

The Downside of the Family-Organized Mental Illness Advocacy Movement

Sylvia Caras

Groomed, mature, confident, the family advocate articulated from the podium, carefully and with strength: "The horror of mental illness . . ."

"Horror."

I felt as if a laser were searing me, shattering my sense of myself as a member of a caring family.

"Horror."

What I heard was "the horror of your illness"—"horror . . . you."

"Horror . . . horror . . . horror."

The speaker was telling me what parents felt—"horror"—what my children wouldn't tell me—"horror"—and what my sister feared.

I felt an intruder. Afraid to speak, I tried to make myself outside as small as I felt inside—shamed, vulnerable, unwanted.

I imagined shaking hands with the speaker, that family advocate. I imagined her wanting to wipe off the touch of my horror on her skirt.

We were at the plenary assembly of a federally sponsored annual meeting reporting the results of innovative community mental health programs. I sat with 250 other invited guests at the Holiday Inn and listened as, again from the podium, another mother brandished "the tragedy of mental illness." At the word "tragedy," many in the audience sighed together in shared grief. Even though my own family was not like this, I pictured visiting my parents, reaching out for an embrace, and

Editor's Note: This month's column is in two parts: a personal account and commentary from Sylvia Caras, a disability rights advocate who finds that the family-organized mental illness advocacy movement can be stigmatizing and patronizing, and a response from William Emmet, a family member and board member of the National Alliance for the Mentally Ill.

watching their hopelessness as they greeted their "tragedy." I felt so dishonored.

That was in the fall of 1993. Until that time I had been facilitating a local mood and melancholy support group. I had attended local mental health system improvement meetings and even a few national conferences. I had met friends and families who were caring and supportive. But I was new to national advocacy, and that meeting at the Holiday Inn was my introduction to the powerful, well-funded mental illness lobby of families whose mission is to make the family issues central, to reveal the family pain, to spare the family image.

Later I learned how in 1979 families had organized to protect themselves from blame, how they had put forward a biological model of disease, and how they were now lobbying, with the pharmaceutical and medical industries, for research dollars to support the biohealth approach to managing behavior.

Now, in 1998, I've served on boards and led more groups and gone to

more conferences. Now I have seen how families' relief at finding exoneration has become an ambition to mediate social disarray. I've felt their shunning since I started publicly to reformulate what I thought about my own 1987 experiences with the mental health system.

The family advocacy I watch seems to focus on the family's misery, the family's despair, the family's efforts and frustrations, the family's engrossment with itself. Despite a convincing collection of serious diagnoses, hospitalizations, and treatments, we who get on with our lives and offer ourselves as examples of recovery are dismissed as not really ill, as exceptions, as misdiagnosed. Our experience is not valued.

Instead, the idea of the loved one that is held on to is of someone who is terribly, terribly sick—without hope. To me, this perspective is an example of self-absorbed collateral family members intent on stilling the patient's voice: the primary voice. By suppressing this voice with, if needed, handcuffs, restraints, sedation, or seclusion, family advocacy has had a chilling effect on the civil rights of individual loved ones. These violent interventions make me wonder what this loved voice might reveal if it were allowed to speak.

But the voice is co-opted by family advocates who don't consider the impact of their patronage on the loved ones, discounting the loved ones as unaware of what they need. Who is well served by this reproduction of stigmatizing, patronizing sympathy, these repeated images of disturbance? I know I am wounded by the advocates' language.

What I want from those who love me is not sympathy. I want my family members to welcome me, as me, just

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for being me. And I want to hear the language of respect.

To paraphrase Weick (1), words express and interpret; words include and exclude; words matter. Verbal categories mold thinking; verbal categories can contribute to integration or to discrimination. Family advocates shape and use words and ideas in ways that seem to me to change the meanings so much that for the sake of clarity, different words should be used.

Family advocates regularly breach privacy by telling their children's stories. These stories are not family property. They belong to the primary patient, not to the family. But family advocates tell of their loved one's labels and behaviors.

So urgent are the wishes of active family advocates for personal relief that they use their children's voices, disallow independence, and sensationalize their children's antisocial activities. I have never heard family advocates assert that they have informed consent to tell these stories. I have rarely seen parents beside their own child, testifying together in advocacy for the same goals.

Not all families are so authoritarian. But authoritarian families curtail growth with coercive interventions and a flourishing fundamentalism, us-

ing fear and polarities, displaying no tolerance for ambiguity, no flexibility, accentuating the nonnegotiable authority of the medical and psychiatric professions. In any social setting, rules must be learned; then rules must be tested and questioned and retested to be sure they are still applicable; that is the way of maturing.

Some families understand the many parts and obligations of parenting. Some family members seem to be grieving for who their loved ones were at some earlier time while objecting to who those loved ones actually are now. Perhaps the hardest, arguably the most important, part of parenting is to trust the child enough to let go. Even children with disabilities deserve the chance to be let go.

Moving counter to social trends of diversity, globalization, and openness, the family advocacy movement fragments, segregates, isolates, imposes secrecy, shames. I believe today's mental health approaches will be remembered along with the Salem witchcraft trials as a dishonorable scapegoating of transformative experiences.

As a person with a disability, what I want is acceptance. When you speak of my life as a tragedy, you are robbing me of my dignity. I want you to see my

potential, and to stop sensationalizing the family's despair. I don't want to uplift you with my pain. If you can't love me as me, or accept me, or respect me, at least create a life for yourself separate from me. Today's family-organized advocacy stigmatizes your loved one—me, you, all of us.

Instead of seeing disease, listen.

Instead of discussing medication and noncompliance as an inability to understand one's condition, listen to your loved one's objections.

Instead of thinking how you gain when your loved one takes medication, think of what your loved one loses.

Instead of forcing your loved one into unwanted treatment, attend to what is wrong with treatment services, attend to why services are refused. Listen to the experiences.

Put the well-being of your loved ones above your wish to fence them off.

Truly listen, for just a moment.

Find the worth—the flair, the ingenuity, the ability.

See that worth, not disease.

Hear hope, not horror.

Listen. ♦

Reference

1. Weick KE: Sensemaking in Organizations. Thousand Oaks, Calif, Sage, 1995, p 132

A Family Advocate's Reply

Why Consumers and Family Advocates Must Work Together

William Emmet

One of the things that the 1990s will surely be remembered for, in terms of U.S. mental health policy, is the growing voice of people with se-

rious brain disorders such as schizophrenia, bipolar disorder, severe depression, and severe anxiety disorders. Consumers are increasingly speaking out, revealing their own stories, advocating for change, and assuming leadership roles in mental health organizations.

The growing strength of the consumer voice is a development to be celebrated. It is the voices of consumers that have contributed so strongly to the push for services aimed

at recovery and a high quality of life. It is their voices and stories that are helping to chisel away at the formidable edifice of stigma and discrimination that still casts its shadow on U.S. and world culture. It is their voices that remind us daily that mental illnesses are real and affect real people.

The National Alliance for the Mentally Ill (NAMI) began 20 years ago as a group of parents seeking services, justice, and hope for their adult children with extremely disabling brain

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disorders. In 1998 NAMI is itself being strengthened by the growing role of consumers. Consumers increasingly are joining family members in NAMI's mission. More than 20 percent of our membership consists of consumers. Nearly half of the state campaign coordinators from our Campaign to End Discrimination are consumers. Four of 16 members of our national board of directors are consumers. At least 25 percent of the staff of NAMI are consumers. Indeed NAMI can fairly claim to be the largest single consumer organization in the country.

A powerful force has been created by consumer and family voices joining together. This advance reflects the success of pioneering consumers, who had the courage to speak out in the face of overwhelming stigma and discrimination. It also reflects, we believe, the significant improvements in treatments that we have witnessed in the last decade, which have made significant recovery a real possibility for ever more consumers. And it builds as well on the success and courage of family members who themselves overcame blame and isolation to put their imprint on the system.

Unfortunately, the courage and success of consumers and their families are too often subsumed by the polarizing misinformation, demagoguery, and outright cynical manipulation of some funding agencies, service providers, and now managed care organizations. The preceding essay embodies much of this negativity.

NAMI, because of its success, is a target of much of this animosity. It is unclear who gains from the tendency to demonize, but it is certain that we all stand to lose much in the time, energy, and credibility expended in the process. It is time for the mental health community—providers, administrators, policymakers, families, and consumers themselves—to end this destructiveness, and for all of us to aim our efforts at reforming the persistent and enormous problems that we all face.

And the problems are enormous. Just recently a large study showed that more than half the time consumers with schizophrenia fail to receive core treatments and services that have been shown to work (1). The study

also showed that consumers are over- or undermedicated; that depression and side effects are ignored; and that rehabilitation, family support, and outreach are all but absent.

It is also time to stop the broad-brush attacks on families. Although there will always be some family members and others who are not pure in intention or action, most families do not disrespect a loved one who has an illness and disability. Quite the opposite is true. The research literature has shown time and time again that families are the primary care providers for most people who suffer from the severest and most disabling mental illnesses. Most



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families work harder than anyone, except consumers themselves, for the consumer's optimal recovery and quality of life. Most families are not co-opted by the pharmaceutical and medical industries. Most families do not patronize, stigmatize, or otherwise demean their loved ones. Yet it is not inconsistent with that picture to say that a family suffers the pain of a loved one's illness, even as that loved one makes the journey toward acceptance and hope for recovery.

The time has long since come to end the silly fiction, perpetuated in the accompanying essay, that illnesses such as schizophrenia or bipolar disorder or severe depression can be categorized, with equal accuracy, as simply social disarray. They are real illnesses, and access to treatment for them is critical for consumers' well-being.

We also need to take the harsh reality of the most severe mental illnesses

into account. Schizophrenia and bipolar disorder can diminish insight into one's own illness. Hallucinations, delusions, and agitation are prominent symptoms of these brain disorders. When untreated, these disorders can sometimes lead to disruptive and even violent actions. And usually a family member is the victim of such attacks. As a community, families and consumers together must face this sad reality of mental illness. Even as we promote recovery, consumer involvement, and indeed the preeminence of consumer wishes, it does not do any consumer a service to deny illness and treatment. As we well know, such a course leaves too many consumers on the streets, in jails and prisons, or dead.

Our continued infighting as a community of individuals concerned about those with serious brain disorders hampers the effectiveness of our advocacy. And it plays into the hands of managed care organizations, funding agencies, and providers who would rather not invest the resources to provide the best, science-based treatments and services for this population. Too many such organizations shamefully use consumer-survivors as window dressing for policies that are in their own fiscal interest.

There is no question that NAMI's own evolution as a consumer and family organization has not always been easy and is far from complete. Although NAMI has a distance yet to travel in fully integrating the voice of consumers into our organization, it is a challenge that we cherish and will work hard to meet. We believe that we have come a significant way along this road. We have a vision of the future in which consumers and families are no longer divided and conquered, but are a united voice—as are most families—for ending discrimination against people with brain disorders and promoting the best recovery for every person who develops such an illness. Together we shall stand, stronger than ever before. ♦

Reference

1. Lehman AF, Steinwachs DM, survey co-investigators: Patterns of usual care for schizophrenia: initial results from the schizophrenia patient outcomes research team (PORT) client survey. *Schizophrenia Bulletin* 24: 11–19, 1998

