FAMILIES OF MENTALLY DISABLED

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NEWSLETTER, Vol I, No. 2, December, 1981

Editor ---- Helen G. Teisher-

Editorial, by Donald and Peggy Richardson, AMI, Los Angeles*

THE HOLIDAY SEASON IS A REASON FOR CARING - A SEASON FOR SHARING

We parents, coping with family members who are suffering from mental illness, need lots of caring around us. However, we need to find ways of dealing with our own emotional turmoil; we need to find alternatives to the stressful life style nurtured by the illness or THE ILLNESS WILL CONSUME US!

WE MUST HAVE HOPE - WE MUST BELIEVE

At the present time we do not know how to cure or prevent most of the chronic mental illnesses. However, to paraphrase Dr. Leonard Stein, who spoke to the <u>Wiscomin Alliance for the Mentally Ill</u> last spring:

We are learning more and more about how to prolong the stable phase to keep the person functioning at a fairly good level for longer periods of time. And we're learning how to shorten the psychotic phase, and then to lengthen the interval between the two.

Dr. Jack Barchas, Stanford University researcher, stated at the October CAFMD conference in San Francisco:

Dr. Richard Hall, professor of psychiatry at the Medical College of Wisconsin, recently predicted that the cause and "cure" for schizophrenia will be found within ten years.

WE MUST GET INVOLVED - WE MUST MAKE IT HAPPEN

Only through the adopting of a strategic approach which considers political, administrative and fiscal realities can we hope to cope with current and future attacks on services for the mentally disabled. Our state organization, California Association, Families of the Mentally Disabled, has a plan for action - political action that allows our voices to be heard where the action counts. With everyone helping this plan will work for the benefit of all.

WE MUST BE A FRIEND - WE MUST CARE

A wise and understanding person once said, "A friend should strive to be like the shadow of a great rock in a weary land, to be a source of refuge and strength to those who walk in despair."

We believe that parent advocates should be sensitively responsive to each other; to join hands and work for purposes and causes that will make living with mental illness easier.

*(See next page for more about the Richardsons)

Follow the leaders

PEGGY AND DONALD RICHARDSON - CHAIRPERSONS LEGISLATIVE ACTION COMMITTEE

Don and Peggy Richardson are both natives of Los Angeles. They received their education in the Los Angeles Unified School District and graduated, Don from UCLA, and Peggy from Pomona College. Both of the Richardsons received their teaching credentials from UCLA/ USC as well as advanced degrees. They have

The Richardsons have organized and directed many adult lecture series, youth programs and community activities. They served in leadership capacity in community organizations as well as professional endeavors. Peggy and Don retired from the educational profession last year; Don from his position as assistant superintendent and Peggy as teacher of English as a Second Language.

The Richardsons were responsible for deve oping the initial Public Affairs Committee proposal last year which served as a key effort for uniting the CAFMD affiliates in a state-wide project. They used many of the experiences of the PAC Project as background for developing the Proposal for Political Involvement that was approved in San Francis on October 24, 1981.

The Richardsons are officers in their loc affiliate organization. Advocates For the Me tally Ill (AMI), and in the Los Angeles Coun Parent Coalition. They have agreed to organize the Legislative Action Committee for CA and to serve as coordinators working with al affiliate groups in the southern part of the

ONE IS NOT ENOUGH FOR THE RICHARDSONS

One coalition in Los Angeles County? NO, Not ONE, TWO COALITIONS IN LOS ANGELES COUNTY in which the Richardsons are deeply involved.

The first is a coalition of seven family groups with Don being President. This coalition meets once monthly to discuss issues and plan strategies to be effective agents in the mental health community of Los Angeles County.

In this parent coalition Don and Peggy are, of course, joined by their fellow advocates who are involved and dedicated too. Together they can speak to the proper policy and decision makers and help to educate them to the consumer viewpoint and the needs of families who are coping with mental illness on a day-to-day, face-to-face basis.

This Parent Coalition of L. A. has been most successful in establishing regular communication through Mary Lee Gray, administrative assistant to Supervisor Dana, to the Board of Supervisors. Supervisor Dana attended the November 6, 1981 meeting. Communications have also been established with the Local Director of Mental Health. Requests have been made that parents be appointed to the Mental Health Advisory Board & the Commission for the Handicapped.

THE LOS ANGELES COUNTY COALITION

This coalition is comprised of 33 groups whi include parent groups with the purpose of bringing together diverse mental health grou working within the county for goals such as:

- to provide standardized information on mental health issues for coalition member legislators and others interested in mental health.
- to develop long-term program and legislat
- to establish a legislative network
- to develop cadres for action throughout Los Angeles County

Don reports that on December 2, 1981 the first meeting was held with about sixty people representing the 33 groups. OF THOS SIXTY IN ATTENDANCE ELEVEN WERE REPRESENTIN THE PARENT COALITION. Parents had the largest single delegation.

"It looks like all systems are GO now!" says Don.

Follow the leaders

FRAN AND TONY HOFFMAN - FAMILIES ASSOCIATION LEGISLATIVE REPRESENTATIVES

Mr. Hoffman was born in Effingham, Illinois. He grew up and received his basic schooling in this small town in central Illinois. At 17 he left home and learned the trade of machinist.

In 1942 he enlisted in the Navy, spent 4 years, part in schools and part in the South Pacific. He was a machinist and deep sea diver. He married Fran shortly before discharge.

Fran was born in South Dakota where she grew up on a ranch. She attended Business College in Rapid City, South Dakota, and worked as a secretary in Rapid City, San Diego, Seattle, and in San Francisco where she met Tony. Since then Fran and Tony have been partners in varied and extensive advocacy work at all levels -- local, state and national.

After discharge Tony went to work as a machinist and studied mechanical engineering in night school.

He became involved in his union's activities and came to believe the only way an individual could receive justice on the job was through group action. He became a fulltime representative of the Machinists Union in 1961.

During these years, two children were born to Fran and Tony, a daughter, Julie, and a son, Edward. At 15, Edward became mentally disabled.

In 1974, Eve Oliphant phoned about six families of mentally disabled people and invited them to her home. The Hoffmans were there and helped to start an organization that came to be "Parents of Adult Schizophrenics" of San Mateo County.

This organization flourished and the Hoffmans decided a similar organization was needed at Napa State Hospital. They started organizing and holding meetings. Frank and Frances Morain became involved early on and took over as leaders of this organization, "Association for the Mentally Ill of Napa State Hospital."

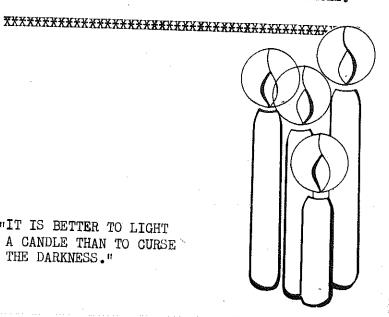
In the meantime, other similar organizations were being formed, mostly in the Bay Area. In 1977 the Hoffmans started holding meetings with these groups with the intent of forming a state organization. In the fall of 1978, the first conference of this organizat on was held. The name chosen was "California Association, Families of the Mentally Disabled."

Mr. Hoffman was elected President, Mrs. Hoffman, Corresponding Secretary. The Association grew throughout California and at a recent conference in San Francisco, delegates from 39 affiliates selected the Hoffmans to be their first Legislative Representatives.

The Hoffmans have also been involved in starting a National organization, "National Alliance for the Mentally Ill." Mr. Hoffman is on the Board of Directors.

For seven years Mr. Hoffman has been a member of the San Mateo County Mental Health Advisory Board and served as its Chairman for one year. He is a co-founder of the State Organization of Mental Health Advisory Boards and is now its Vice President.

Although Mr. Hoffman has retired from his full-time position with his Union, he is still active, especially in Community Services for the San Mateo County Central Labor Council.



"IT IS BETTER TO LIGHT A CANDLE THAN TO CURSE THE DARKNESS."

SACRAMENTO BEAT

We will give you the good news first. We met with Sharon Dorsey, President of Family Effort, the Sacramento Families organization. Pat Williams, of Families for Mental Recovery, Yolo County, arranged the meeting and was present. Sharon told us that her group is just becoming interested in politics and will provide support for us. We were invited to their Christmas Party on Dec. 7, which we attended. This festive party was well attended and we met a number of parents and families, many of whom expressed a willingness to be of help. We look forward to working with this group, and will attend one of their regular meetings in the near future.

In addition, a long time member of the Association for Mentally Ill of Napa State Hospital, <u>Ken Jacobsen</u>, lives in Sacramento and is interested in legislative activity. He has been following legislation for the Napa group. Ken has quickly grasped the intricacies of the legislative and political process and is currently helping us.

Elaine Jacobson, President of the Schizophrenia Association of Sacramento, has invited us to speak to her organization.
Elaine plans to accept membership on the
Advisory Board of the Orthomolecular Program at Napa State Hospital. She has been
active in starting a 6 bed orthomolecular
residential program in Sacramento county.
This program will start operation in January and is the first of its kind, to the
best of our knowledge.

*Derek Casady, Senator Mills Administrative Assistant, informed us that Senator Mills is Chairman of a new committee, Nutrition and Environmental Influences Upon Human Health. Casady is a consultant for this committee. Senator Mills and Mr. Casady are long time supporters of the orthomolecular approach.

We have been pleased to renew contact with some of our friends in the Department of Mental Health. Many of them have been supportive in the past and express willingness to work with us at present. We noted that some of our old friends have moved up and are in influential positions. Many are concerned about the problems in the Mental Health System and value consumer in-

put because they know we can give them a viewpoint they cannot get from any other source.

Although most of the legislators have not been at the Capitol, we have visited with a number of their administrative assistants. Several have told us that if we need an author for a bill, their senator or assemblyman is available.

Remodeling of legislative offices continues at a furious pace and is supposed to be completed before Christmas. The restoration of the old Capitol Building will also be completed and a week of celebration is being planned, starting January 4, 1982.

BUDGET PRIORITIES

Now for the bad news. We have been informed that there will be a 5% across the board cut in funding to all departments. We need to establish some CAFMD priorities for services which will be of the most help to the chronically mentally ill. We ask that affiliates inform us as to their priorities, so that we can press for these services with the legislature.

Block grants from the Federal government to the state, and block grants from states to counties will be the topic of hearings when the legislature convenes in January.

Since this is election year, predictions are that there will be fewer bills introduced, and that if the bill has a financial impact, the bill will not pass.

TRICKLE-DOWN THEORY

At a recent meeting in Emeryville, Ca, we witnessed an example of what happens to the tax dollar in the bureaucracy, or the trickle-down theory.

The State received a \$600,000 training grant from NIMH. Some counties were selected as possible recipients. Representatives of these counties were invited to meetings. The staff explaining the plan pointed out that the people from the state, 3 full time administrators, plus staff would be involved and the people from the counties would be unpaid volunteers. It was also pointed out that only \$225,000 would be distributed among four counties, \$375,000 for the State. It appears that not enough is trickling down.

ADVISORY BOARD INDEPENDENCE

On our last day in Sacramento, we discovered that the funding and structure (independence) of Mental Health Advisory Boards and the *Mental Health Advisory Board Project was again under attack from the Mental Health Department.

We contacted representatives in the Senate and Assembly Health Committees and received assurance of their support.

We arranged a meeting with Ken Wagstaff,
Deputy Director of Health and Welfare, an
old acquaintance, and found he was still
consumer minded and sympathetic to our cause.
We received assurance of his support. He
also indicated his support in the appointment of Pat Williams to the Citizens Advisory
Council.

S.S.I.

At the recent board meeting of the National Alliance for the Mentally Ill, it was noted that the problems with Supplemental Security Income are nationwide. Mentally ill persons benefits are being disallowed or reduced without just cause.

Allen Jensen, House Ways and Means Committee, a Specialist on S.S.I., is investigating *this problem. It was his recommendation that the individual who has experienced problems should contact his own Congressman, and also send a one-page documentation of the problem to our national office, NAMI, 1234 Massachusetts Ave., N.W., Washington D.C., 20005. Our national office will work with Mr. Jensen to try to solve the overall problem. It is very important for the national office to have these written testimonials, even if they are unsigned.

AB2144

AB2144, also known as "the parents right to know bill", is now included in the Welfare ** and Institutions Code, Section 5328.1. If you wish to be notified as to a family members presence in a facility, transfer, prognosis, diagnosis, medications prescribed, progress of patient, etc., send a letter or form requesting this information to the facility.

ASSEMBLY HEALTH COMMITTEE, INTERIM HEARING ON STATE HOSPITALS, ART TORRES, CHAIRMAN Held Dec. 7, 1981 at Sacramento

The morning hearing was on Level-Of-Care Staffing Standards. Psychiatric technicians from all of the State Hospitals testified as to the problems created by staff shortages and the hiring of untrained staff, both as to patient care and treatment and staff/patient health and safety. Several attempts have been made by the Legislature to improve the situation, Torres AB 2481, in 1978, and Keene ACR 103, 1978.

In spite of all these activites, the issue remains unresolved. Level-of-care staffing standards are now developed but have never been implemented at 100% level. For example, while most developmental disabilities units are staffed at 100%, the 1981-82 Governor's Budget included an increase for staffing of clients in medical/surgical and continuing medical care programs to raise the staffing from 93% to 97% of the ACR 103 standards. More striking is the situation in mental health programs, which are staffed at only 88% of the standards.

The specific action that led to today's hearing was the introduction of AB563 at the request of the Communications Workers of America, AFL-CIO Psych Techs Union in response to increasing concerns over understaffing and high injury rates. The Union has charged that psych techs have an injury rate second only to firefighters.

Department of Mental Health staff testified that there is a high attrition rate for psych techs. Untrained students are hired as a means of recruitment for training for eventual licensing. Dr. Loeb commented that with the current financial crunch, we will be fortunate to keep the status quo.

Assemblyman Tom Bates made the statement that it is incumbent for the legislature to speak out regarding this problem.

The afternoon hearing heard testimony on The Role of Physicians in State Hospitals.

ISSUES

Actual vs Projected Census: The projected census is within 1-3% range. The increase in judicially committed patients is a major policy question. Average cost in state hospital is \$100.00 per day.

Dr. Allen of Camarillo State Hospital reported that they turn away 25-50 patients per week now, and 154 beds will be dropped January 1, which are currently always full.

Dr. Barter, Clinical Director DOMH, responded that the performance agreement with Los Angeles County reduces utilization of beds at Camarillo, and increases local funding at Martin Luther King Center. We do not have double funding so we can't have money in both places. The County is responsible for acute treatment facilities.

Dr. Allen stated that projections have become goals and goals to reduce state hospital population are reached by threatening counties with total cost of state care. The least restrictive alternative in the community is often a locked facility which lacks the amenities of the state hospital. Involuntary custody by private contract is risky business.

Reclassification of State Hospital Beds:

State hospital beds are being reclassified to Intermedicare Care and Skilled Nursing rather than Acute Care. Proponents of this reclassification claim that it results in increased appropriateness and decreased cost. Opponents allege that it is solely a cost-cutting revenue generating device that results in inadequate care.

Dr. Herbert McGrew of Napa State Hospital expressed concern regarding changing class of beds. They get the most difficult patients and need increased staffing. In a financial crunch, good intentions to keep staffing standards high may crumble. He felt the reason Napa is presently at its lowest census is not because there are more community facilities and care, but rather pressure not to admit by notification of fully billed overage.

Staffing Standards: Dr. Jerome Lackner, former Director of the Department of Mental Health, who campaigned vigorously during his term for better staffing standards, testified in favor of better staffing and for availability of alternative treatment modalities. He said, "Do not let the impact of fiscal problems fall on those least able. Large doses of chemicals are not the answer".

* Dr. McGrew, Napa, stated that thanks to

Dr. Lackner's efforts, Napa enjoyed increased staffing, peer review, medication review, death investigation, client auditing, etc., and he does not want to lose these benefits.

Role of Investigator, Clinical Director, Pharmacist

Generally, the Pyschiatrists challenged the need for the above positions in the personnel of state hospitals. They felt that they were unecessarily challenged by some of the above personnel, and that more doctors were needed on staff instead of them.

*Dr. O'Connor, Napa Director, said he had no problem with having the Special Investigator, Clinical Director and Pharmacist on staff. He found their contribution useful and felt that they provided a system of checks and balance. Patient deaths have been reduced by one-half in recent years.

* * * * * * *

Our brief time on the job has reinforced what we already knew; that we can have an impact, and that we can't do it alone. We need help from others, especially within our organization. We are encouraged to note that help is forthcoming.

DON'T DROP THE BALL NOW! IF OUR PROJECT IS TO SUCCEED IT WILL NEED THE CONTINUAL SUPPORT OF ALL OF US. IF ANY SECTOR OF THE CIRCLE IS INCOMPLETE, THE CIRCLE WILL BE BROKEN, AND NOTHING WILL BE ACCOMPLISHED.

DON'T DROP THE BALL NOW!

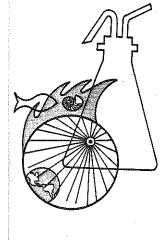
AFFILIATE MEMBERS AND INDIVIDUALS, PLEASE!

You have the information now given to us in Fran's and Tony's laudable report. Now it is our turn to follow up with appropriate communications, with letters of inquiry, appreciation or statements of facts, and requests for more information and action. Look especially at the starred (*) items in the SACRAMENTO BEAT section and take the action you think would be effective.

Thank you for all you do, Halon Teisher

MRA

(MENTAL ILLNESS RESEARCH AWARDS)



Most of our initial 6000 brochures went to local and California family alliances. Only about 400 were distributed at the Seattle NAMI Conference. We have just over \$6,000 in MIRA Fund now from 99 contributors. Coinciding closely with the news early in November of a deepening recession, the rate of contributions dropped off sharply.

However, this is no time to get discouraged. Wasn't it JFK who said, "When the going gets tough, the tough get going."? It is time for the next step in the program. So we ordered 4000 more brochures reproduced and folded, which were completed in a couple of hours on a Xerox 9500 machine in Encinitas. With some help from daughter Janice 131 envelopes, each containing a packet of 25 brochures and an appropriate letter, were mailed out on November 30 to all dues-paying family alliances in the other states and even one each to Canada, New Zealand, and England. They were asked to distribute the brochures to their members and friends and help us save expense by Xeroxing more if needed, and to join us in building MIRA to a motivating size, hopefully at least as large as a Nobel Prize.

This effort has taken a very large slice of my time. There is one area where I really need help. Along with checks, which I process for our Treasurer, Virginia Reese, there are sometimes interesting letters with questions and encouragement. I try to answer some, because helpers do not live close to me, but this is more than a one-man job, and the PAS Office is busy with two newsletters per month. Is there a good letter-writer out there with time and postage money? I also shall be getting some volunteers together for the next step in the program.

As has been said at our meetings before, we can't afford to lose our sense of humor altogether in this serious task. The following little "gem" comes by courtesy of a nimble-fingered typist at NAMI, Washington, D.C., who provided me with a list of all dues-paying Affiliates of NAMI:-

Alliance for the Mentally III Sane County Box 1502 Madison, Wis. 53701

I couldn't believe it! The atlas said Madison is in Dane County.

One parting thought. We all know the importance of our combined efforts on the political scene, upgrading the board and care facilities, the jail problems, etc. These problems won't go away as long as we have schizophrenia, and schizophrenia will go away only when we have done the necessary research. Please help us push research faster with MIRA!

Warren K. Smith Chairman, Research Committee PAS of San Diego County



** WINTER CONFERENCE, CALIFORNIA ASSOCIATION, FAMILIES OF THE MENTALLY DISABLED, HOSTED BY FAMILIES AND FRIENDS OF THE MENTALLY ILL, VENTURA, FEBRUARY 19 and 20, 1982

Some FFMI members and their friends have offered to provide sleeping space (no meals) in their homes Friday and Saturday nights to people who are coming from out of the area. If you wish this kind of accommodation, let us know early. It will be provided on a first come, first served basis, and we cannot promise accommodations to everyone, but we will do our best. Deadline January 15, 1982.

If you prefer a motel, you might try one of these: Pierpont Inn (805) 643-6144

Pierpont Inn (805) 643-6144 Holiday Inn (805) 648-7731 Vagabond Motor Hotel 800-522-1555 Hotel Six

PLEASE RETURN YOUR RESERVATION AS QUICKLY AS POSSIBLE

RESERVATION FOR CONFERENCE, FEBRUARY 19 and 20, 1982

MAIL TO: FAMILIES AND FRIENDS OF THE MENTALLY ILL, Post Office Box AH, Ventura, CA 93002

Room accommodations in the homes of members and friends (indicate single or double, number of people, and whether you will stay both Friday and Saturday nights:

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Dinner Friday Night	(\$11 each) Number Amt.	- .	Total	re die namel som die North aus die North aus aus gegen zu des gegen zu deutsche der der der
Luncheon Saturday	(\$10. includes conference room and coffee breaks)		Total	
Saturday - no lunch	(\$3.00 for conference room and coffee breaks)		Total	· · · · · · · · · · · · · · · · · · ·
		Total amount enc	losed	

AFFILIATES: Please do all you can to publicize this conference. It should be one of our largest and best. We do try to move "upward and onward" all the time. Lou Matthews and her group are planning an important agenda with workshops planned for Friday afternoon which will be led by experts on various topics of interest to us. A refreshing feature will be the meeting place - Poinsettia Pavilion Womens' Center, 3451 Foothill Road, Venture. MORE INFO LATER

CAFMD - Newsletter 4120 — 30th St., Suite 103 San Diego, CA 92104