Recovering Our Sense of Value after Being Labeled Mentally Ill

Patricia E. Deegan

In the final decade of this millennium, after centuries of being so fundamentally and brutally devalued by our culture, there is a glimmer of hope that people who have been labeled with mental illness can reclaim their dignity, can be viewed by others as being people of worth, and can begin to achieve valued roles. There is no doubt that the landmark piece of civil rights legislation, the Americans with Disabilities Act, will help to remove many of the barriers that have historically prevented those of us with psychiatric disabilities from achieving valued roles in this society. We are all charged with the valued role of carrying a new message of hope, of healing, and of recovery back into the communities where we live, love, work, and worship.

As I was preparing this article, I found myself wondering how those of us who have experienced being profoundly devalued as a result of being labeled with a mental illness move from thinking we have little or no value, to discovering our own unique value. How do we reclaim and recover our sense of worth and value when we have been devalued and dehumanized? In the course of my reflections I found myself thinking back to the days when I was an adolescent and was first diagnosed with major mental illness. I was thinking about my first two hospitalizations and how I was labeled with schizophrenia and three months later, at my second hospital admission, I was labeled with chronic schizophrenia.

I was told I had a disease that was like diabetes, and if I continued to take neuroleptic medications for the rest of my life and avoided stress, I might be able to cope. I remember that as these words were spoken to me by my psychiatrist it felt as if my whole teenage world—in which I aspired to dreams of being a valued person in valued roles, of playing lacrosse for the U.S. Women’s Team or maybe joining the Peace Corps—began to crumble and shatter. It felt as if these parts of my identity were being stripped from me. I was beginning to undergo that dehumanizing and devaluing transformation from being a person to being an illness; from being Pat Deegan to being “a schizophrenic.”

As I look back on those days I am struck by how all alone I was. This profound sense of being all alone only served to compound my sense of feeling worthless and of having no value. Granted, people gave me medications, people monitored my blood pressure, people did art therapy, psychotherapy, occupational therapy, and recreational therapy...
with me. But in a very fundamental way I experienced myself as being all alone, adrift on a nameless sea without compass or bearing. And that deep sense of loneliness came from the fact that although many people were talking to me about my symptoms, no one was talking to me about how I was doing. No one came to me and said, "Hey, I know you're going through hell right now. I know you feel totally lost in some nightmare. I know you can't see a way out right now. But I've been where you are today. I got labeled with schizophrenia and a whole bunch of other things too. And I'm here to tell you that there is a way out and that your life doesn't have to be about being in mental institutions. I'm around if you want to talk."

No one ever came to me and said those words. All I knew were the stereotypes I had seen on television or in the movies. To me, mental illness meant Dr. Jekyll and Mr. Hyde, psychopathic serial killers, loony bins, morons, schizos, fruitcakes, nuts, straight jackets, and raving lunatics. They were all I knew about mental illness, and what terrified me was that professionals were saying I was one of them. It would have greatly helped to have had someone come and talk to me about surviving mental illness—as well as the possibility of recovering, of healing, and of building a new life for myself. It would have been good to have role models. Someone I could look up to who had experienced what I was going through—people who had found a good job, or who were in love, or who had an apartment or a house on their own, or who were making a valuable contribution to society. But as I said, this did not happen for me in those early years.

So today I want to take the opportunity to say the things that no one ever said to me back then. I want to talk with the seventeen-year-old girl that I once was. I want to talk to her about what I know now but didn't know then. I want to talk to her and in so doing peak to all of us who have been labeled with mental illness, who have suffered deeply, who have known despair, who have been told that we have no value and who have felt alone, abandoned, and adrift on a dead and silent sea.

**A Bleak, Monotonous Existence**

I turn my gaze back over the twenty-one-year span of time that separates me from that seventeen year old girl. I am trying to see her; it's difficult to look at her. I can see the yellow, nicotine-stained fingers. I can see her shuffled, stiff, drugged walk. Her eyes do not glance. The dancer has collapsed and her eyes are dark and they stare endlessly into nowhere. It is the time between the first and second hospitalization and she is back living at her parents' home. She forces herself out of bed at eight o'clock in the morning. In a drugged daze she sits in a chair, the same chair every day. She is smoking cigarettes. Cigarette after cigarette. Cigarettes mark the passing of time. Cigarettes are proof that time is passing and that fact, at least, is a relief. From nine A.M. to noon she sits and smokes and stares. Then she has lunch. At one P.M. she goes back to bed to sleep until three P.M.. At that time she returns to the chair and sits and smokes and stares. Then she has dinner. She returns to the chair at six P.M.. Finally, it is eight o'clock in the evening, the long-awaited hour, the time to go back to bed and to collapse into a drugged and dreamless sleep.

This same scenario unfolds the next day, and then the next, and then the next, until the months pass by in numbing succession, marked only by the next cigarette and then the next . . .

And as I watch her, I know it is not so much mental illness that I am observing. I am witnessing the flame of a human spirit faltering. She is losing the will to live. She is not suicidal but she wants to die because nothing seems worth living for. Her hopes, her dreams, and her aspirations have been shattered. She sees no way to achieve the valued roles she had once dreamed of. Her future has been reduced to the prognosis of doom she had been given. Her past is slipping away like a dream that belonged to someone else.
ill alone, adrift, senselessness came, as no one had, "Hey, I know a nightmare by. I was labeled to tell you that the time."

Prototypes I had seen. Mr. Hyde, straight jackets, at terrified me early to help to— as well as the. It would have strength what I've, or who had contribution to ever said to me. I want to talk and in so doing suffered deeply, I who have felt irrates me from the truth. I can see walk. Her eyes stare endlessly and she is a back in the morning, king cigarettes, are proof that on she sits and it to sleep until tares. Then she in the evening, a drugged and the next, untilrette and then observing. I am alive. She is not Her hopes, her love the valued nosis of doom to someone else.

Her present is empty but for the pungent cigarette smoke that fills the void like a veiled specter. No, this is not mental illness I am seeing. I am seeing a young woman whose hope for living a full and valuable life has been shattered. She feels herself to be among the living dead and her spirit is waverling under the weight of it all.

**What I Wish I Could Tell Her**

I walk into the room and sit near her. Want to talk to her. Just the thought of it makes me want to start to cry. What should I say to her? I lean towards her as she sits smoking in her chair.

"Patricia... I'm worried about you. I can see that you are suffering deeply. Your suffering is not invisible to me. I know that the professionals have been very busy observing you treating your symptoms and trying to rehabilitate you; but no one has addressed the way you are suffering. The fact that you have felt so alone in your suffering doesn't mean there's something bad or shameful about you. Try to understand that most professionals— in fact most people—are afraid to sit quietly and to be with a person who is suffering. It's the same sort of thing that happens at a funeral— when people line up to console the person who is bereaved they get all anxious and awkward and don't know what to say.

"People find it frightening to just spend time with people who are in great pain. You see a person who is in great-anguish is crying out. Even if they are totally silent like you are, way down deep I can hear you crying out. Thus, to be with a person who is anguished is to risk experiencing the cry that is way down deep inside each of us. That is why the professionals have been so busy doing things to you, rather than being with you. Granted, it's their job, but it's also true that staying busy by doing things to you helps keep their anxiety under control, which in turn helps to distance them from the cry that your suffering might evoke in them.

"I also hear anger in your suffering. You are angry because you have been diagnosed with a major mental illness. You feel angry because all your friends are doing normal stuff like going to school, going on dates, and dreaming their dreams. You feel 'Why me. Why has this happened to me?' I don't know the answer to that question. I don't know why you were dealt this hand of cards. But what I do know is this: You may have been diagnosed with a mental illness but you are not an illness. You are a human being whose life is precious and is of infinite value.

"You are at a critical juncture, a very important time. The professionals are telling you that you are a schizophrenic. Your family and friends are beginning to refer to you as 'a schizophrenic.' It is as if the whole world has put on a pair of warped glasses that blind them to the person you are and leaves them seeing you as an illness.

"Almost everything you do gets understood in reference to your illness.

"You used to feel sad sometimes but now you are said to be depressed. You used to disagree sometimes but now you are told you lack insight. You used to act independently but now you are told that your independence means you are uncooperative, noncompliant, and treatment resistant.

"But now that you have been labeled with a mental illness the dignity of risk and the right to failure have been taken from you. No wonder you get angry.

"But this is a critical time for you because there is the great danger that you might succumb to the messages you are being given. You might slowly find yourself putting on those same warped glasses and viewing yourself as others are seeing you. The great danger is that you might undergo that radically devaluing and dehumanizing transformation from being a person to being an illness; from being Patricia to being 'a schizophrenic' (or 'a bipolar' or 'a multiple').

"Once you and the illness become one then there is no one left inside of you to take on
the work of recovering of healing of rebuilding the life you want to live. Once you come
to believe that you are a mental illness you give away all your power—and others take
responsibility for you and for your life.

"That is why I say that this is a critical and dangerous time. It is important that you
resist the efforts however unintentional they might, be to transform you into an illness.
In this regard let your anger, especially your angry indignation be your guide.

"Your anger is not a symptom of mental illness. Your angry indignation is a sane
response to the situation that you are facing. You are resisting the messages you are being
given. In and through your fiery indignation your dignity is saying, 'No, I am not an ill-
ness. I am first and foremost a human being. I will not be reduced to being an illness or a
thing. I will keep my power and save a part of myself that will, in time, be able to take a
stand toward my distress and begin the process of recovery and healing. . . .

"One of the biggest lessons I have had to accept is that recovery is not the same thing
as being cured. After twenty-one years of living with this thing it still hasn't gone away.
So I figure I'm never going to be cured but I can be in recovery. Recovery is a process, not
an end point or a destination. . . .

"To me recovery means I try to stay in the driver's seat of my life. I don't let my illness
run me. Over the years I have worked hard to become an expert in my own self-care. For
me, being in recovery means I don't just take medications. Just taking medications is a
passive stance. Rather I use medications as part of my recovery process. In the same way
I don't just go to the hospital. Just 'going to the hospital' is a passive stance. Rather, I use
the hospital when I need to. Over the years I have learned different ways of helping myself.
Sometimes I use medications, therapy, self-help and mutual support groups, friends, my
relationship with God, work, exercise, spending time in nature—all these measures help
me remain whole and healthy, even though I have a disability. . . .

"I have found that although my symptoms may seem the same or even worse, relaps-
ing while in recovery is not the same thing as 'having a breakdown.' When I relapse in
recovery, I'm not breaking down; rather I am breaking out or breaking through. It may
mean I am breaking out of some prison or fear-filled place where I have been trapped
inside of myself. It may mean I am breaking through to new ways of trusting people and
myself. So you see, when I have a relapse within the context of my recovery, I try not to
see it as a failure. It means I am growing, breaking out of old fears and breaking through
into new worlds—like learning to make friends and keep them, to trust people, and to
love people. . . .

"It is important to understand that we are faced with recovering not just from mental
illness, but also from the effects of being labeled mentally ill. I believe many of us emerge
from mental institutions with full-blown post-traumatic stress disorders that are a direct
result of the trauma and abuse we may have experienced or witnessed in mental institu-
tions or in community based programs. We are also faced with recovering from the
process of internalizing the stigma we are surrounded with; as well as the effects of dis-
crimination, poverty, and second-class citizenship. Indeed, there's no doubt that the label
of mental illness comes as a 'package plan' that too often includes poverty, trauma, dehu-
manization, degradation, being disenfranchised, and being unemployed. Many of us find
that the recovery process goes hand in hand with the empowerment process. We find
that recovery means becoming politicized and aware of the social, economic, and human
injustices we have had to endure. We find that empowerment and recovery means find-
ing our collective voice, our collective pride, and our collective power, and challenging
and changing the injustices we face.

"Finally, Patricia, I want to mention one other thing that can happen and that you
must guard against during these early years of being in the mental health system. You
might hear professionals referring to you or other people as being 'high functioning' or
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‘low functioning.’ Whether you get labeled high functioning or low functioning, don’t
fall into the trap of believing it. These are not attributes that exist inside a person. They
are value judgments that are put on a person. All these words really mean is that there
are those people whose actions or talents or gifts we value and there are those people in
which we find no value. There are no high-functioning or low-functioning people. There
are people whose contribution we are able to see and value and there are those whose
gifts we have failed to see and have failed to value. When you hear a mental health work-
er say that someone is low functioning, say to yourself, ‘That person is not low function-
ing. It’s just that the mental health worker has failed to see and value the gifts and special
talents of that person.’

“The real challenge in all this is to somehow learn to value yourself. That can seem
like such an impossible task because you get bombarded with messages and images that
are so negative and degrading. How is it, when we are surrounded by such messages of
despair, that we can begin to value ourselves? That’s a difficult question to answer. I am
twenty-one years older and I am still working on really valuing myself—but somehow
when I look back at you, Patricia, as I watch you smoking and staring, when I see the
way you are suffering and are all alone, somehow, despite all they have said about you, I
see you and a tenderness fills my heart. You are precious and good. You are not trash to
be discarded or a broken object that must be fixed. You are not insane. You do not belong
in institutions for the rest of your life. You don’t belong on the streets. And even though
they tie us down in four-point restraints and though they lock us up against our will like
animals, you are not an animal. You are a human being. You carry within you a pre-
cious flame, a spark of the divine.

“Patricia, if I could reach back through the years I would hold you. I would say
you are beautiful. I would say don’t listen to the prognosis of doom. You are more than
all their words. There is a place for you. There is a reason. This is not suffering for
the sake of just more pain. A new life can be born of this labor. A water that is life
giving can be found in this desert. Don’t give up. Although there is no magic answer,
no magic drug, and no magic cure, I would hold you now. I would tell you I love you. I
would want to protect you. I would want to rescue you, but I know that I couldn’t. It’s
not about being rescued. It’s about taking up your journey of recovery, finding good
people who will accompany you on that journey and then following your journey to
wherever it leads you.

“They may tell you that your goal should be to become normal and to achieve valued
roles. But a role is empty and valueless unless you fill it with your meaning and your pur-
pose. Don’t become normal. Our task is not to become normal. You have the wondrously
terrifying task of becoming who you are called to be. And you are not called to be an
inhuman thing. You are not called to be a mental illness. You were born into this world
for a reason and only you can discover what that reason is. You were born into this world
to grow and it is possible to grow into a whole, healthy person who also has a psychiatric
disability. Your life and your dreams may have been shattered—but from such ruins you
can build a new life full of value and purpose.

“The task is not to become normal. The task is to take up your journey of recovery
and to become who you are called to be. You were born to love and to be loved. That’s
your birthright. Mental illness cannot take that from you. Nobody can take that from
you. Patricia, become who you are called to be. Do what you do with love. Loving and
being loved is what matters. That is the value.”