

CAMI FAMILIES SPEAK  
QUESTIONNAIRE RESULTS

July 1983

by Pat & Bill Williams  
Robert Sommer

This report is a summary of questionnaire results from 199 members of the California Alliance for Mentally Ill. Robert Sommer PhD will follow up with an in-depth analysis of the data set which includes some 10,000 separate answers. People who join a support group such as CAMI usually are parents of severely mentally ill off-spring. These parents have seen and learned a lot about the mental illness of their loved one, and usually know the whole history of the ill family member. Yet often they have not been listened to by professionals. Parents want very much to be part of the treatment team, and help in the recovery process. These survey results are another window into the mysteries of serious mental illness. It is hoped that this survey will be a step towards more understanding, better treatment, and better facilities for the seriously mentally ill. We will do another questionnaire in October and are already gathering the questions.

Survey Area. Two-thirds of the respondents were from southern California, and one-third from the northern part of the state, with San Diego County having the largest representation.

1. Diagnosis. Schizophrenia was by far the most often mentioned diagnosis, 66%, and an additional 17% listed it in combination with another mental illness usually affective disorder. So there was a schizo component in 82% of the cases. Of the rest, 10% mentioned affective disorder by itself, and another 13% mentioned it in combination with another mental illness, usually schizophrenia. So there was an affective disorder component in 23% of the cases. 3% mentioned personality disorder specifically. Another 8% mentioned it in combination with something else.

2. Age. The present age of the mentally ill person was recorded. The majority of them were between 25 and 34 years, and 84% were between 20 to 39 years. Very few members of CAMI recorded parents with mental illness.

3. Onset. Almost two-thirds noticed their family member's illness between age 15 and 24 years. Only 9% of the respondents became aware of the problem before the age of 10 years, and 4% before the age of 5 years. Mental illness apparently does not show clear early signs. The peak period for severe mental breakdown is clearly in the late teens, 42%.

4. Help was first sought for two-thirds of the mentally ill between 15 to 24 years. Most sought help almost immediately. 42% noticed the problem between ages 15 to 19, and 42% sought help in that period.

5. Sex. Almost three-quarters of the mentally ill were male, 73%. Are males more vulnerable? Does our society put more stress on them? Is it harder to be the parent of a mentally ill son? Do males use more "street drugs"?

6. Relationship. Eighty-seven percent of the respondents had a mentally disordered son or daughter. Only 4% had an ill spouse. It is clear the members of CAMI are predominantly parents.

7. Source of Assistance. This question dealt with where the troubled person went for assistance and how helpful the source was. The percent of those using each source and how helpful each was perceived was ranked from high to low.

Table 1. Source of assistance and its helpfulness.

Source of help	% sought	Source of help	Rank % helpful
Private psychiatrist	88	Crisis house	1
Mental health clinic	78	Skilled nursing facility	2
Board and care	58	Socialization center	3
State hospital	54	Private hospital	4
Private hospital	53	State hospital	5
Family counselor	43	Mental Health Clinic	6
Clergy	40	Private psychiatrist	7
Vocational rehab.	30	Halfway house	8
Socialization center	29	Family counselor	9
Halfway House	28	Board and care	10
Skilled nursing facility	22	Vocational rehab.	11
Crisis house	19	Clergy	12

Comments: It appears that the most helpful things were among the least available. Many added a note that they wanted work and training that was appropriate for their family member with support and low pressure.

8. Drugs. Eighty-five percent responded that neuroleptic drugs were very or somewhat helpful, and 11% said they didn't help or were negative. It is excruciating to watch a mentally ill family member decompensate until they become psychotic because they won't take their medication. They usually end up on the street, in jail, or in the hospital. The family sometimes cannot stand the stress and break up. It is worse to be in the same situation with a mentally ill loved one who is allergic (toxic) to medication, is helped by nothing, and must be hospitalized in a locked ward or seclusion room and put in four point restraints for control.

9. Most helpful drugs. The three medications that helped the most were said to be prolyxin 19%, lithium 14%, and haldol 13%. No drug really helped everyone. There was no single drug that even 20% described as most helpful. However, there was strong correlation between affective disorder and lithium, and schizo-affective illness and lithium.

10. Least helpful drugs. The three medications that helped the least were said to be thiorazine 18%, haldol 12%, prolyxin 11%. Here again there was no drug that even 20% judged as least helpful. There was no consensus. If you compare the ratio of those mentioned as most helpful to those least helpful, the best ratio is prolyxin followed by lithium and stelazine in that order. By far the worst ratio was achieved by thiorazine where more than twice as many rated it as least helpful as compared to most helpful, 18% to 7%.

11. Residence. Only 30% currently are living at home.

12. Conservatorship. Half have at sometime been on conservatorship.

13. Jail. Half have been in jail. Some respondents wrote in that the jail stay was just an overnight detention until they could get into the hospital.

14. Type of help.

Table 2. Things that helped the mentally ill person improve.

Type of Help	Total %
1 Medication	37%
2 Family support	22
3 Talk therapy	13
4 Social center	13
5 Community residential	12
6 Locked facility	11
7 Work/volunteer work	10
8 Religious	9
9 Ortho/holistic	7
10 Other	-

15. Most needed improvements.

Table 3. Improvements the county needs to provide.

Needed Improvements	Total %
1 Quality residential	41 %
2 Voc.rehab/work	20
3 Socialization	16
4 Professional help	11
5 Locked facility	10
6 Self-help group	9
7 24-hr mobile crisis	7
8 Ortho/holistic	5

16. Other ill relatives. 10% of the parents had mental illness. Of these, 14% were fathers and 7% were mothers. 10% of the siblings had mental illness.

17. Community residential treatment system (CRTS) Those responding were affirmative. Included were crisis house, long term, halfway house, satellite housing, socialization center, and vocational rehabilitation center.

18. What do you want the California State Department of Mental Health to do to help you and your loved one? Housing, work, social opportunities and research were mentioned most often by the respondents.

DATE \_\_\_\_\_

**QUESTIONNAIRE FOR CALIFORNIA ASSOCIATION FOR MENTALLY ILL**

Please do not write in this column

Please return to:  
Pat Williams  
718 Oeste Drive  
Davis, Ca. 95616

My county is \_\_\_\_\_

1. Is your mentally disabled family member:

(1) Schizophrenic \_\_\_\_\_

(2) Affective Disordered (manic, depressive, etc.) \_\_\_\_\_

(3) Personality disordered \_\_\_\_\_

(4) Other (please specify) \_\_\_\_\_

2. How old is this family member now? \_\_\_\_\_

3. At what age did you first notice the problem? \_\_\_\_\_

4. At what age was outside help first sought for the problem? \_\_\_\_\_

5. Is the person  
(male) (female)  
1 2

6. Relationship of the mentally disabled person to you  
(son or daughter) (spouse) (parent) (brother or sister) Other, specify  
(1) (2) (3) or (4)

7. In the left hand column, check all those agencies and individuals to whom you have gone for assistance. In the right hand column, please indicate how helpful each of them has been to your family member. How Helpful Were They? Cannot

(Check as many as apply) Very (1) Moderately (2) Slightly (3) Not (4) Sure (5)

a. Private psychiatrist \_\_\_\_\_

c. Family Counselor \_\_\_\_\_

d. Clergy \_\_\_\_\_

e. Mental Health Clinic \_\_\_\_\_

f. State Mental Hospital \_\_\_\_\_

g. Halfway House \_\_\_\_\_

h. Board & Care Home \_\_\_\_\_

i. Skilled Nursing Facility \_\_\_\_\_

j. Private Hospital Ward \_\_\_\_\_

k. Satellite Apartment \_\_\_\_\_

l. Socialization Center \_\_\_\_\_

m. Vocational Rehab Center \_\_\_\_\_

n. Crisis House \_\_\_\_\_

o. Long Term Farmhouse \_\_\_\_\_

p. Other, please specify: \_\_\_\_\_

8. Have neuroleptic medications (tranquilizers or other psychotropic drugs) been helpful?

Very (1) Somewhat (2) Not at all (3) Negative Influence (4)

9. Which medications have helped the most? \_\_\_\_\_

10. Which medications have helped least? \_\_\_\_\_

11. Does your mentally disabled family member currently live at home?

Yes (1) No (2)

12. Has your mentally disabled family member ever been on conservatorship?

Yes (1) No (2)

13. Has your mentally disabled family member ever been in jail?

Yes (1) No (2) Don't Know (3)

14. What things have helped your mentally disabled family member to improve?

15. What do you need in your County that would help your mentally disabled person?

16. Which other family members have been afflicted with mental disability? Check as many as apply.

On father's side: Parent, Brother or Sister, Aunt or Uncle, Grandparent, Other (1) (2) (3) (4) (5)

On mother's side: Parent, Brother or Sister, Aunt or Uncle, Grandparent, Other (1) (2) (3) (4) (5)

17. The following are examples of community residential treatment services (CRTS) facilities. Do you have these in your area?

(Check as many as apply) Yes (1) No (2) Don't Know (3)

a. Crisis House (2-14 days) \_\_\_\_\_

b. Long Term Residential \_\_\_\_\_

c. Farmhouse or home \_\_\_\_\_

d. Halfway House \_\_\_\_\_

e. Satellite Housing \_\_\_\_\_

f. Socialization Center \_\_\_\_\_

g. Vocational Rehab Center \_\_\_\_\_

18. What do you want the California State Department of Mental Health to do to help you and your loved one?