminish the need for involuntary treatment. The State should ensure that involuntary treatment is only an option when no other form of treatment is effective. Inadequate access to voluntary care does not warrant the use of involuntary care.
- The dimensions of the problem that LPS reform would address. Preliminary data suggest the rate of involuntary commitment is increasing; it is unclear why. How has the use of involuntary commitment changed over time? How does the law affect different ethnic groups? How would a reformed law change outcomes?
- The capacity of state and local authorities to better serve existing clients through other "involuntary" models, such as CONREP, mental health courts, or probation.
- The ability of the State to improve the quality of involuntary care and decrease the level of fear clients associate with forced treatment."

**News from CASRA and Caras**

Sylvia Caras, Ph.D., was mental health advisor for a health guide with a disability focus released in February. The Wellness Guide: Ideas for Living and Staying Well in California is in both English and Spanish. See wellnet@uclink4.berkeley.edu

CASRA Spring Training Conference is May 3-4 at the Walnut Creek Marriott. Theme will be "Keeping Social Rehabilitation on Track Through Recovery."

**Client Membership**

NAME:________________
________________________
MAILING ADDRESS:
________________________

CITY__________________
Zip_________
Phone _________________
❒ Check here if the office can give your phone number out to those who want to network in your area on client affairs.
**E-mail Address:**
______________________
FAX where you can get me:
______________________
❒ Yes, I am currently or have in the past been a mental health client and want to belong to the California Network of Mental Health Clients.

**I am choosing this option:**
❒ Here is $5 for 1 year membership starting ______, 2001.
❒ Renew my membership.
❒ Here is $5 for my membership and an additional donation of $_____ for someone else.
❒ Right now I cannot afford $5, but I would like to be a member and want to receive the *Cal Net Gazette*. I am willing to donate time and skills as I am able.
❒ Make me a Friend of the Network. Here's $10-$100. Send me the *Cal Net Gazette*.

Make checks or money orders out to CNMHC: mail to 1722 "J" Street, #324 Sacramento, CA 94814

# Zinman Testifies on Need for Voluntary Services

Sally Zinman's partial testimony on the state's Little Hoover Commission report at the Joint Informational Hearing January 30, in Sacramento follows:

**Pointing to the Answers**

*Being There, Making a Commitment to Mental Health* affirms a goal of the client community: a mental health system that provides voluntary and holistic community services on demand. Instead of blaming people with mental disabilities for their suffering, the report clearly targets a failed mental health system that has not provided community services and kept the promise made with deinstitutionalization. Instead of using judgmental language such as lack of insight, medication noncompliance, and broken brains about clients, it judges a system that denies care to an estimated 1.5 million Californians in need, turning away all but the most critical, and often even them. It lays the responsibility for the increase of people with mental disabilities in our jails and among our homeless on the failure of a system to provide assess to voluntary and holistic community services, not a failure of the people. The theme throughout the Report is that jail, homelessness, and forced emergency interventions are too often the result of the lack of the right kind of care, or even any kind of care, at the point at which it is requested. Although the Report measures the huge cost to society in terms of dollars, the cost should equally be measured in human terms of experiences of degradation and abuse, loss of trust, broken spirits and often, lost lives.

**Call for Holistic Services**

The recommendation that "mental health care means more than medication and emergency services" echoes the voices of clients. Clients repeatedly, over years, have voiced their need for an array of comprehensive services that meet the needs of the whole person. They have known that recovery is possible with supports including housing, employment, substance abuse treatment, independent living skills, physical health care, and peer support; the system, except for model programs that are not replicated as a norm, has not responded. In a recent survey of homeless individuals with mental health problems conducted by the San Francisco Coalition on Homelessness, 92 % of those surveyed said that if programs were designed that met their individual needs, they would enter them. (One third of those who tried to get services, were turned away.)

**Call for Voluntary Services**

The Commission prioritizes voluntary care as the first response. It explicitly states that forced treatment should not be used because of inadequate access to voluntary care. It also suggests that improved access to voluntary care could diminish the need for forced treatment. The report echoes the client value of self-determination and choice. It lends support for the view that the expansion of forced treatment is a way of covering up the gaps in services and an excuse for lack of services. It points in the direction that available and accessible voluntary services are the answer to the suffering that surrounds us.

The Report not only echoes the client voice. It also echoes the recent report, Mental Health: A Report of the Surgeon General. "Almost all agree that coercion should not be a substitute for effective care that is sought voluntarily." "One point is clear: the need for coercion should be reduced significantly when adequate services are readily accessible to individuals with severe mental disorders who pose a threat of danger to themselves or others."

*"jail, homelessness, and forced emergency interventions are too often the result of the lack of the right kind of care"*

**How Do You Get There?**

Although clients were actively involved in the information gathering processes leading to the Report and it echoes many of the concerns voiced by the client community, the Report ignores clients as part of the solution, of "how you get there." In spite of the trend in the current mental health system of including clients in the provider workforce and on policy and monitoring bodies, we are not presented as active participants in our own and the system's recovery, but rather as the stereotype passive recipient of care. The Report describes doing things for us, but not with us. Clients are not presented as partners in their own individual treatment plan and in systemic planning. Client initiatives, such as self-help programs, which are proven to be effective, are excluded. The mental health system is not going to get from here to there without breaking down the barriers of them and us, and including clients as partners in the community.

# Client Forum 2000 Sets Priorities

The Client Forum 2000 Conference was held on December 2-3, at the San Diego Marriott Mission Valley. There were day long membership meetings. The membership approved the Public Policy Priorities for 2000-2001 and By law changes.

**CNMHC**
**Public Policy Priorities**
**2000-2001**

The following ongoing priorities have been voted on by the membership and Board. In most cases, they are worded in the exact manner as voted on.

- No expansion of forced treatment or involuntary outpatient commitment.
- Client-run crisis teams/develop client-run alternatives to involuntary treatment.
- More funding for mental health programs, i.e., vocational rehabilitation and, on a 24 hour seven day a week availability, patients' rights advocates.
- Work incentive issues regarding Social Security, including maintaining health benefits.
- Advanced Directives as a strategy under the priority to fight the expansion of forced treatment/ outpatient commitment and as a safeguard against forced treatments.
- Improved regulations of and rights protections in board and care homes.
- Restoration of "mental patient" Cemeteries and Histories - anti-discrimination campaign.

**The CNMHC has prioritized Community Services and Supports as follows:**

1. Voluntary and client-run community-wide crisis services, including outreach, mobile units, and peer support;

2. More affordable housing with supports, with 24 hour help upon request;

3. Client-run board and care review teams;

4. Consumer-run self-help, including hotlines and drop-in centers.

### **Lines Inspired by the Client Forum** by Gabriela Swift

Twas the night before the conference and all
Through the House, not a creature was
Stirring except for Sally and Cheryl and Willie,
Kathy and Irma and all those other little elves
Who stayed up late planning this glorious
Spectacle for you—the clients!
At a quarter to midnight ole Sally
Said “We’d better head to San Diego
To start a new day.
Hey’ it’s warm down there and the clients
Are cool (especially Leonard)
They surf and they’re buff like nobody’s fool.”
So they jumped on the plane and down here they flew
Then they rushed to the hotel ; they met with the Crew.
There was huffing and puffing all over the place
And Sally was in a frenzy trying to keep up the pace.
The food was divine and the workshops were neat
Senator Chesbro was a hit
His speech was so good it made us all shout
“We clients are organizing; so you’d better watch out.”
We’re transforming the system and that ain’t no joke
We’re jazzy, we’re snazzy, we’re smart and we’re proud,
So you’d better listen to us ‘cause we’re going to be loud.
We’ll sing our blues to get your attention.
We’ll dance the hip hop to songs we won’t mention.
….
Now Tipper, she’s chipper, she’s on our side.
So let’s go get her and give her a sleigh ride
Over to California where the movement’s alive.
We’ll tell her our stories of how we survive.
Merry Christmas to all and to all a good night,
Our Movement, our Network, we’re a radiant light!!

## Group Membership Created with Bylaw Changes

During the Membership Meeting at the Client Forum 2000, members voted to add an "affiliate" membership status to the CNMHC. During the reorganization of the California Network of Mental Health Clients (CNMHC) in 1995, California clients determined that a state organization should be composed of both individual members and groups. Creating "affiliates, a vehicle for group membership, fulfills this reorganization directive from clients.

The following Bylaw amendments were passed, with some revisions. The second sentence of Article 5, Section 1, "Definitions", was sent back to the Board for review with the goal of inclusiveness, and Section 5, "Responsibilities" "a", was sent back to the Board for review and clarification.

Article 5. Local Affiliates *

Section 1. Definition

An Affiliate shall be a group of ten or more clients which has been granted status as an Affiliate of CNMHC. Affiliates must be independent of other agencies or advocacy groups, and of the CNMHC, with its own non-profit incorporation. There will be a Probationary Affiliate status for groups that are seeking not-for -profit incorporation.

Section 2. Name

An Affiliate shall include "An Affiliate of the California Network of Mental Health Clients" in all published materials.

Section 3. Membership

An Affiliate must be composed entirely of mental health clients, as defined in Article 3, Section 2, of these Bylaws.

Section 4. Mission

An Affiliate must agree with the mission and purposes of the CNMHC, as defined in Article 2, Sections 1 and 2 of these Bylaws.

Section 5. Responsibilities

a. Affiliates will pay dues as determined from time to time by resolution of the Board of Directors. The dues shall be based on the number of members of the group, and in accordance with the dues established for individual members.

b. Affiliate will provide the CNMHC with a list of members, who will become members of the CNMHC.

c. Affiliate will advise the Board on local issues.

## Contact the California Network

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# Report on Client Forum by Carmen Lee

It was a great Conference with over 300 attendees, and, at least what I experienced, it was a friendly, productive and positive experience.

Senator Chesbro spoke about the disarray in the Mental health system, beginning in the 60's with the closing of the institutions, and how dedicated he is to do everything he can to support the CNMHC's agenda. He did mention that he thought the forced treatment issues (AB1800) comes from frustration from families and their drastic need to get the attention of the government. He agreed that this isn't the way to go.

After Senator Chesbro spoke, there an "open mike" when people were able to comment and ask the Senator questions. Housing issues were brought up several times, the abuse in B&C homes, social security, police training, being penalized in trying to return to work, the criminal justice system, self-help and peer support, indignities within the system, and respectability.

I then attended a workshop, titled " Client-Run Programs: Philosophy and Models," moderated by Judi Chamberlain with a panel of people who run self-help groups around California. Bill Compton from Project Return, The Next Step, Connie Apone form Sacramento Self-Help Center, Gitane Williams from Alameda Network of MH Clients (very good and funny speaker), Kathy Zatkin, Alameda Network of MH Clients. Mainly they all spoke about their growth, their funding, their present obstacles, and what their work means to them personally. It was an uplifting and encouraging workshop.

At lunch on Saturday, Sally and the Network members received some awards and recognitions. The lunch was delicious and Sally's History of the Movement was interesting and, once again, very encouraging to all to see how far the movement has progressed since the 70's. A labor of love.

The Stamp Out Stigma (SOS) workshop followed after lunch and went well with over 25 attendees, and many people who were interested in beginning a similar program in their area. Unfortunately, I did not attend the second afternoon workshop as I need to "debrief" after giving a workshop.

The dinner keynote speaker was Gilberto Romero from New Mexico. He, too, was warm and interesting.The Howie Harp Award was given to Joyce Ott and the Public Service Award to Wendy Walker-Davis. Then the party began and on Sunday morning, there were many droopy eyes and tired bones.

*Forum Planning Committee, left to right: Willie Collins, Georgia DeGroat, Cheryl Milgrom, Irma Kendrick, Sally Zinman, Mary Jo O'Brien, Carole Ford, Leonard Mishley*

Judi Chamberlain gave a good talk at the beginning session on Sunday morning and at 11 AM the regional membership meetings began. Of course, I went to the Bay Area Regional meeting that was led by Roy Crew and Mickey Shipley. The 1999-2000 priorities were discussed, and outside of some word changes, all remains the same. There was a resolution passed that voted for the change from "stigma" to the word discrimination, as the word stigma marginalizes us away from other group's who suffer from "discrimination". The word discrimination also has a legal overtone. I did explain, however, that this will take some time to do with the Stamp Out Stigma program. Not only will we have to come up with a name change, but, also, have to use up our remaining brochures, letterheads, etc., before changing over. I would imagine that other organizations will also take some time in changing over, not only with the concept, but with their already printed material.

The fun highlight of the Conference was the presence of the entire 49er football team...staying at the same hotel!! Several CNMHC members got numerous autographs (I was only able to get Jeff Garcia) and it was certainly something out of the ordinary!

It was a good and productive weekend, and I hope for those who didn't get to go that you'll plan to go next year.

# Recognizing Those Who Lived and Died in State Hospitals

**By Lori Shepherd**

California mental health clients join ex-patient/survivors across the country in bringing dignity and recognition to those who lived and died in state hospitals. It is time to remember and honor the thousands of people who lived, who are living, and those who died in state hospitals.

The CNMHC and the Peer/Self-Advocacy Unit at Protection & Advocacy, Inc. are working jointly on a project to reclaim our history at state hospitals. This project has 3 parts: recording the stories of people who lived in the state hospitals by decade, restoring the cemeteries at the state hospitals, and documenting the history of the ex-patient/survivor movement in CA.

## Telling our stories: Life in the state hospitals

It is critical that our voices be heard about what it was like to live in a state hospital from our perspective. Most of what is written about state hospitals is from the staff's and families' perspective, but there are few first person experiences from those who were patients. We will be collecting stories of those who lived in the state hospitals. We need to get these very important stories down on paper from people who lived in the state hospitals over the past decades, before those stories are lost forever.

## Cemetery Restoration

At many of the state hospitals, people were buried at the hospital grounds in unmarked cemeteries. Sadly, these cemeteries are in total disrepair and neglected and don't even resemble a cemetery.

On November 8, 2000 a group of 12 ex-patient survivors from the CNMHC and the Peer/Self-Advocacy Unit along with Pat Deegan, an ex-patient activist from Massachusetts, had the opportunity to visit the cemetery at Napa State Hospital. We were led to an unmarked field filled with brown weeds behind the hospital. There we were told that there were a little over 3,000 people buried in this field. As we stared at the field in disbelief, we were stunned that people could be treated in such a callous and disrespectful way. Gradually the weight of sadness lifted and a determined resolve to right the terrible wrong came over the group.

Pat Deegan is from the National Empowerment Center in Massachusetts and has a grant from Center for Mental Health Services to provide technical assistance to client groups in different states to restore state hospital cemeteries. During lunch, Pat showed us an inspiring slide show of other ex-patient/survivor's efforts of restoring cemeteries in their states. There are efforts going on in Massachusetts, Minnesota, Arizona, Connecticut, Ohio, South Dakota, and Washington.

We ended the day by visiting the local cemetery in Napa where the cremated remains of 3,158 Napa State Hospital residents were re-located when they closed the hospital crematorium in 1963. We met an amazing woman, Reby Simmons. Reby is the general manager for the Napa Chapel of the Chimes and Memorial Park. In 1995 she got a beautiful marker donated to acknowledge the patients buried in the community plot. She told us that people were buried 9 rows deep, 16 across by 23 down. As we realized how many of our brothers and sisters were buried here, we were also struck by the humanity and kindness shown by one person.

We left that day with a strong mission to bring dignity and recognition to those who died nameless and forgotten.

Since that time, we have begun to talk about what we want to do in California to recognize and honor those who died in state hospitals. It is clear that for the project to have meaning, it needs to be lead by those who have lived in state hospitals. For it is those whose lives have been forever changed by being committed to a state hospital who need to lead the way to bring honor and dignity to those who have died in a state hospital. It is their voices and experiences that should guide this project. We are forming a steering committee of Peer/Self-Advocacy staff and CNMHC representatives to develop a plan for restoring the cemeteries in California. In addition to Napa, we are gathering information about other state hospitals: Agnews, Camarillo, De Witt, Fairview, Mendocino, Metropolitan, Patton, Sonoma, and Stockton.

We are forming committees in each of the 5 CNMHC regions to work on the state hospitals in those regions. We especially want people who were patients in a state hospital to be involved. Each committee will be doing research on their respective hospitals and the cemeteries, collecting stories from people who lived in the hospitals, and developing a plan for restoring these cemeteries.

We will be talking about legislation to ensure that the state takes responsibility for the care and up keep of each hospital cemetery. There is much work to be done and we encourage everyone to get involved. By bringing dignity to the dead, we will bring dignity to the living. We need to keep in mind the saying by George Santayama "Those who can't remember the past are condemned to repeat it."

**California Network of Mental Health Clients**

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