

## Recovery: The Lived Experience of Rehabilitation

by Patricia E. Deegan, Ph.D.

*Patricia E. Deegan Ph.D. is an independent consultant who specializes in researching and lecturing on the topic of recovery and the empowerment of people diagnosed with mental illness. She is the creator of CommonGround, a web application to support shared decision making in the psychopharmacology consultation. It won the American Psychiatric Association's, Psychiatric Services Gold Achievement Award, the 2013 Scattergood Foundation Innovation Award in behavioral health and was a finalist in an international competition for Patient Empowerment by the Ashoka Changemakers Foundation and was recognized by the Agency for Healthcare Research and Quality as a practice innovation. Pat is an activist in the disability rights movement and has lived her own journey of recovery after being diagnosed with schizophrenia as a teenager. She is an Adjunct Professor at Dartmouth College School of Medicine and at Boston University, Sargent College of Health and Rehabilitation Sciences.*

**Abstract:** This paper distinguishes between recovery and rehabilitation. Psychiatrically disabled adults do not “get rehabilitated” but rather they recover a new and valued sense of self and of purpose. Through the recovery process, they become active and responsible participants in their own rehabilitation project. The experiences of recovery as lived by a physically disabled man and a psychiatrically disabled woman are discussed. Recommendations for creating rehabilitation environments that facilitate the recovery process are also given.

The application of rehabilitation approaches and technologies to psychiatrically disabled adults is a relatively new and exciting development in our field. The discovery and application of rehabilitation models allow us to think about this population in new and exciting ways. Of significance is the fact that from the perspective of the rehabilitation approach, it is no longer necessary to isolate the psychiatrically disabled as totally different from other groups of persons with disabilities. Today, artificial boundaries between groups of disabled persons can be bridged through the understanding that most disabled people share the same fundamental needs and aspirations: The need is to meet the challenge of the disability and to re-establish a new and valued sense of integrity and propose within and beyond the limits of the disability; the aspiration is to live, work, and love in a community in which one makes a significant contribution.

It is important to understand that persons with a disability do not “get rehabilitated” in the sense that cars “get tuned up” or televisions “get repaired.” Disabled persons are not passive recipients of rehabilitation services. Rather, they experience themselves as recovering a new sense of self and of purpose within and beyond the limits of the disability. This distinction between rehabilitation and recovery is important. Rehabilitation refers to the services and technologies that are made available to disabled persons so that they might learn to adapt to their world. Recovery refers to the lived or real life experience of persons as they accept and overcome the challenge of a disability. We might say that rehabilitation refers to the “world pole” and recovery refers to the “self-pole” of the same phenomenon.

The recovery process is the foundation upon which rehabilitation services build. This is most evidenced in the simple observation that we can make the finest and most advanced rehabilitation services available to the psychiatrically disabled and still fail to help them. Something more than just “good services” is needed, e.g., the person must get out of bed, shake off the mind-numbing exhaustion of the neuroleptics, get dressed, overcome the fear of the crowded and unfriendly bus to arrive at the program, and face the fear of failure in the rehabilitation program. In essence, disabled persons must be active and courageous participants in their own rehabilitation project or that project will fail. It is through the process of recovery that disabled persons become active and courageous participants in their own rehabilitation project.

We see then that recovery is an important and fundamental phenomenon upon which rehabilitation efforts depend. It is therefore surprising that very little has been written in our professional and scientific journals regarding it. Perhaps the phenomenon is elusive precisely because it is so fundamental. Perhaps it is because the recovery process cannot be completely described with traditional scientific, psychiatric, or psychological language. Although the phenomenon will not fit neatly into natural scientific paradigms, those of us who have been disabled know that recovery is real because we have lived it. At a recent conference that brought together persons with diverse disabilities, I had the pleasure of talking with a man who was paraplegic. We shared our stories of recovery.

### **The Experience of Recovery**

At a young age we had both experienced a catastrophic shattering of our world, hopes, and dreams. He had broken his neck and was paralyzed and I was diagnosed as being schizophrenic. We recalled the impact of those first days following the onset of our disabilities. He was an athlete and dreamed of becoming a professional in the sports world. I was a high school athlete and had applied to college to become a gym teacher. Just days earlier we knew ourselves as young people with exciting futures, and then everything collapsed around us. As teenagers, we were told that we had an incurable malady and that we would be “sick” or “disabled” for the rest of our lives. We were told that if we continued with recommended treatments and therapies, we could learn to “adjust” and “cope” from day to day.

Needless to say, we didn’t believe our doctors and social workers. In fact, we adamantly denied and raged against these bleak prophecies for our lives. We felt it was all just a mistake, a bad dream, a temporary setback in our lives. We just knew that in a week or two, things would get back to normal again. We felt our teenage world was still there, just waiting for us to return to it. Our denial was an important stage in our recovery. It was a normal reaction to an overwhelming situation. It was our way of surviving those first awful months.

The weeks passed us by but we did not get better. It became harder and harder to believe we would ever be the same again. What initially had seemed like a fleeting bad dream, transformed into a deepening nightmare from which we could not awake. We felt

like ships floating on a black sea with no course or bearings. We found ourselves drifting farther and farther away from the young, carefree people we had been. He lay horizontal and in traction while his friends were selected to play ball for prestigious colleges. I stood drugged and stiff in the hallways of a mental hospital while my classmates went off to their first year of college.

We experienced time as a betrayer. Time did not heal us. Our pasts deserted us and we could not return to who we had been. Our futures appeared to us to be barren, lifeless places in which no dream could be planted and grow into a reality. As for the present, it was a numbing succession of meaningless days and nights in a world in which we had no place, no use, and no reason to be. Boredom and wishfulness became our only refuge (Knowles, 1986).

Our denial gave way to despair and anguish. We both gave up. Giving up was a solution for us. It numbed the pain of our despair because we stopped asking, "Why and how will I go on?" (Harrison, 1984). Giving up meant that for 14 years, he sat in the day rooms of institutions gazing at soap operas, watching others live their lives. For months I sat in a chair in my family's living room, smoking cigarettes and waiting until it was 8:00 p.m. so I could go back to bed. At this time, even the simplest of tasks were overwhelming. I remember being asked to come into the kitchen to help knead some bread dough. I got up, went into the kitchen, and looked at the dough for what seemed an eternity. Then I walked back to my chair and wept. The task seemed overwhelming to me. Later I learned the reason for this: when one lives without hope, (when one has given up) the willingness to "do" is paralyzed as well.

All of us who have experienced catastrophic illness and disability know this experience of anguish and despair. It is living in darkness without hope, without a past or future. It is self-pity. It is hatred of everything that is good and life giving. It is rage turned inward. It is a wound with no mouth, a wound that is so deep that no cry can emanate from it. Anguish is a death from which there appears to be no resurrection. It is inertia which paralyzes the will to do and to accomplish because there is no hope.

It is being truly disabled, not by a disease or injury, but by despair. This part of the recovery process is a dark night in which even God was felt to have abandoned us. For some of us, this dark night lasts moments, days, or months. For others, it lasts years. For others, the despair and anguish may never end.

Neither the paralyzed man nor I could remember a specific moment when the small and fragile flame of hope and courage illuminated the darkness of our despair. We do remember that even when we had given up, there were those who loved us and did not give up. They did not abandon us. They were powerless to change us and they could not make us better. They could not climb this mountain for us but they were willing to suffer with us. They did not overwhelm us with their optimistic plans for our futures but they remained hopeful despite the odds. Their love for us was like a constant invitation, calling us forth to be something more than all of this self-pity and despair. The miracle

was that gradually the paralyzed man and I began to hear and respond to this loving invitation.

For 14 years, the paralyzed man slouched in front of the television in the hell of his own despair and anguish. For months I sat and smoked cigarettes until it was time to collapse back into a drugged and dreamless sleep. But one day, something changed in us. A tiny, fragile spark of hope appeared and promised that there could be something more than all of this darkness. This is the third phase of recovery. This is the mystery. This is the grace. This is the birth of hope called forth by the possibility of being loved. All of the polemic and technology of psychiatry, psychology, social work, and science cannot account for this phenomenon of hope. But those of us who have recovered know that this grace is real. We lived it. It is our shared secret.

It is important to understand that for most of us recovery is not a sudden conversion experience. Hope does not come to us as a sudden bolt of lightning that jolts us into a whole new way of being. Hope is the turning point that must quickly be followed by the willingness to act. The paralyzed man and I began in little ways, with small triumphs and simple acts of courage: He shaved, he attempted to read a book, and he talked with a counselor; I rode in the car, I shopped on Wednesdays, and I talked to a friend for a few minutes. He applied for benefits, he got a van and learned to drive; I took responsibility for my medications, took a part-time job, and had my own money. He went to college so he could work professionally with other disabled people; I went to school to become a psychologist so I could work with disabled people. One day at a time, with multiple setbacks, we rebuilt our lives. We rebuilt our lives on the three cornerstones of recovery—hope, willingness, and responsible action. We learned to say: “I am hopeful,” “I am willing to try,” and “I discover that I can do” (Knowles, 1986). This is the process of recovery which is the ground from which springs effective use of rehabilitation services.

Recovery does not refer to an end product or result. It does not mean that the paralyzed man and I were “cured.” In fact, our recovery is marked by an ever-deepening acceptance of our limitations. But now, rather than being an occasion for despair, we find that our personal limitations are the ground from which spring our own unique possibilities. This is the paradox of recovery, i.e., that in accepting what we cannot do or be, we begin to discover who we can be and what we can do.

Recovery does not refer to an absence of pain or struggle. Rather, recovery is marked by the transition from anguish to suffering. In anguish, the paralyzed man and I lived without hope. We experienced anguish as futile pain, pain that revolved in circles, pain that bore no possibility other than more pain, and pain that lead nowhere. However, when we became hopeful, our anguish was transformed into true suffering. True suffering is marked by an inner peace, i.e., although we still felt great pain, we also experienced a peace in knowing that this pain was leading us forward into a new future. A biologist who is handicapped with spina bifida captures this spirit of true suffering in recovery when she writes: “Suffering is peaceful. You know the pain may kill you, but it won’t destroy you. In a very risky way, you are safe.”

For many of us who are disabled, recovery is a process, a way of life, an attitude, and a way of approaching the day's challenges. It is not a perfectly linear process. At times our course is erratic and we falter, slide back, re-group and start again. Our experience of recovery is similar to that described by the poet Roethke who was himself afflicted with major mental illness:

### **Cuttings**

...One nub of growth Nudges a sand-crumble loose, Pokes through a musty sheath Its pale tendrillous horn...

...This urge, wrestle, resurrection of dry sticks, Cut stems struggling to put down feet,

What saint strained so much,

Rose on such lopped limbs to a new life?

Recovery is the urge, the wrestle, and the resurrection. Recovery is a matter of rising on lopped limbs to a new life. As professionals, we would like nothing more than to somehow manufacture the spirit of recovery and give it to each of our program participants. But this is impossible. We cannot force recovery to happen in our rehabilitation programs. Essential aspects of the recovery process are a matter of grace and, therefore, cannot be willed. However, we can create environments in which the recovery process can be nurtured like a tender and precious seedling.

Some of the principles for creating such environments in rehabilitation programs are given below.

### **Recovery in Rehabilitation Programs**

As we have seen, recovery is not a linear process marked by successive accomplishments. The recovery process is more accurately described as a series of small beginnings and very small steps. To recover, psychiatrically disabled persons must be willing to try and fail, and try again. Too often, rehabilitation programs are structured in such a way as to work against this process of recovery. These programs tend to have rigid guidelines for acceptance. They tend to have linear program designs in which a person must enter at point "A" and move through a series of consecutive steps to arrive at point "B." Failure at any point along the way will require that participants return to entry level. Finally, some of these programs define failure in absolute terms, e.g., a program participant dropped from a vocational placement for failing to attend work for X number of days is simultaneously dropped from the program and must completely re-apply to the program when ready to accept the program's rules and expectations. In all of these ways, the design and structure of rehabilitation programming can work against the process of recovery.

Rehabilitation programs can be environments which nurture recovery if they are structured to embrace, and indeed expect, the approach/avoid, try/fail dynamic which is the recovery process. This means that rehabilitation programs must have very flexible entry criteria and easy accessibility. The design of rehabilitation programming must be

nonlinear, i.e., with multiple points of entry and levels of entry into programming. The real challenge of rehabilitation programs is to create fail-proof program models. A program is fail-proof when participants are always able to come back, pick-up where they left off, and try again. In a fail-proof environment where one is welcomed, valued, and wanted, recovering persons can make the most effective use of rehabilitation services.

A second point regarding the establishment of rehabilitation environments conducive to the recovery process derives from the understanding that each person's journey of recovery is unique. Of course, there are certain fundamental constituents of the process of recovery that are similar in all persons with a disability, e.g., the experience of despair and the transition to hope, willingness, and responsible action. However, disabled people are, above all, individuals and will find their own special formula for what promotes their recovery and what does not. Therefore, it is important to offer recovering persons a wide variety of rehabilitation program options from which to choose, e.g., supported work programs, social clubs, transitional employment programs, consumer-run drop-in centers and businesses, workshops, skill training programs, and college support programs.

Consumer-run self-help groups, self-help networks and advocacy/lobbyist groups can also be important resources for recovering persons and should be available as options. Of course, these important resources can only be established and maintained by persons recovering from psychiatric disability. Creating these resources, as well as linking with other groups of disabled persons and sharing existing resources, is one of the greatest challenges that face those of us who are recovering.

Additionally, if we truly hope to offer a wide variety of rehabilitation programs to the psychiatrically disabled, then it is important to examine the values upon which so much of our programming is based. Too often we project traditional "American" values on disabled people, e.g., rugged individualism, competition, personal achievement, and self-sufficiency. Too often our program models have tacitly adopted these, and only these, values. We might ask ourselves: Are all of our local area's vocational rehabilitation programs built on a competitive model in which individual achievement is stressed more than cooperative group efforts? Are our residential rehabilitation programs all geared toward preparing people to live independently?

For some psychiatrically disabled people, especially those who relapse frequently, these traditional values of competition, individual achievement, independence, and self-sufficiency are oppressive. Programs that are tacitly built on these values are invitations to failure for many recovering persons. For these persons, "independent living" amounts to the loneliness of four walls in the corner of some rooming house. For these persons, "individual vocational achievement" amounts to failing one vocational program after another until they come to believe they are worthless human beings with nothing to contribute. For these persons, an alternative type of rehabilitation program, and even lifestyle, should be available as an option. Instead of competitive vocational training based on individual achievement, a cooperative work setting stressing group

achievement could be established. The value here is cooperation in the achievement of work goals and the sharing of responsibility for work production so that the group or work community can compensate for the individual during periods of relapse. Residential program options should include the possibility for communal living situations such as the L'Arche communities pioneered by Jean Vanier. When these types of options are made available and exist alongside rehabilitation programs based on more traditional values, then we can feel confident that we are offering a truly comprehensive network of services from which recovering persons can choose their own course of rehabilitation.

The third recommendation for creating programs that enhance recovery involves recognition of the gift that disabled people have to give to each other. This gift is their hope, strength and experience as lived in the recovery process. In this sense, disabled persons can become role models for each other. During that dark night of anguish and despair when disabled persons live without hope, the presence of other recovering persons can challenge that despair through example. It becomes very difficult to continue to convince oneself that there is no hope when one is surrounded by other equally disabled persons who are making strides in their recovery!

Hope is contagious and that is why it is so important to hire disabled people in rehabilitation programs. Because recovery is a phenomenon that is similar for all disabled people, it can be very effective to have persons with divergent disabilities act as role models for one another. Additionally, a person need not be "fully recovered" in order to serve as a role model. Very often a disabled person who is only a few "steps" ahead of another person can be more effective than one whose achievements seem overly impressive and distanced.

Finally, and perhaps most fundamentally, staff attitudes are very important in shaping rehabilitation environments. There are a number of common staff attitudes that are particularly unhelpful to recovering persons. For instance, too often staff attitudes reflect the implicit supposition that there is the "world of the abnormal" and the "world of the normal." The task facing the staff is to somehow get the people in the "abnormal world" to fit into the "normal world." This creates an us/them dichotomy wherein "they" (the disabled) are expected to do all of the changing and growing. Such an attitude places staff in a very safe position in which they can maintain the illusion that they are not disabled, that they are not wounded in any way, and that they have no need to live the spirit of recovery in their own lives. Indeed, when the us/them attitude prevails, "staff" and "clients" are truly worlds apart. Such an environment is oppressive to those disabled persons who are struggling with their own recovery.

If a rehabilitation program is to be a dynamic setting that promotes and nurtures the recovery process, then the rigid walls separating the "world of the disabled" and the "world of the normal" must be torn down. Staff members must be helped to recognize the ways in which they, too, are deeply wounded. Perhaps they have experienced anguish in their lives or perhaps they have known personal tragedy or struggle. To embrace and accept our own woundedness and vulnerability is the first step toward

understanding the experience of the disabled. In so doing we discover that we share a common humanity with the disabled and that we are not “worlds apart.”

A dynamic rehabilitation environment is one in which staff members are vitally involved in their own personal growth and/or recovery. Therefore, they empathize deeply with the woundedness and vulnerability that the disabled experience. They understand that in some mysterious way to be human means that all of us must “rise on lopped limbs” to a new life.

Sources:

Dunne, J. Sense of community in L'Arche and in the writings of Jean Vanier: Daybreak monograph 20. Richmond Hill, Ontario: Daybreak Publications.

Harrison, V. A biologist's view of pain, suffering and marginal life. In F. Dougherty (Ed.), *The deprived, the disabled and the fullness of life*. Delaware: Michael Glazier.

Knowles, R.T. *Human development and human possibility: Erikson in the light of Heidegger*. Lanham: University Press of America.

Roethke, T. *The lost son and other poems*. In *The collected poems of Theodore Roethke*. New York: Anchor Press/Doubleday.

Vanier, J., & Wolfensberger, W. *Growing together*: Daybreak monograph 2. Richmond Hill, Ontario: Daybreak Publications.