

## The Downside of the Family-Organized Mental Illness Advocacy Movement

By Sylvia Caras

Groomed, mature, confident, the family advocate articulated from the podium --- carefully, 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”

I heard “the horror of your illness”, “horror ...you,”

“horror,” “horror,” “horror”

The speaker was telling me what my parents felt,

“horror,” “horror,”

what my children wouldn't tell me,

“horror”, “horror,”

what my sister feared.

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

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

We were at a plenary assembly of a federally sponsored annual meeting reporting the results of innovative community mental health programs.

I sat with 250 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 conjectured visiting my parents, reaching out for an embrace, and 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 family who were caring and supportive. But I was new to national advocacy and that was my introduction to the powerful, well-funded mental illness lobby of families whose mission it 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 behaviour.

Now, in 1997, I've served on boards and led groups and gone to conferences. Now, I have seen the families' relief at finding exoneration become an ambition to medicate social array. 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 grossment 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, exceptions, misdiagnosed. Our experience is not valued.

Instead, the idea of the loved one that is held on to is of one terribly, terribly sick -- without hope. To me, this 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, seclusion, family advocacy has a chilling effect on the civil rights of individual loved ones. Those 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 (these loved ones) themselves 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 for being me. And I want to hear the language of respect.

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 behaviours.

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 anti-social 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, using fear and polarities, displaying no tolerance for ambiguity, no flexibility, accentuating the non-negotiable 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 they remember the 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 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 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 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 creat 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 non-compliance as an inability to understand one's condition, listen to your loved one's objections.

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

Instead of forcing your loved one into unwanted treatment, attend to what is wrong with 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.

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NARPA – National Association for Rights Protection and Advocacy