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A JOURNEY TOWARD RECOVERY: FROM THE INSIDE OUT

DALE WALSH

DALE WALSH, MA, IS VICE PRESIDENT AND CHIEF OPERATING OFFICER AT RIVERBEND COMMUNITY MENTAL HEALTH IN CONCORD, NH. SHE IS ALSO A DOCTORAL STUDENT IN PSYCHIATRIC REHABILITATION AT BOSTON UNIVERSITY, BOSTON, MA.

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I have worked in the field of mental health for about 20 years. I can talk about this part of my life easily. I have also been a survivor of a long-term psychiatric disability for most of my childhood and adult life, and I am a survivor of the mental health system, both public and private. This is the harder part of my life to talk about. I have walked on both sides of the fence, so to speak. I want to share with you my own personal path toward recovery and what I see as a consumer/practitioner to be necessary to support the recovery process of people who use the mental health system.

First, a word about language. There is no clear consensus within either the professional mental health community or among the people who have actually experienced psychiatric treatment as to what we are to be called. In the 1970s, when people who were former “patients” started to come together and share their experiences, they called themselves just that—ex-patients or former patients. Later, as the movement developed and grew and people collectively began to express their anger, some people used the name “psychiatric inmate” to make clear their dissatisfaction with the prevailing power inequities of the medical model and with

the way they were treated. In California, the term “client” came to be used, because it met the dual goals of neutrality and descriptiveness. And in the 1980s the term “consumer” began to be used, mostly by the mental health system and by family groups (usually groups of parents who had an adult child with a severe psychiatric disability) in an attempt to find a label which was non-stigmatizing, yet acceptable to them. Other people who have been through the mental health system and consider themselves in recovery may use the phrase “psychiatric survivors.” This debate over language is more than semantics. What people choose to call themselves is a key element in forming a group identity. It is also an indication of people’s felt sense of empowerment and the place they feel they occupy within the hierarchy of the system of mental health care or services. It is important for the mental health system to be respectful and to take careful note of the names or phrases used to describe the people who use their services. Since I knew I was one, I have called myself a “survivor” or “person with a psychiatric disability.” Recently I have been with some colleagues who prefer the phrase “person with a psychiatric label.” I like that because the phrase speaks to the stigma carried and experienced by

those of us who have been through psychiatric “treatment.”

I have been dealing with the aftereffects, the stigma, and the shame of having a psychiatric disability for most of my life. As a child I was overly good. I was very anxious. I had multiple physical problems, nightmares, and trouble sleeping. As an adult, I have always been restricted in performing many of life’s everyday functions—going to a shopping mall or to the bank, taking vacations or doing other leisure activities, going to social events like weddings, and working full time. Many times just leaving my house has been too anxiety provoking for me to handle. I have had many episodes of depression so severe that basic functioning has been difficult. Most of the time I live with some level of anxiety and a sense of terror and foreboding that come not from the present but from my past history of abuse. Feeling safe in the world is something I work on a daily basis.

For many years I believed in a traditional medical model. I had a disease. I was sick. I was told I was mentally ill, that I should learn to cope with my anxiety, my depression, my pain, and my panic. I never told anyone about the voices, but they were there, too. I was told I should change my expectations of myself and realize I would always have to live a very restricted life.

After I was diagnosed, I was put in a box up on a shelf. Occasionally I was taken down and my medication was changed. But no one really talked to me. No one helped me figure out why I should be content to take my medication and be grateful things were not worse. After all, at least I did not have to live my life in the back wards of a state hospital.

Because of my history and because of the society in which I lived, I easily turned the notion of illness into think-

ing there was something wrong with me. I was the problem. I felt deformed, everything I did was wrong. I had no place in the world. I was a freak. I was deeply ashamed of who I was and I tried my best to cover up my abnormality. I learned from those around me that psychiatric disability and its aftereffects were something to hide. As a result I lived marginally. I worked in a constant state of terror and tried to look normal. For the most part I succeeded—but at a tremendous cost to myself in terms of my energy, my self-image, my fear, and my inferiority. There were times when the stresses got to be too much and I ended up hospitalized, defeated, and feeling a failure because I couldn’t tolerate even the day-to-day problems of what seemed to be a fairly simple life.

I worked in the field of mental health and I was very careful not to let anyone know my shameful secret. I was constantly terrified someone would find me out. I kept myself in entry-level positions because I was having a hard enough time without the added stresses of climbing up the ladder in my field. I went to therapy. I took my medication and waited to feel better. I waited and waited. . . .

I sometimes felt angry at my caregivers, but mostly I felt angry at myself. At times my symptoms were better but I wasn’t. I felt powerless. I felt empty. I looked outside myself to the doctors and professionals to cure me, or at least take away some of my pain. But they didn’t. Maybe I was one of those hopeless cases. I felt despair and deep loneliness.

This old patriarchal system of treatment and culture of disease is characterized by a hierarchical arrangement of power, a mechanistic view of the mind, causality due to organic forces outside the person’s self, an emphasis on a person’s deficits, and treatment administered by an expert—always at a professional

distance. Did they think they might catch it? Why were they all so careful to maintain that professional distance? For years I felt trapped because I knew no other way to look at myself and my process.

Then about 8 years ago I read *The Courage to Heal*. I started talking to people—professionals and survivors who knew about the effects of trauma and psychiatric disability. I was lucky enough to stumble on 12 Step and other self-help groups. Finally my symptoms, my dreams, and my fears started making sense. I discovered the principles and the practices of recovery. I discovered hope. I had lived for years in despair because the pills and the therapy did not make me better. I began to see that if my life was to become better, I would have to do it myself. I saw that other people with histories similar to mine had been able to move beyond their symptoms. I started working with a therapist who was able to communicate to me that she trusted and believed in my own capacity to grow and move forward. She was willing to assist me but she respected my own pacing. I began to believe I could actually participate in a healing process. As I looked within myself I discovered over the following years, slowly and sometimes painfully, that healing, making positive changes in my life, and feeling better, were all possible. Especially helpful to this process were several self-help groups where I didn’t have to hide, where people understood and were engaged in struggles similar to mine. I saw people who were further along in their recovery who served as role models. I also got to know people who were not so far along as I was—whom I could mentor. Giving back and learning how to get out of myself and into someone else’s frame of reference has been, and continues to be, an important step in my recovery.

What I found through my own experience is that in order to travel the path of true recovery I could not rely on externals, wait, hope to be rescued, or be made better because of someone or something outside me. Instead, I learned that both the power and the possibility of change reside within me. I could make decisions that would affect my life. But I found I could not do this alone. I needed a supportive community around me. Slowly and gradually I found people who understood. I found friends and support people who could help me hold the hope when I was going through tough times and when I reached what felt like an insurmountable obstacle. These people believed in my capacity to heal. As I learned to take risks, I found that I could actually set and accomplish goals very much like people who were chronically normal.

Recovery is not a return to a former level of functioning. I have heard so many people—professionals and survivors alike—say that mental illness is not curable. I agree that we can never go back to our “premorbid” selves. The experience of the disability, and the stigma attached to it, changes us forever. Instead, recovery is a deeply personal and unique process of changing one’s attitudes, values, self concept, and goals. It is finding ways to live a hopeful, satisfying, active, and contributing life. Everyone is changed by major happenings in their lives. We cannot return to the past. Recovery involves the development of a new meaning and purpose in one’s life. It is looking realistically at both the limitations and the possibilities. It is much more than mere symptom relief.

As I continued on my path of recovery, I found I could handle responsible jobs. I am now slowly expanding my social network as I feel safer in the world and more comfortable with who I am. And, very importantly, I have come out of the

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closet and announced publicly, as a representative of those with psychiatric labels, who I am, where I have been, and where we as a community of oppressed people can go if we can find our voices, recapture our power, and exercise it to take charge of our lives and our journey toward wholeness. I am still in recovery, for it is a process—not a sudden landing.

Discovering and participating in this culture of healing has given me the hope and courage to travel the path of recovery. This is a culture of inclusion, hope, caring, and cooperation; of empowerment, equality, and humor; of dignity, respect, and trust. Forming relationships and creating systems of mental health care based on these principles are vital to supporting the growth of people who are users of the system. Traditionally, people who have been labeled as mentally ill have been considered to have poor judgment. They need to be taken care of. They do not know

what is best for them. They are told what is wrong with them, what they need, what their future is to be like, and what is in their best interest. The stigma and discrimination that those of us who are labeled as mentally ill have suffered steals our hope, isolates us, and is a barrier to our healing.

Part of healing and recovery is the ability to participate as full citizens in the life of the community. As psychiatric survivors begin to break their silence and advocate for their humanity, the call and demand for basic civil rights becomes increasingly stronger. People want to be able to make their own choices about their own lives. They want to be seen, heard, and taken seriously. They want to be part of the decision making which so deeply affects their everyday experiences. This taking back of power and being taken seriously are both necessary components of recovery.

The notion that there is a recovery process that goes on internally within each person with a psychiatric label, often very separate from the treatment the person receives, is a new and somewhat threatening concept for the psychiatric treatment community. As recovery begins to be talked about and recognized by psychiatric survivors, it offers a way of taking back dignity, self-responsibility, and a sense of hope for the future.

By taking back power from the system of care, a consumer/survivor acknowledges that the ability to cope and heal comes from within. No one else, including the best of service providers, can do anything but facilitate the healing process. However, this facilitation—if it takes the form of good attention, respect, validation, and genuine connection—is an essential part of recovery.

Empowerment is a vital component of our recovery. Allowing and supporting a

change within a program, agency, or system requires trust among administrators, staff members, and the people served. This change requires a shift, from power being retained exclusively by administrators to it being shared among all constituencies. It requires a willingness to take risks in not only allowing—but actively encouraging—people to work toward their own goals. It means that choice and self-determination are to be considered foremost when consumer/survivors and staff members are developing treatment and rehabilitation plans. When treatment or rehabilitation is seen as more than prescribing the right formula, and when the emphasis is placed on maintaining the functioning and identity of the person, an atmosphere that promotes recovery is created. We who use the mental health system need to play a significant role in the shaping of the services, policies, and research that affect us. We need to have a place at the table and become participants in a shared dialogue.

When people assert control over their own lives and make their own decisions, they also take on responsibility for the consequences of their decisions. Often, as service providers, we want to protect people from failure. We know, or at least think we know, what is best. We do not like to see people fail—both because of the pain it may cause to the person, but also because of the pain and feelings of failure we may experience. Sometimes when psychiatric survivors decide to make changes in their lives, they may not succeed. And, like other people, they may or may not learn from their failures. Like other people, they have a right to take risks. And sometimes they succeed, surpassing all expectations.

How many of you have tried something new and found it did not work? An in-

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“BY TAKING BACK
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vestment perhaps? Or maybe a new relationship, or a marriage? You were allowed to take these risks even if the money you put into the investment was money you could not afford to lose, even if the relationship was the same kind of destructive relationship you had been through in the past. Maybe you learned from these situations, but maybe you didn't. People with psychiatric labels have these same rights. Part of sharing power is nurturing, encouraging, and fostering these rights.

Decision making in an environment that fosters recovery involves more peo-

ple and more time. It is much easier for an administrator to make a decision alone than to bring it to the community for discussion and input. Often, decision making has to be taught to people who have grown accustomed to having their decisions made for them, who have been told so many times that, because of their “illness,” they are unable to make responsible choices, and that any preferences they do express should be discounted because they are sick and unstable.

It takes time, patience, and a lot of listening to teach people to take the major risk of making their own choices again. But this type of power sharing through conversation can provide for a climate of equality, which can insure that all people can be free to express and reach for their own hopes and aspirations. Power sharing allows both staff members and clients alike to become much more involved in, and invested in, their own growth. In an environment that fosters recovery, the barriers of discrimination and stigma, which destroy self esteem, perpetuate learned helplessness, and convince people they are incapable of self-determination, are broken down.

Many people who have been diagnosed as mentally ill hate labels and object strongly when people are called schizophrenic, bipolar, or borderline. After people are diagnosed, everything that happens to them is seen through the filter of their labels. A couple of years ago I was admitted to a hospital on an emergency basis. The next morning I called my office to say I wouldn't be in because I was in the hospital. At the time I worked in a very progressive agency with several people who themselves had psychiatric disabilities. My colleagues assumed I was in a psychiatric unit. These same colleagues called every psychiatric unit in the Boston area trying to find me. In reality, I had

been admitted to the hospital because of a respiratory infection. They had assumed that if I was in the hospital on an emergency basis of course I was having a psychiatric emergency.

An environment that fosters recovery must be one in which hope is an essential component of each activity. Often people with psychiatric labels have lost hope. They see their disability as a death sentence. They think they can never get any better. When you are in the midst of despair it is almost impossible to see the other side. Too often providers echo these feelings and cement them into reality for those with whom they work. Have you ever found yourself angry at a person who has given up hope? I have.

During difficult times it can be easier to give up. Do we blame ourselves? Sometimes. This can serve to fuel our own despair. More often, though, I think professionals blame the people who are in despair. Despairing clients are seen as lazy, non-compliant, and manipulative, and they don't want to get better. They don't want help. They should be discharged from the program so they can hit bottom—then maybe they will appreciate how good they had it.

In a system where this continually happens, people within the system and the system itself can get caught up in the despair and become rigid, distancing, and lifeless. As an administrator, I try to use these times to take an honest look at the services my agency is providing: are they relevant to what people need and want? Are staff members burning out and in need of support from me or from each other?

In these days of more work and fewer resources I often find that the issues, the traumas, and the life experiences of the people who use the mental health center trigger myself and my staff. We

can only be with people in their pain to the extent we are willing to be with our own pain within our own life experiences. I model this with my staff by talking about the feelings the work evokes in me. And I invite others to share also. I have found that creating an environment of safety for staff members as well as for clients is necessary for this open sharing to go on. Safety to reveal one's own vulnerabilities without fear of sanctions is vital for an environment that fosters recovery. Confidentiality, respect, and sincere attempts to empathize and demonstrate understanding to others are components of such an environment. Well developed interpersonal skills, on the part of both staff members and administrators, can serve to support the atmosphere of safety and compassion.

When I decided to return to school to get my doctorate, I did so for several reasons. First of all I wanted to learn more. Second, I thought that the title "doctor" before my name would help me feel validated, and that I had a place in the world. And third, because I wanted to give back some of what had been given to me by those who supported my recovery. As I looked at various programs I was disappointed at the values and the sterility of the various programs. Then I talked to someone at Boston University, where I had gotten my master's many years before. I liked the idea of rehabilitation with its emphasis on functioning rather than illness and limitations. It was suggested to me that I read some of Bill Anthony's work to see if the principles expressed resonated with my own. As I did, I found that both the principles and practices gave a context and a structure as well as a guide for helpers to foster recovery instead of encouraging passivity and compliance. In psychiatric rehabilitation the person and his or her preferences and thoughts are essential to the process. When I learned of the values of

involvement, choice, comprehensive-ness, support, and growth potential, I saw these were the same values that helped free me from feeling trapped in traditional treatment. I was excited at the possibility of learning how to put these values into practice with other survivors of the psychiatric system. I learned in the very best way possible—by teaching. I taught courses in rehabilitation counseling for 4 years. Over the past several years I have been using these principles to help mental health systems put a recovery paradigm into practice. I have seen, in myself and in the people with whom I work, that when these values form the basis of the structure and programming within a system, people learn to take responsibility for themselves and their actions. These principles provide the soil for people to choose to grow and change. I have come to think of psychiatric rehabilitation as providing an external structure, while recovery is the internal process.

Through recovery I have found myself capable of making changes toward more satisfaction and success in my life. The quality of my life has greatly improved. I still have my limitations—I am not a finished product. And from an acceptance of my limitations has come a belief in my own unique possibilities. I have the power to move toward wholeness.