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. . . Over the last 25 years, I have worked in mental health as a professional, administrator, clinician, teacher, and now at the National Mental Health Association. I would say even though the NMHA was founded by a consumer in 1909, it’s not an old organization; in many ways it’s a brand-new, revitalized, expanded, more aggressive organization.

I’m joined here by a number of my board members: Yvette Sangster, Jon Brock, Margaret Donnelly, who are working to make consumer empowerment and consumer issues central to our work. A lot of the thoughtfulness we do have — and that needs to be expanded a great deal — is a result of our relationship initially with the National Mental Health Consumers’ Self-Help Clearinghouse.

Six years ago, when I came in, we were down and out and poor and small at the national level. We had some powerful and strong affiliates. We’re at a cusp time at our organization, where we’ve built up expertise and credibility in the field, and have a substantial program and staff resources. Now we need to mature into an organization that will hit the ball out of the park. I don’t see us taking over the consumer movement; I think the consumer movement might co-opt the NMHA.

I’m glad the tone of all the speakers was about outreach and inclusion and finding common ground. NMHA is poised to listen and learn and grow that way. . . .

We [at the National Mental Health Association] feel very good about just about everything in the plank report.

What I liked most about today were the messages about outreach and inclusiveness. I think that’s so important. I think in the mental health community at large — and I say this humbly — the consumer/survivor community has shot itself in the foot by being so much about “us” vs. “them.” Knocking down some of the barriers between us is a great idea; that is a central value for the NMHA.

We were created by somebody with a severe mental illness who survived abuse in the back wards of state hospitals and worked until he died to start a national movement that would stand up for the rights of people with mental illnesses. The organization he started merged with a group of Quakers after World War II who were conscientious objectors and who had some of the same attitudes about justice, and who had worked in military hospitals during the war. The education branch of the American Psychiatric Association that was interested in changing the public’s attitudes about mental health [also got involved]. Those groups became part of the modern-day NMHA.

I would like to think we are part of the consumer/survivor movement. We’re in a place where we have a lot more work to do than we have taken on in the past. It’s important to include family
members and citizens who are compassionate. I don’t think the civil rights movement would have been the civil rights movement if it only included African Americans, if black leaders didn’t pull together with people from academia and the unions and Jewish religious communities. So much strength came from that. It sends a message about outreach and us, instead of us and them.

I agree with some caveats about the formation of a national consumer/survivor organization. It’s a great idea if it’s doable, if the process of its creation reflects the kind of dialogue and working together that has happened here today, but not if it becomes a war between consumers and survivors, pissing away important energy that is needed to work on issues.

My Number One job is to build the NMHA movement, where consumers can find a legitimate, real place to work and to lead. I think that, regardless of what happens in terms of a presence in Washington and the national consumer/survivor movement, we have not yet begun to scratch even the surface of influencing other organizations to carry our water about justice, rights, and compassionate responses to people who are vulnerable. At the NMHA we have a director of consumer advocacy. We have come a long way, but there is so much farther to go. The NMHA has re-created itself. There are a lot of wonderful people, some of the coolest people I’ve met in my life, who work there. We have a large organization to contend with. We have to break down barriers between [government] departments and consumer advocacy. There’s a lot of pressure on Brian [Cooper, director of consumer advocacy], and a whole lot of growing and struggling ahead of us as an organization.

To tell you the truth, I think the Bazelon Center, NAMI, the NMHA, and the Federation of Families for Children’s Mental Health hold a huge potential not acted on to the extent it can be. I think the consumer/survivor movement could have a great influence on us and should not be let off the hook at all. I think it’s logical and strategic to target the existing organizations that have been created to work on behalf of people with mental illness or people who are labeled with psychiatric illnesses; that should be energetic.

I’m an MHA guy because I believe in mental health; I believe the most important thing in life is the quality of that life as it is experienced by individuals.

In terms of the targets of our advocacy, the Center for Mental Health Services is an extremely important entity. We have some really wonderful people who have worked very hard to make the investment pay off for consumers/survivors. I think Neal Brown [Chief of the Community Support Program Branch] is a terrific asset to that agency and so are a number of his colleagues. It’s really pitifully small and poorly positioned within the Department of Health and Human Services and within the world. The dollars that should be at CMHS should be multiples of what’s there. The organization is understaffed. Some of us bitch about what we think is not enough strategic planning or inclusion or thoughtfulness. I think what they pull off given the resources and political binds they are in is remarkable. But we should expect more from CMHS and we should expect a hell of a lot more from the U.S. Congress, not just dollars. We should ask for visibility, respect, and inclusion in social policy at a level that’s not there.
I think there is so much power and influence and knowledge within the National Institute of Mental Health, but a lot of it is being whizzed away. So little is being done to bring the science forward, and to turn it into benefits for consumer/survivors and families. We really need to pay attention to that, through a centralized consumer/survivor office in Washington or by demanding that our existing organizations be more articulate.

It is important to tell the truth about what our leaders really see. Nobody talks about the fact that [studies show that] one out of every four African American men is going to be incarcerated, or that a hundred thousands kids are incarcerated. There is very little pubic dialogue about mental disorders. In many ways we keep substance abuse and the plight of the junkies out there at arm’s length. The consumer/survivor movement that I envision would have all these things on its mind and would worry over them and would bring leadership in those areas also.

I liked so much what was said here today. Sally [Zinman] struck a chord, ironically, when she talked about the NAMI family members in California putting out the messages saying, don’t use [fear of] violence to get this law [broadening the commitment standards] passed.

Some organizations have conflicts with NMHA or Bazelon. In NAMI’s case, Fuller Torrey has done a lot of damage.

There is a controversy about parity. Of the two parity laws, Representative Roukema’s in the House is wonderful and provides for full parity, whereas Domenici-Wellstone’s is flawed and diagnosis-based. But I believe, contrary to what the plank report says, that we should not automatically dismiss it. At the national level, we’ve made a deal with ourselves that, if we can get the language expanded to include all kids with mental health needs, we’ll fight for that. To be black and white about any policy issue is dangerous, in my mind.