

Chapter 10

Finding and Using Our Voice: How Consumer/Survivor Advocacy is Transforming Mental Health Care

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Abstract In the past 30 years, the consumer/survivor movement has been developing a consensus national advocacy voice. This chapter reviews three important components in the development of this strong and unified national consumer/survivor Voice: (a) A consensus by the movement that recovery, wellness, and complete community integration are attainable goals for persons labeled with mental illness in contrast to the traditional negative prognosis of maintenance during a life-long disability.; (b) Training programs in advocacy designed and carried out by consumer/survivors, such as Finding Our Voice.; (c) Building the National Coalition of Mental Health Consumer/Survivor Organizations, which amplifies the voice of consumer/survivors at the state and federal level.

Introduction to the authors. This chapter is written by two authors who found our Voices (“Voice” with capital V is used when we are referring to a person’s uniquely personal Voice or that of the consumer/survivor movement) and recovered a meaningful place in the community after being diagnosed with schizophrenia. Dan Fisher became a psychiatrist, founded the National Empowerment Center, was appointed to the White House New Freedom Commission on Mental Health, and was able to use the Voice of the consumer/survivor movement to ensure that the Commission report focused on recovery. Lauren Spiro became a psychologist, a senior manager in a non-profit mental health agency, a CARF (Commission on the Accreditation of Rehabilitation Facilities) surveyor and advisor, and co-founded two non-profit mental health corporations before being hired as the first staff person to represent the national coalition in Washington, DC.

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After long debates, our movement has settled on the self-description, “consumer/survivor.” We acknowledge that we have all had an interruption in a major life role, however, “consumer” refers to those still using services and “survivor” refers to those who have survived the mental health system.

10.1 Introduction to the Chapter

This chapter consists of three essential elements in the evolution of the consumer/survivor movement. The first part of the chapter deals with the replacement of the medical model of mental illness with an empowerment paradigm of mental health recovery. On both an individual and collective basis, there has been a historic shift in thinking by a critical mass of persons labeled with mental illness from considering ourselves the object of neuro-chemical forces to being empowered agents who are finding the freedom to begin to creatively and effectively run our own lives. This paradigm has emerged through self-help groups in which mental health consumer/survivors have been sharing our lived experience of personal recovery. These shared recovery experiences clearly contradicted the professionally promoted misconception that people could never recover from a serious "mental illness." The second part of the chapter highlights a training program called "Finding Our Voice." This training informs and inspires consumer/survivor advocates, newly freed from the feeling of being the object of neuro-chemical forces, to gain a Voice in the running of their lives. The third part describes the coming together of empowered advocates who began by forming statewide consumer/survivor-run groups, which developed into a national coalition of consumer/survivor-run statewide organizations. These large-scale groups enable the Voice of consumer/survivors to be amplified at the state and federal levels, positively impacting national policies and legislation affecting everyone's recovery. The unifying theme throughout this chapter is the evolution of the Voice of consumer/survivors. We will trace what qualitative research tells us about the emergence of a person's Voice, and how that Voice enables the person to become the architect of their recovery and their life. In a similar manner, the consumer/survivor movement itself has built a Voice, which has powered its evolution into a force for transforming the mental health system and society into a more humane, inclusive, and respectful place to live.

We will share our experiences of advocacy as well of those of other advocates. The importance of consumers finding our Voice is highlighted by the New Freedom Commission Report, which calls for a recovery-oriented, consumer-driven system. To fulfill this Commission goal, however, there needs to be a greater number of effective, informed consumer advocates. This chapter will trace how individuals and groups of consumers have been finding their Voice and using that Voice over the last 30 years in the United States and around the world to promote a recovery-based system and culture. This feat is particularly remarkable in light of how resistant the traditional system is to such a change.

What do we mean by Voice? Just as an artist needs to find their unique artistic Voice to express their creative work, each person, needs to find their unique life Voice to enable them to create a meaningful life, based on their personal values and principles. When people who have developed a life Voice are in emotional distress, they know how they feel and are able to communicate those feelings to those around them. This skill enables both the person experiencing emotional distress as well as those supporting the person to think effectively about what the person needs, to support the person in making informed decisions, to create reasonable

accommodations if needed, and to ensure that conditions arise encouraging the person to resume meaningful roles in his/her life. It is not surprising that people in severe distress hear voices, for it seems that in the absence of hearing one's own Voice, we create substitutes for it. Just as John Nash, in the book *Beautiful Mind* (Nasar, 1999), searched for guidance in random numbers in the newspaper, many of us, in periods of severe distress, have looked outside ourselves for a magical message telling us what to do. Dan was convinced that everyone except him received instructions about what to do each day. He thought the instructions were shoved under everyone else's door each morning. So our life Voice is a reflection of the degree to which we are able to influence the opinions of others and affect the important decisions in our life. Without such a life Voice, we feel compelled to seek guidance for our decisions from outside ourselves.

Master Eckhart, a medieval mystic, captured some of the meaning of Voice when he wrote, "the soul has something in it, a spark of speech that never dies . . . which is untouched by space or time" (Evans, 1924). Dan and Lauren feel this understanding resonates with their lived experience. Dan found that even during his 1-month period of muteness, he experienced a spark, an ember inside which continued to be vigilant, yearning for an opportunity to speak, if only he could find a safe, trusting relationship. Lauren, though overwhelmed with 'delusions' for over 6 months always remained keenly aware of a core deep inside her that was whole and intact despite all the madness swirling around her. She yearned for safety, someone with whom she could confide in to help clear up the confusion.

One element of finding one's voice is to recognize it is always inside even though we may not express it. Martin Buber said that this spark or Voice is central to our decisions, "for the genuine spark is effective in the single composure of each genuine decision" (Buber, 1965). Having a Voice, therefore, means we have the power to make decisions and run our own lives.

How do we gain our unique, life Voice? Does the consumer/survivor movement embody a Voice? Relationships are essential to the healthy development of one's Voice. I am because you are. As Fichte said in 1797, "The consciousness of the individual is necessarily accompanied by that of another, of a thou, and only under this condition possible." (as quoted in Buber, 1965, pg. 69). This view also corresponds to the philosophy of Ubuntu, a native South African concept. In Zulu, a saying, which epitomizes Ubuntu is, "a person is a person through other persons." Mental health recovery does not happen in a vacuum and it does not happen "to" us. It happens within us as a result of healing, loving relationships in which we find safety to reveal our genuine Voice.

Why is it so important to us individually and collectively to find and to express our Voice? Because our existence depends upon it. Without our Voice we do not experience our life. We can only go through the motions and observe from afar lives that others are living. We are alienated from our deepest self.

Locked in a seclusion room at the age of 16 with a diagnosis of chronic schizophrenia, Lauren thinks back, was a metaphor of her life at that point. She felt trapped, alone, caged, and desperately wanted to belong, to feel she had a

meaningful role in the community. Her heart and values pulled her one way, while the culture around her pulled in the opposite direction – toward conforming to roles and principles that did not reflect her deepest yearnings. She became lost in the void between these two overwhelmingly conflicted worlds that never ceased tearing her in opposite directions. Lacking resources and supports that she could trust to assist her in understanding and reconciling these opposing forces, the tension built until it boiled over. The boiling-over bypassed the usual cognitive channels, and instead came out as “delusions.” The content of the “delusions,” however, reflected verbatim the very conflict she was trapped in. She needed to feel that her life mattered, that she mattered; she needed meaning and purpose that genuinely reflected her Voice in a world that seemed very irrational. And she could not find it. One night – everything changed. That sleepless night in a 9 × 9 foot white barren cell with bars on the windows, she decided that she could no longer bear the pain and agony (of “schizophrenia”) and gave herself permission to end her life – to end the torment. Ironically, that decision led to the opening of a new door. She realized that if one option was death, then it made sense to put every ounce of energy she had to focus on finding a life worth living. To find that life she knew she had to reconstruct herself and stop listening to the endless screaming voices and images in her head. She thought that that would make surviving another day possible, bearable. That night, unbeknownst to her at the time, was the beginning of her road to recovery – the beginning of the journey of discovering who she really was.

Dan had to go to the depths of his existence to decide if his life was worth living. Having been a dutiful son who carried out his family expectations, he found himself at age 24 without any sense of his living for himself. He had achieved much, having obtained his Ph.D. in biochemistry and secured a job at the National Institutes of Mental Health. But he was only living for others. He had no idea how he felt. He was pure thought and no feeling. His heart had stopped talking to him. He was only aware of being too angry to go on as he had gone on. Like Martin Luther he said to himself “this is not I!” His biggest step of recovery was to say to himself, stop acting and just be. To do so he stopped going to the job in the Laboratory of Neurochemistry where he was discovering the chemicals responsible for feelings. The chemicals did not define his feelings. The job was not him. He stopped talking, because the words were always ones he used for others. He even stopped moving because all movements seemed alien, not his own. From this very quiet, self-observing place, he decided he would only emerge when he could express the Voice that was uniquely his own. He was hospitalized in Bethesda Naval Hospital in what was described as a catatonic psychosis. Gradually the lowest ranking aides, the corpsmen reached him through nonverbal communication. But his next step in recovery occurred when he could transfer his anger from a stubborn no to life to a yes. It came when he was trapped in seclusion and vowed that he would humanize the mental health system so that everyone similarly suffering could recover. Then his anger became his passion and purpose. This was his deepest Voice speaking to him. It seems the only way for Dan to be freed from the delusion that others were controlling his life, was for him to truly gain a Voice by which he controlled his own life.

Professors Harrop and Trower of England have concluded that, "the life long experience of being intrusively controlled and of having an alien not an authentic (self-constructed) self, and the concomitant loss of a center of initiative, is likely to cause profound dysfunction in the normal operation of consciousness . . . and account for some of the anomalous experiences of psychosis." (Harrop & Trower, 2003, p. 85). In other words, if a person is not able to develop a strong, centered, authentic self they have the types of disturbances of consciousness, which can cause them to lose touch with reality and become psychotic. They propose that development and recovery are facilitated by self-construction through relationships.

10.2 Finding and Using Our Authentic Individual Voice

10.2.1 *Empowerment Paradigm of Recovery and Development*

One of the essential elements in gaining a Voice is to understand that the traditional, chronic disease model for mental health issues has not been a useful construct for many persons who have recovered from states of severe emotional distress. The disease model is not useful in describing how people are able to recover and develop into highly competent and skilled leaders in the recovery movement and elsewhere.

The chronic disease model conceptualizes mental health issues in the same manner as other medical diseases, such as diabetes. But unlike diabetes, this model considers the person's sense of self to be permanently diseased. This explanation incapacitates the very source of a person's empowerment and agency for their recovery. Perhaps the greatest weakness of the chronic disease model is in its description of the most dramatic form of mental illness, schizophrenia. Dr. Richard Bentall (1990) has pointed out that schizophrenia fits few of the characteristics of a disease because:

1. There is such great variability in the symptoms of schizophrenia
2. Diagnoses of schizophrenia frequently overlap with bipolar disorder or major depression
3. There remains great debate over the causation of schizophrenia
4. The outcome and course of schizophrenia is highly variable and unpredictable
5. There is no treatment found to work for everyone and, in fact, each person needs to play a role in designing their own treatment

These findings have led Dr. Bentall to conclude that schizophrenia is a disease with "no particular symptoms, no particular course, no particular outcome, and no particular treatment." (Bentall, 1990, p. 33).

Despite all this variability, schizophrenia is still widely studied through a narrow disease paradigm. Its onset is typically in late adolescence. In the second World Health Organization study of schizophrenia in nine countries, 83% of persons with schizophrenia had their onset in the age range from 15 to 35 (Jablensky and Cole, 1997). The chronic disease model does little to explain why schizophrenia invariably

appears during adolescence. Furthermore, the medical model places agency outside the person. The condition is to be primarily controlled by external agents such as the medication and the doctor, not by the person themselves. The first and second WHO studies also concluded that the rate of recovery from schizophrenia was much higher in the developing countries than in the industrial countries (Jablensky et al., 1992). "Patients in developing countries experienced significantly longer periods of unimpaired functioning in the community, although only 16% of them were on continuous antipsychotic medication (compared to 61% in developed countries)" (Jablensky and Sartorius, 2008.) The chronic disease model is found lacking in light of these findings.

As an alternative to the chronic disease model, NEC has proposed an empowerment paradigm of development and recovery, illustrated in Fig. 10.1, which is discussed in greater detail by Fisher (2008).

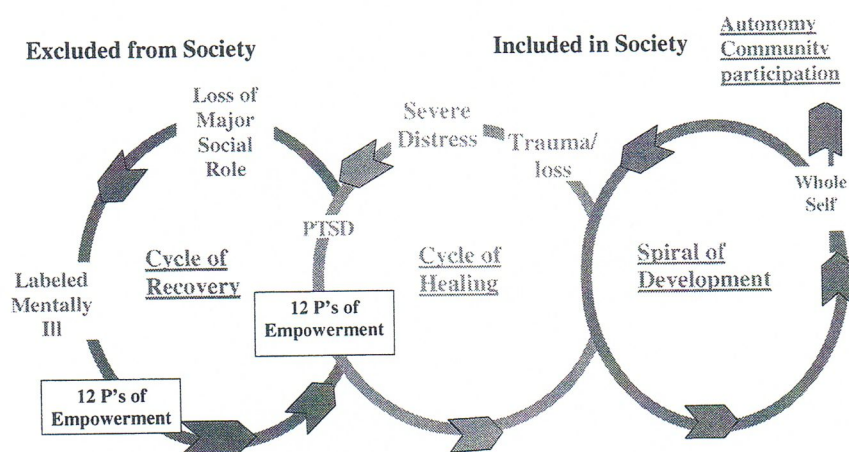


Fig. 10.1 Empowerment paradigm of development, and recovery © 2008 National Empowerment Center

The circle on the right, we call the spiral of development. Though the constraints of using a two dimensional format require us to represent development as a circle, we consider development as a spiral of increasing growth of a person's Voice and Self as they pass into adulthood. This development is nourished by many of the principles of empowerment and wellness (as discussed below) we have found vital to healing from trauma and recovery from what is called "mental illness." Through construction of a strong Voice and a sense of Self, a person is able to establish meaningful relationships, love, and work. Trauma, loss, and insufficient supports, knowledge, and resources may inhibit development and result in severe distress and anger. If the person experiences empowerment and people who believe in them, they can heal and return to their process of development. If they are unable to establish personal, trusting connections, the person feels isolated, powerless, disconnected,

and humiliated. Understandably, this often results in a protective strategy of shutting down and their experiencing that their heart no longer speaks to them. In the process of disconnection from one's heart, they are vulnerable to hearing Voices and losing their major social role. At that point they enter the red circle on the left. They are labeled mentally ill and marginalized from society. Then they need to go through recovery to return to their development, which is much more arduous and lengthy.

Harrop and Trower have been developing a similar theory of psychosis. They hypothesize that the self-construction is essential to healthy development. The self-construction depends on a combination of expressions of oneself in the world, which we are calling Voice combined with positive acceptance and understanding by the significant others, we would call people who believe in the deepest you. From this hypothesis, they propose, "The main prediction of this study was that a typical sample of people diagnosed as having schizophrenia [and they are quite critical of this diagnosis] would report emotional episodes which would clearly demonstrate blocks to self-construction" (Harrop & Trower, 2003, p. 96). They go on to do interviews with 21 persons labeled with schizophrenia and show that their hypothesis is validated. In a majority of cases there is a great deal of suppressed anger, which they interpret as the result of blocks in self-construction. A Jungian psychiatrist, Dr. John Weir Perry, came to a similar conclusion. He found that psychosis was part of a person's reorganization of their deepest self such that they could return to their development in a more integrated fashion (Perry, 1974).

Another important support for the connection between lacking Voice and psychosis is the work of Seikkula and Trimble. They propose that psychosis results when people are trapped in monologue. They recommend systems, network therapy to assist persons at their first psychosis in reestablishing dialogue with the significant persons in their life. This approach has been very successful in not only bringing young persons out of psychosis, but also doing so without hospitalization and without long-term disability (Seikkula and Trimble, 2005). Persons are trapped in monologue, as Dan and Lauren were, may be unable to speak with their authentic Voice from their heart.

10.2.2 Developing More Consumer Advocates Through Finding Our Voice Training

When the New Freedom Commission Report (2003) was released in July 2003, the White House gave it little recognition or support, never publicly announced it or advocated for the legislation needed to implement its recommendations. NIMH has similarly distanced itself from the concept of recovery, which is the vision of the report. Given such lack of support at a federal level, it was clear that consumer/survivors, whose very lives were at stake, needed to organize to change the system. There is, however, a drastic shortage of consumer/survivor advocates. Therefore, the most important next step in developing consumer-driven policies is the development of a large number of consumer advocates. The

National Empowerment Center (NEC) has begun piloting such trainings, which are called "Finding Our Voice" training. The training is based on 12 principles of empowerment, which NEC has derived from interviewing of a variety of experienced advocates. The goal of the training is to develop advocates who can amplify their voice to effect change and assist other consumer to develop their Voice.

These 12 principles of empowerment all start with the letter P and are best introduced in a sequence as shown in Fig. 10.2. Following is a brief summary of these principles of empowerment:

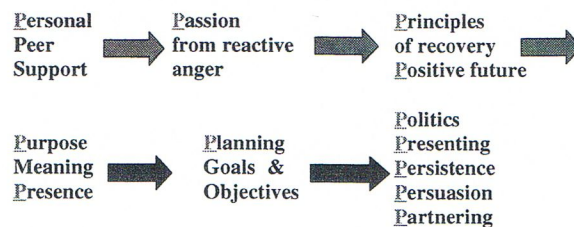


Fig. 10.2 How the 12 Ps of empowerment lead to recovery and transformation

1. *Personal connections*: Perhaps the most important first step in becoming an empowered advocate is to get together with other advocates.
2. *Passion*: It is essential to transform anger and resentment into passion.
3. *Principles of recovery*: Outline a recovery-based system which is consumer-driven and self-determining on the individual and systems levels, centered on peer support and self-help which enables people to achieve full community participation, or social inclusion, through valued roles (e.g., worker, student, parent, tenant, etc.).
4. *Positive view of the future*: Hope needs to reside deeply, insistently inside one's being to inspire oneself and others to hope again.
5. *Purpose*: Many of us have had to find a purpose to anchor and invest in our lives, rather than passively or actively seeking an exit. Empowerment is about finding purpose because having a sense of purpose empowers our life.
6. *Persistence, perseverance, and patience*: Never give up, never quit . . . With enough persistence anything can come to be . . . what we believe can become reality.
7. *Presence*: Capacity to quickly, positively impact people through pride, poise, and politeness.
8. *Persuasion*: Capacity to get people to see your point of view through discussion.
9. *Practical prioritized advocacy plan which needs to come from a well-prepared participant*: If you are going to change policies you need a concise, prioritized plan, which you can propose.

10. *Public presenting*: Learning how to present your self and your ideas to others is another vital aspect of individual and collective empowerment
11. *Partnering through mediating, and negotiating*
12. *Politics*: Politics is the process by which groups of people make decisions

10.2.3 The Purpose of the Training

The purpose of the training is twofold. First there is the development of the person's individual voice. This means going through the stages of connecting personally to one's self, to the group, to transforming our anger into passion, and to finding purpose. The next phase is to learn about how to work together in a group.

For many consumers this skill has not been well-developed because as discussed previously, we have had an interruption in our development in which we experienced blocks in our self-construction; many of us experienced being trapped in monologue, which has hindered our ability to develop the skills needed to negotiate with others. Thus, participants are taught the skills of engaging in and facilitating dialogue to achieve their goal of learning to collaborate in a group. Then they finish by developing a plan together, and each person makes a presentation to the group.

Following is an outline of the 4 days training:

Day 1: Finding our personal Voice

Module I: Introduction to the program; including creating group comfort zones; introductions are done by all participants and presenters as a warm up exercise, in a circle.

Module II: Personally connecting in small groups.

Module III: Transition to passion from anger and fear; small groups to discuss the meaning of this transition for participants.

Module IV: Review principles of recovery and community building; individual purpose from passion + principles + positive future = Passionate, Principled purpose. Dyads coach each other on getting in touch with their passionate purpose and draft a paragraph on it.

Day 2: Learning to engage in genuine dialogue

Module V: Stages of dialogue; moving from discussion to generative dialogue.

In the large group, practice what participants feel are the most important elements of an advocate; clarify the nature of generative dialogue and give feedback to the group on how they are doing in moving from discussion into dialogue.

Module VIa: Personal to political; a facilitator introduces the priorities of the National Coalition of Mental Health Consumer/Survivor Organizations. Then, each small group picks one of the priorities of the National Coalition and develops the plan to address the priority, which they will present on the last day. Small groups begin a dialogue about the subject area they picked. Participants are encouraged to draw on their passionate purpose.

Vib: Local version of the history of the movement; after developing local histories, engage the large group in dialogue about them.

Day 3: How to go from generative dialogue to strategic dialogue

Module VII: Strategic dialogue principles; develop a practical plan through strategic dialogue.

Module VIII: Presenting in public (to large groups); a representative from each group will present the group's plan (5 min each) and then will engage the group in dialogue, ending with feedback from participants and presenters on how well the group presented and dialogued.

Day 4 – Presenting practical plans, feedback, contracts

9 A.M. noon: Continue presentations to the large group.

Module IX: Conclusion; general discussion about contracting as self-employed contractors with your statewide group. Obtain feedback from the group on how to improve the training. Review how to use the training in developing new leaders in their counties. Review materials, manual, when to start making presentations, getting contracts (thus the training also promotes entrepreneurship), business.

10.2.4 Personal Peer Support

The first step in our Finding Our Voice training is to connect the participants with one another on a personal level. This is the essence of peer support. Instinctively, the consumer/survivor movement has learned how vitally important peer support is. By sharing from our deepest truth, we assist one another in our personal and collective evolution by continuously awakening to our completeness as human beings. We evolve in relation to other people. By giving and receiving, sharing and trusting, we become more empowered and aware of interpersonal dynamics. This is essential so we learn and experience that our most important developments are learned in relationships of mutual trust and understanding. Initially this is best accomplished among peers, who because of their experience in the mental health system, share a common bond. Connecting with peers provides further opportunity for the self-construction of a person's Voice. These groups are similar to women's consciousness raising groups. Once the bond has started to form the group is ready to address the issue of how to transform their anger into passion. Initially the training involved teaching the principles of recovery once the peer-support group had bonded. However, piloting the training showed us that the next step needs to be addressing the anger that most people feel as a result of being labeled, hospitalized (which often involves re-traumatization), and marginalized from society. No other learning or planning can effectively take place until peers have had an opportunity to express their anger and move beyond it to passion.

10.2.5 Transforming Reactive Anger into Passionate Advocacy

When individuals are unable to construct their self and find their Voice, they experience a welling up of suppressed anger which often gets expressed in a reactive manner, which in turn impedes successful advocacy. When a consumer/survivor attends a board meeting before they have transformed their anger into passion, they are either very silent or flare out with the anger in a manner that disqualifies their testimony.

Many effective consumer leaders work on deepening their awareness and appreciation of the source of their anger, which is typically rooted in feelings of righteous indignation due to past hurtful or humiliating experiences when their voice was invalidated. Therefore, in our training program for advocates we pay close attention to this issue of how people can be aware of their anger and use it strategically to affect positive change in their community.

As advocates, Cathy and Barry Creighton of Alaska expressed: "angry is something to use – not something to be." In this manner, the energy and the outrage behind their anger is not suppressed but is translated in to a passion, which can then be the source of effective action. Indeed, studies have shown that "people were inclined to easily give up to those who were perceived by them as angry, powerful, and stubborn, rather than soft and submissive" (Tiedens, 2001, p. 86).

It is our belief, that uses of anger may be our greatest challenge as mental health advocates. On an individual or group basis, expressions of anger are important moments of change in awareness and in the conversation. A skilled advocate becomes very adept at using anger to achieve their goals as illustrated in a recent event. Lauren and Dan are part of a cross-disability coalition, Justice For All Action Network (JFAAN, see below), to bring ideas for change to the Obama administration. In a recent teleconference discussion, several members of the group said they were frustrated by the lack of results of their advocacy. Soon there was agreement and the frustration was shared across the group. At that point, a very skilled advocate said, "I think we need to change our tone, and start expressing more anger." In the discussion that followed, there was an interesting debate about when and how much to change our tone and express more anger. Dan marveled at the conversation because he could never recall such a cooperative and strategic discussion of the conscious uses of anger by a group of advocates. Several days later he described the experience to a group of peers who are experienced advocates, and asked "Do we as mental health consumer/survivors face special challenges in our uses of anger not faced by other disability groups?" The other advocates immediately said we do face special challenges (due to discrimination) and as a result we have not developed the skill of effectively using our anger. In this section, we will explore why mental health advocates have unique issues to deal with anger and give some suggestions about what we can do to overcome these barriers, which are the result of discrimination.

In many ways, our difficulty with anger stems from what it means to be labeled mentally ill. In this regard, it is useful to look at the origin of the term mental illness. Before medical descriptions of mental illness existed, there were and are many

lay expressions of what constitutes mental illness. Perhaps the most revealing is the term madness. In English, the word mad has two meanings. For those of us who have been labeled mentally ill, we are considered in less clinical circles as being mad meaning crazy. We were at times called madmen. But if you have not been labeled as a crazy person, being described as mad can mean you are angry. Normal people get mad and they are not diagnosed. They are listened to. A peer of ours captured this distinction very well. She said she worked within a department of mental health and noticed that her colleagues were frequently getting angry at each other and about their work. When they expressed their anger there was no clamping down on their behavior. In fact, it seemed the norm, for them. However, when she expressed her anger, there were stern looks of censure. Her unlabeled colleagues would inquire in patronizing tones, "Are you feeling alright?" "Perhaps you are having a breakdown?" "It would be a good idea to see if you need more medication." Thus, it seems that there are two very different uses of anger and attitudes toward persons expressing anger. People who have not been labeled can express anger as a day-to-day part of their life without being told that they must not be feeling well. Now there are exceptions, which also are revealing. For instance, women are not given as much freedom in their expression of anger as men. In fact, women who express anger too frequently or too loudly are given the B-h label. In mental health circles, people who express anger are given another B label: borderline. In fact, supervisors frequently told Dan, during his training, that the best way to know that you were dealing with a borderline (invariably a woman) was if they made you feel angry. It also is frowned upon for an employee to express too much anger toward a supervisor. In the days of slavery, an angry slave was uppity and at risk of punishment. So anger is closely related to issues of power. Peer support then is extremely valuable because we are the freest to express our anger with peers where the power is equal. All other relationships involve power imbalances, where we as consumers are in a lower power position. It is usually risky to express anger in a relationship where you have less power. Yet, expressing anger we saw is a way to gain power.

10.2.6 What Do Experienced Advocates Say About Using Anger?

To gain a deeper understanding of this issue, we elicited feedback from experienced consumer/survivor advocates:

Barry and Cathy Creighton of Alaska: "Culturally, anger is not an easy subject. There is a semi-conscious religious stigma that anger is not Christian. (A saint would never use it.) That makes anger a very concentrated word. So we have found that one of the first steps is to broaden the word anger to be just one of the many colors on the palette of emotions. Next, bring in another word, 'listening' – a skill and an art that our newly elected President has demonstrated enormous capacity for."

"Advocacy implies that one is speaking to a political group or cultural prejudice. In that, one would want to listen very carefully and openly to the thought patterns and even prejudices and emotions of those you are addressing. One needs to grok [grok is the concept of deeply understanding a situation and comes from the book,

Stranger in a Strange Land by Robert Heinlen] who and what you are talking to. Then it becomes possible to use the entire palette of emotions – all the way from anger to compassion – effectively. In this respect, the amounts used of any particular emotion are a critical part of the dance between the advocates and who they are addressing.”

“We have done this successfully with the Alaska legislature. In the process of addressing possible political change, we have used anger at some of the stigmas in our culture to enroll legislators in helping us bring about incremental change.”

Crystal D. Choate of Alaska: “I have let my anger motivate me to gain more knowledge and do more research so that I can speak with a clear voice, firmly and calmly. Words sometimes have more meaning when you put them on paper, then I can re-adjust thoughts so they are not so angry.”

Kamaree Altafer of Alaska: “If I take the time to break the anger down, it’s other things that I’m feeling. In the beginning of my recovery, my anger was more frustration and hopelessness. In talking about professionals, I could not find anyone that would listen to what I was saying. If I didn’t follow their agenda, they didn’t want to work with me. The impression was that they didn’t know what to do because of my dual diagnosis issues, stuff like that. I think the break for me was getting someone that would work WITH me. If I were to say how I used my anger, it would be persistence. Now that I am recovered, I use my anger, which I continue to feel is more frustration than anything, as a tool to drive my helping others along in recovery. I cannot stay angry and stay healthy. Anger leads to negativity and bitterness.”

Jim Gottstein of Alaska: “Most of the time when consumers use anger in advocacy it is not only ineffective, but counterproductive and even dangerous since it is labeled a symptom. I think anger is most often effective for those with power over the person against whom the anger is expressed. That’s not always the case of course.”

Mike Wood of Iowa: “. . . anger crops up when I begin to take the actions or lack of actions of others personally. I have a fairly sophisticated filtration system, but occasionally anger tilts toward rage. I begin writing poison pen e-mails, make phone calls and otherwise lessen my short and long-term effectiveness as an advocate.”

“I believe on the lower end of the anger scale, I can be effective. Dissension, frustration, discomfort in group settings seem to focus attention on the unresolved issues. Those people to whom we wish to reach are usually very uncomfortable with our anger. I think it shuts them down rather than activating them.”

“My anger is usually suppressed. That leaves frustration. This may take a toll on me, but provides a better position to deliver a message. When I remain angry, I get all twitchy and it is sort of ugly. The suppression method was learned early from family.”

“I have been researching some and have found a 1969 book by James C Coleman titled *Psychology and Effective Behavior*. One sentence reads, ‘In many situations anger and hostility are normal reactions that may lead to constructive action.’ And then, ‘Anger and hostility aroused by autocratic and unjust treatment of oneself or others may be used constructively in working for social reforms’.”

Debbie Whittle quotes Kenny Logans as saying his “anger fuels his truth.”

Heather Peck of Virginia: "Holding onto anger is like picking up a burning coal to throw at the object of my anger all the while deeply burning myself" according to the Buddha as quoted by Thich Nhat Hahn. "I am powerless over the thoughts, words, and actions of others. I am responsible for the focus of my thoughts, words, and deeds." "Feeling anger informs me that I have been unfair to myself or another person has spoken or acted in a way that I perceive is unfair."

Molly Cisco of Wisconsin: "The use of anger is most effective when a conscious decision has been made to use this strategy among many to be considered. It is important to stick to strategy no matter your emotions. I have used my anger effectively, for example, in writing letters to editors, testifying before policy making bodies and teaching advocacy to others. When used well, people listen. If anger is used as just raw emotion, you risk losing your credibility and your issue. So use anger wisely."

Amy Shipman of South Dakota: "When I am part of an advocacy group, and we are able to achieve even a modest goal, I feel some of the anger seep out of me."

From these examples there are certain conclusions we can draw about anger and advocacy:

- 1) Raw anger interferes with advocacy.
- 2) Anger is a healthy reaction; it reflects a passionate desire to affect positive change to get our needs met.
- 3) Expressing and working out one's anger and frustration ahead of time can be a motivator of social change.
- 4) Anger is most effective when we feel we can use it rather than be it.
- 5) Being part of an advocacy group gives individuals more power which itself decreases frustration and anger.
- 6) Advocacy is much more important when practiced as part of a group because the cohesion of the group allows one to transform anger to passion more readily and one can effect more change when part of a group which further reduces anger and frustration.
- 7) If we do not learn to let go of our anger, it eats away at us and destroys our ability to positively contribute to developing a cooperative and cohesive community.

Drawing on the developmental model, we can consider the progression of an advocate as learning that "angry is something to use – not something to be." To Dan, this has meant to develop a greater sense of who he is. In his early years of advocacy he felt his anger so intensely that there was little opportunity to observe either his own reactions to the anger or to other peoples' reactions. He would be dismissed as overly biased toward consumers and no middle ground could be found. A good example was his advocacy for a consumer who was hospitalized in a mute state. He had made an agreement with her that she would not be forcibly medicated as long as she did not harm herself or others. She kept her end of the bargain, but the hospital staff wanted Dan to forcibly medicate her anyway. After several days, he lost the showdown with the supervisors, partly because his outrage made negotiation and

broader advocacy impossible. It also did not help that he was a psychiatric resident (a relatively low status position in the psychiatric hierarchy) at the time.

Recently Lauren found herself challenged to effectively express her anger and communicate her concern about misleading the public and fueling discrimination. She had been part of a panel of experts on a TV show covering the topic of forced treatment. She felt that the consumer/survivor perspective was not well-represented. Because of the nature of her job and the topic that needed addressing, she asked others for feedback. Several advocates quickly became passionately involved, and together sculpted the letter, which literally and figuratively expressed our collective Voice. Below are some excerpts:

“I am writing to express my disappointment concerning the fact that the panel (for a television show) did not actually constitute a dialogue. The word ‘dialogue’ implies that more than one opinion is well represented. . . .”

“There are at least two perspectives on the issue of forced treatment. Some believe that it can be lifesaving – and that position was given a disproportionate percentage of attention during the taping. Others believe that forced intervention is, by definition, traumatizing and counterproductive. I am hoping that the final version of the program addresses this imbalance by including more information about the need for choice and self-determination in regard to mental health treatment, and the short- and long-term damage inflicted by the use of force and coercion. . . .”

“Because of the pervasive abrogation of individuals’ civil rights – even a person accused of serious criminal behavior is given greater legal protection and due process than a person diagnosed with mental illness – these issues are not being properly considered by the courts” (Gottstein, 2008; Perlin, 2005; Morris, 2005).

Lauren is inspired by the righteous indignation, courage, passion, and tenacity that have brought the consumer/survivor movement this far. We will not be silenced. We are building our national Voice and awakening to a renewed sense of meaning, purpose, and belonging. We will continue to learn from our experiences, share our knowledge and become wiser about harnessing our passion. Lauren is confident that we are moving closer to an inclusive world community, where human differences are respected and diversity is honored. When she goes into stillness and hears the “violin strings playing in the gentle breezes,” the cries of those whose voice was not heard, and carries them with the love and support so apparent today – this is the wind under her wings.

With education, support, and experience we will continue to develop the art of using anger instead of being angry. Harnessing that passion will open doors and accelerate our movement.

10.3 Finding and Using Our Authentic Collective Voice

This section will focus on the national organizing we have done to use our Voice to influence local and federal policy. The authors have also been involved in statewide organizing. The NEC published a book on this topic called “Voices of Transformation.” This resource is based on the NEC’s surveying the experiences of

consumer-run, statewide advocacy organizations in Maryland, Vermont, California, and Ohio over the last 25 years. It has also been helpful in organizing consumers in other states to form new groups, including those Iowa, South Dakota, and Oregon.

10.3.1 Forming and Using a National Voice of Consumer/Survivors

The National Coalition of Mental Health Consumer Survivor Organizations (NCMHCSO) was built on the foundation laid by the courageous work of those who started the mental health consumer/survivor movement in the early 1970's. Those early leaders were people labeled with mental illness, who were inspired by people who were finding strength, courage, and power by joining together to work for human and civil rights. The visionary leaders of the consumer/survivor movement understood the only way to gain rights and independence was to come together and unite in a common cause. Through meetings in churches, apartments, and basements, we discovered the power of sharing our stories, of *being heard and of being understood*, instead of the idea that our labels defined us. We discovered we could shift into a vision of leading independent lives where we become authors rather than victims in our lives. Following in the footsteps of this early leadership, hundreds of self-help groups, consumer-run initiatives, and statewide consumer organizations formed all over the country. These groups have had some success in influencing policy and practices on the local level. Despite this, we had, until 2006, been unable to form a single, national organization, which could gain recognition and influence on a national level. In order to effect change at the national level, we needed to have a united national consumer/survivor voice. Leaders of other national groups in Washington, DC, elected officials, and the media have been searching for our united consumer voice. Without such a group to directly represent us, family groups or organizations of providers have been "speaking" for us and we have protested this misrepresentation. We have proclaimed, "Nothing about us without us."

Today consumers and survivors are uniting nationally as never before. Our movement has gained the experience, wisdom, and maturity to realize that it is time to see beyond our differences to the greater struggles urgently at hand. In May 2006, a series of teleconferences began to be held with representatives of major consumer/survivor groups from a number of statewide, consumer-run organizations and three national federally funded Technical Assistance Centers (CONTAC, Self-help Clearinghouse, and NEC). The formation of this national coalition was built on passion forged from collective anger. The final outrage was an essay written by Dr. Sally Satel, a highly placed psychiatrist in the Bush administration who criticized the ten components of recovery developed by SAMHSA. The psychiatrist particularly criticized self-determination, saying that persons with mental illness could never be self-determining. She also called for the dissolution of SAMHSA. From this groundswell of outrage, the coalition crafted a mission, a statement of purpose and formed a Steering Committee, whose bios are on our website, www.ncmhcs.org. The fundamental principle of the coalition is self-determination. The Steering

Committee hired a Director of Public Policy, Lauren Spiro, and we opened an office in Washington, DC. The Steering Committee developed a set of membership criteria, for admitting statewide consumer-run organizations or Technical Assistance (TA) Centers as members:

1. The group be genuinely consumer/survivor run, meaning that the majority of the board and the staff are consumer/survivors.
2. The organization be involved with consumer/survivors statewide or in a significant region of their state and that the organizations agree to be in regular communication with their networks and ensure that they are inclusive and representative of their state.
3. The organization's board approve in writing the mission and statement of purpose of the coalition.
4. The organization agrees to work out differences among themselves and any other member organizations in a collaborative fashion.
5. The organization advocate that the voice of consumer/survivors be central to decision making at all levels.

Currently, there are 31 member states, and efforts are underway by the Coalition and the TA Centers to organize statewide consumer organizations in the other states not yet represented.

We have conducted three annual open face-to-face meetings, typically having over 200 consumer/survivor participants. Our first annual meeting was held in Portland, Oregon and was an opportunity to announce the formation of the coalition and answer questions from across the country. Our second meeting, held in October 2007, in St. Louis, MO, was primarily used to develop a set of priority public policy issues. Our third annual meeting was held in October 2008 in Buffalo, New York where we fine-tuned our public policy priorities, heard from a state that has been very successful in securing state funds and shared some of our accomplishments in the past year. We reaffirmed that our top priority is adequate funding to ensure sustainability of consumer/survivor-run networks in every state.

10.3.2 Major Accomplishments of NCMHCSO During 2007–2008

- I. September 2007: The Coalition expanded its CD Series: "Voices of Hope and Recovery: Our Stories, Our Lives" to 12 extraordinary stories to educate and inspire. These are personal stories of recovery by leaders and others involved in the consumer/survivor movement. These stories – honest, gut-wrenching, and triumphant – demonstrate the power of the human spirit to prevail.
- II. September 2007: The coalition secured a contract to create a history exhibit of the mental health consumer/survivor movement. The coalition formed an advisory committee that selected the artifacts for the exhibit, which were collected from across the United States.

- III. November 2007 and July 2008: The coalition co-sponsored two Presidential Forums. During that forum, the National Coalition, along with more than 20 other national disability rights organizations, co-hosted a *Presidential Candidates' Forum: A National Forum on Equality, Opportunity and Access*, in Manchester, New Hampshire. This historic, day-long event featured presidential primary candidates speaking on disability issues and answering questions from the audience. There were over 500 people and over 30 television cameras with Ted Kennedy, Jr. moderating when the first speaker, Senator Hillary Rodham Clinton, electrified the room. The second forum occurred in Columbus, Ohio, July 26, 2008. This Forum featured the 2008 Presidential Candidates. John McCain and Senator Harkin, who served as the surrogate for Barak Obama, presented their visions for the future of disability policy in America.
- IV. March 2008: At the Sante Fe (NM) Summit, Lauren Spiro introduced the coalition to the audience and invited them to work with consumer/survivors in their state to develop or strengthen a statewide consumer/survivor network. Participants in the session on the National Healthcare Address included among others, Tommy G. Thompson, former Health and Human Services (HHS) secretary and four-term governor of Wisconsin. The 3-day Summit ended with participants sharing the actions they would take. Lauren said "the most important thing is that I will continue to advocate that people with the lived experience of recovery and their families will be at the head table. We will continue to move towards eliminating the oppressive policies, practices and attitudes that contribute to spiraling healthcare costs, unnecessary suffering, and premature death.
- V. July 2008: Press release by the Coalition: WASHINGTON, D.C. "*Mummies of the Insane*" Galvanizes National Coalition of People with Psychiatric Histories. "A national coalition of people who have psychiatric histories is demanding an end to the 'sideshow' exhibition of two mummified female cadavers, whose bodies were sold in 1888 by the West Virginia Hospital for the Insane to an amateur scientist."
- VI. June 2008: The National Coalition began developing Emotional CPR (eCPR), a peer-developed educational program for the general public designed to teach individuals to assist people through an emotional crisis by three simple steps of C = Connecting, P = emPowering, and R = Revitalizing. eCPR is based on the principles of trauma-informed care, counseling after disasters, peer support for recovery from mental health problems, emotional intelligence, suicide prevention, and cultural attunement.
- VII. September 2008: The Coalition conducted its first grant funded organizing effort which took place in Washington, DC on September 16, 2008. One hundred and fifty participants from diverse communities, working together, from diverse communities formulated recommendations to transform mental health care in the Washington, DC Metropolitan Region. This is a step toward ensuring that our voice is heard and that together we work toward improving the system of care so that it does a better job in meeting the real needs of people.

- VIII. September 2008: Coalition received a contract to produce materials about speaking from our heart with our advocacy voice and changing the world. We did a conference workshop, have a webcast scheduled, and a manual in development.
- IX. December 2008: President-elect Barack Obama's transition team invited representatives from the coalition to meet and discuss our policy priorities. These meetings were made possible through the coalition working collaboratively with other disability groups. Through collaboration, the coalitions' Voice has grown much stronger.
- X. December 2008: Press release: WASHINGTON, DC, *Tragedies Underscore Crisis in U.S. Public Mental Health System: National Advocacy Organization Demands Reforms*, "In the wake of the deaths of two persons in public psychiatric institutions – highlighting a pattern of abuse and neglect of those who have psychiatric disabilities – a national coalition of such individuals is calling on the incoming Obama administration and the nation's top mental health officials to institute widespread, substantive reforms in America's mental health treatment system. These would include raising standards and regulatory expectations, and identifying and funding pilot programs to demonstrate best practices in psychiatric emergency, inpatient and community-based care."
- "The death of Steven Sabock, a 50-year-old man diagnosed with bipolar disorder who died on April 29 in a North Carolina state psychiatric institution after he had choked on medication – while, nearby, hospital employees, ignoring his plight, entertained themselves with cards and TV – is just one example of the dangerous dysfunction of the public mental health system,' said Dan Fisher, M.D., Ph.D., of the National Coalition of Mental Health Consumer/Survivor Organizations (NCMHCSO)." In response to a similar death of a consumer in the waiting room of a New York hospital, supporter organization, NYAPRS held hearings throughout New York state to seek solutions. These hearings highlighted the need for alternatives to psychiatric hospitalization such as warmlines and peer-run crisis respite.
- XI. Most recently, we helped secure for FY 09 just under one million dollars from congress to fund, through the Substance Abuse Mental Health Services Administration/Center for Mental Health Services, 12 additional consumer-run statewide networks bringing the total of networks funded to 32.

Though we are pleased with what we have accomplished in a short period of time we look forward to building more statewide networks and a stronger national coalition. We have found the common ground that unites us in the values of human and civil rights and our passion for recovery. We are building our infrastructure and accelerating the progress of our movement, which provides the vehicle for having the consumer/survivor voice heard so that we can impact decisions on policy, regulation, evaluation, training, funding, services, and other areas that influence our lives. We are increasing our effectiveness by working in partnership with organizations such as the Judge David L. Bazelon Center for Mental Health Law, the

American Association of Persons with Disabilities, and other person-led national disability organizations.

10.3.3 International Organizing

In August 2007, in St. Catherines, Canada, Dan assisted in the formation of an international coalition of national consumer/survivor organizations. This coalition's name is Interrelate (www.interrelate.info) which reflects the value the group places on relating deeply, as equals. The group consists of representatives from Australia, Canada, England, Ireland, New Zealand, Scotland, and the United States. Interrelate plans to participate in the next International Initiative on Mental Health Leadership to be held in Australia in March 2009. The mission of the group is, "to inspire hope and strengthen the capacity of people with mental health issues to lead in the creation of national and international policies, which achieve recovery and well-being." Connecting with each other and sharing our experiences gives greater courage to each of the members of the group. Through the formation of Interrelate we truly know that the recovery well-being, and protect of human rights.

10.4 Conclusion

Consumer/survivors have made remarkable progress in organizing at the local, state, national, and the international levels. Each level inspires and reinforces the further development of the others levels. Continued progress will require that peer support keep up with advocacy development. Our leaders often have just enough energy and skills to gain a voice but still need to attend to an equal complement of peer support to sustain these gains. Often a person's first involvement with the consumer/survivor movement is as a consumer who wants additional support rather than systems change. Gradually, through peer support, consumers get in touch with their anger toward a system and a society, which has marginalized them. They learn that they are neither isolated nor passive victims of societal misunderstanding and discrimination. When this outrage can be forged into passion for change, peers transition into advocates and survivors. Other disability groups are further along in the development of their empowered, advocacy Voice and serve as models for us in their use of political strategy to affect systems change. It will be increasingly important to learn to collaborate with other disability organizations led by persons with disabilities as well as the larger community of disability organizations.

The National Coalition of Mental Health Consumer/Survivor Organizations has begun to build these connections at a national level. Three examples of strong national disability groups led by persons with disabilities are the American Association of Persons with Disabilities (AAPD), National Council of Independent Living Centers (NCIL), and ADAPT, a nationwide grassroots organization of people with disabilities. AAPD was founded by legendary disability leaders, Justin

Dart and Fred Fay. They both were excellent at reaching out to leaders in the consumer/survivor movement. As a result the NCMHCSO has entered into a national cross-disability network organized by AAPD consisting of NCIL, ADAPT, and nine other national disability groups run by persons with disabilities, called Justice For All Action Network or JFAAN. As a result of being part of JFAAN, NCMHCSO has been invited to two meetings with senior policy officials from the Obama White House. We are using our voices to enter into respectful dialogue with these allies in this historic struggle to humanize post-industrial society.

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