



Working together for ourselves, our families and our community.

NAMI-SCC National Alliance for the Mentally Ill

Santa Cruz County
P.O. Box 360, Santa Cruz, CA 95061 www.namisc.org

4/4/2002

Dear Simon,

This letter is in response to your letter concerning a request for corrective action regarding the quality of service rendered to your son by the Santa Cruz County Mental Health Services. First, everyone here at NAMI is saddened by the death of David. Please accept our deepest sympathy to you and your family. NAMI-SCC is eager to help in anyway that we can and we certainly are available to respond with our comments. We acknowledge that the circumstances that brought about David's death are complex and respect your assessment of the three reasons that he took his own life.

We would like to review your third assessment and invite the County Mental Health System to respond to these concerns, then actively and immediately pursue solutions them. They are: 1. What was (or is) the basis of release from 7th Avenue Center? 2. Why was County Mental Health staff supporting prosecution for an act that occurred when David was in a psychotic state? 3. Why was the legal action in this case drawn out when it caused stress and anxiety to the client in recovery? 4. Why was the family alienated in David's treatment, including their concerns about his medication? Was cultural sensitivity included in their management of this case? and 5. What is wrong about the environment at 7th Avenue Center?

In addition to these questions we respectfully assert that the current system of care must undergo a dramatic change not only in its method of care delivery but also in its fundamental program philosophy. Santa Cruz County has seen this challenge and it appears that it is attempting to address it with the implementation of a new program called the "Village Concept" or the AB2034 grant.

Recently, we were fortunate to have Pam Rogers-Wyman, supervisor for the AB2034 grant and Julie Conway, housing coordinator speak about Santa Cruz County's version of the "Village Concept" of care here in Santa Cruz County. This concept, which includes integrated intensive case management is the path that we believe our county should be taking in regard to the system of care for all Santa Cruz County Mental Health Consumers. In addition to this dramatic change in the delivery model for services we would urge that the providers for these services include families that are involved in their loved one's care. Including families in the overall treatment team approach, especially the transition age youth, is not only essential but also acknowledges the family's role as primary support system for the consumer.

It is our belief that if the system of care were to change so that it provides integrated intensive care as in the "Village Concept" model, even if the consumer is transition age and living at home as in David's case, the need for hospitalization would decrease. The need to admit our sons and daughters into the dismal locked "mental health rehab" programs would diminish or maybe be eliminated.

We believe that the County Mental Health System and those that work within the system do their best within the narrow guidelines established by the state to deliver services to the psychiatrically disabled here in Santa Cruz County. However, we too share your concerns about the current quality of life for those suffering from a severe mental illness, especially those who are subjected to the locked facilities. We ask that those programs look at ways to implement or at least discuss the following suggestions from Pat Deegan, Ph.D. Her suggestions, we believe, could be implemented into the existing system of care and would address many of your concerns outlined in your letter.

"We must commit ourselves to removing environmental barriers which block people's efforts towards recovery and which keep us locked in a mode of just trying to survive. For instance, I would suggest examining the following questions:

- 1. Are the people we work with overmedicated? Very often the apathy, lack of motivation, and indifference we observe is an effect of narcoleptics. Are we teaching consumer/survivors about this drug effect and helping them effectively advocate for medication changes and/or reductions? The multinational drug industry is literally making a fortune through the sales of these drugs. Our priority is not to increase their quarterly profit margins. Our priority is to support people in their recovery process. It is not possible to actively participate in our own recovery process when we are in state of drug induced mental Parkinsonism, apathy and indifference.*

2. Are consumer/survivors in both community based and hospital programs involved in evaluating staff work performance? Who better knows how effective a staff person is than those receiving services from that staff person? Additionally, are we providing consumer survivors with the skills training and support to conduct such evaluations?
3. Are program participants and hospital inpatients receiving peer skills training on how to participate in and effectively get what they want from a treatment team? Are we allowed to sit through the entire treatment–planning meeting and are staff committed to speaking in plain English so we can understand the conversation? Are there peer advocates who are available to come to the treatment planning meetings with us? Are there opportunities to meet prior to the team meeting in order to strategize what we want to get out of the meeting and how to go about presenting our ideas? Is there time to role-play speaking up and dealing with questions prior to the treatment-planning meeting?
4. Are there separate toilets or eating space for staff and program participants? If there are, they should be eliminated. This is called segregation and creates second-class citizens.
5. Who can use the phones? Who makes what decisions? Who has the real power in this program? Information is power and having access to information is empowering. What are the barriers to getting information in the program?
6. Do we understand that people with psychiatric disabilities possess valuable knowledge and expertise as a result of their experience? Do we nurture this important human resource? Are peer run, mutual help groups available? Are we actively seeking to hire people with psychiatric disabilities and to provide the supports and accommodation they may request?
7. Have we created environments in which it is possible for staff people to be human beings with human hearts? Do we offer supervision or staff surveillance? Perhaps we could help create more humanized work environments if we sought to view working with people as a journey in which we both move and are moved by the people we seek to serve. Perhaps we could offer our workers what Jean Vanier (1988) calls “accompaniment”. Accompaniment means offering to walk with our staff as they make that sometimes painful, sometimes joyous journey of the heart we call the “direct care relationship”. Directly caring. Ah! Now there’s true change.
8. Do we work in a system which rewards passivity, obedience and compliance? Is compliance seen as a desirable outcome? As a friend who is a consumer/survivor told me, “Tell those casemanagers that they have it all wrong. Tell them to stop saying that compliance is the road to independence”. And indeed, compliance is not the road to independence. Learning to become self-determining is an outcome that is indicative of environments that support opportunities for recovery and empowerment.
9. Have we embraced the concept of the “dignity of risk” and the “right to failure”? “Chronically normal people” (CNP’s !), or people who have not been psychiatrically labeled, are allowed to make dumb, un insightful decisions all the time in their lives. My favorite example is Elizabeth Taylor who just got her eighth divorce. We might say, “She lacks insight! She is failing to learn from past experience!” However, when she embarks on marriage #9, no SWAT team of nurses with Prolixin injections will descend upon her “in her best interest”. But just imagine if a person with a psychiatric disability were to announce to their treatment team that they were about to get married for the 9th time! People learn, and sometimes don’t learn from failures. We must be careful to distinguish between a person making (from our perspective) a dumb or self-defeating choice, and a person who is truly at risk.

These are just some suggestions about how to create environments in which it is possible for people to grow.

Then, as we build these hope filled environments, we must recognize that people with psychiatric disabilities do not “get rehabilitated” in the same sense that cars “get tuned up” (Deegan 1988). We are not passive objects which professionals are responsible for “rehabilitating”. Many of us find this connotation of the word rehabilitation to be oppressive.

We are not objects to be acted on. Rather we are fully human subjects who can act, and in acting can change our situation. We are not objects to be fixed. Such a connotation robs us of our own sense of autonomy and self-determination. It places responsibility in the wrong place. It perpetuates the myth that we are not and cannot be responsible for our own lives, decisions and choices.”

Your concerns, these suggestions and the complete change in the delivery of support services as defined by the “Village Concept” of care are truly the only solution to a mental health system that the taxpayers of California are entrusting local government to deliver to those with serious psychiatric disabilities in our community.

Sincerely,

The Board of the National Alliance for the Mentally III – Santa Cruz County