

**I Don't Think It Was My Treatment Plan That Made Me Well:
Self-Directed Recovery, Peer Support and the Role of the Mental Health
Professional**

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Today Phillip is raising his son, working full time, living in the community and has not been in a hospital since 1990. However, staff working with Phillip fifteen years ago perceived him to be severely and persistently mentally ill. They felt he belonged on the chronic unit of a state hospital and that he was one of the ones who would never get well. Indeed, the picture of Phillip's life at that time was bleak. Phillip had been in hospitals seventeen times, spent two years in a psychiatric custodial facility known as an adult-home, and was diagnosed with a variety of severe mental disorders and substance abuse. Despite the hopelessness and the prognosis of doom that surrounded him, Phillip recovered.

It was not Phillip's treatment plan that made him well. Rather, Phillip's recovery was self-directed. It began with a turning point that occurred when he was looking out a window in a state hospital. He looked down on the same exercise yard he had been looking at for years. But on this day he saw something new. He saw a new possibility for himself and his life. Here are his words:

I remember looking out at the back yard and seeing everybody walking around, and something hit me that life was wonderful. Something just hit me at that moment, and it stood in my mind, all these people are just wasting our lives. The backyard was packed. It was a sunny day. And I

said, 'We're wasting our lives sitting in this place. I think from that day on is when I realized that something clicked. That life was worth it. That I needed to work on things. It hit me that I had a problem. I had to trust my judgment and just work at things and feel what inside told me to do. What I felt to get myself better...I decided to quit smoking and start exercising. But before I quite, I started exercising in the back yard. Instead of me walking around smoking, I decided to start jogging around. I concentrated and put my mind together and started jogging once or twice...I finally got, in the behavior treatment unit, a doctor who listened. So every time I asked to lower the meds, he actually did it. It was helping. I was able to run more and somehow I realized the running caught up to my brain that was going so fast. I just couldn't put the two together. Finally, the running actually synchronized the both of them, I realized. (Deegan & Strecker, 2004)

Phillip experienced a turning point that was quickly followed by a self-directed recovery plan. He decided to quit smoking and start jogging in the hospital exercise yard. He intuited that the jogging helped his body catch up with his mind that was racing so fast. Professionals did not understand this plan, but Phillip did not need approval from others in order to persevere. He had found a new, inner authority: "I had to trust my judgment...and feel what inside told me to do." Importantly the clinicians did not stand in the way of Phillip's plan and the

psychiatrist continued to lower Phillip's medication. This allowed him to have more energy to pursue his "jogging cure".

Phillips story helps us understand that people with psychiatric disabilities are resilient. We are not merely passive victims afflicted with major mental disorders. We do not simply lie down and give up in response to our distress. Rather, like most other people faced with adversity and catastrophic life events, we search for ways to survive, to cope, to adapt, to overcome and, ultimately, to thrive.

Our emerging understanding of the innate self-righting capacity, or resilience, of people with psychiatric disabilities, paired with emerging data on the effectiveness of peer-support, presents many challenges to mental health professionals. How do professionals, trained to be experts in diagnosing and treating illness, approach people who are resilient and who wish to be self-directing? What should professionals' role be in relation to Phillip's self-directed recovery plan that began with a "jogging cure"? What is the role of professionals in relation to peer-support?

In this paper we will explore the changing role of mental healthcare professionals in relation to the new model of self-directed recovery. We will explore the resilience and self assessed health resources of people with psychiatric disabilities. We will explore the concept of personal medicine and how clinicians can support clients in the use of their personal medicine in order to enhance the

recovery process. We will explore both contemporary and historical examples of self-directed recovery and coping strategies and make suggestions as to how clinicians can help support people in that work. Finally, we will discuss the evidence that peer support is helpful and offer suggestions as to how professionals can support it.

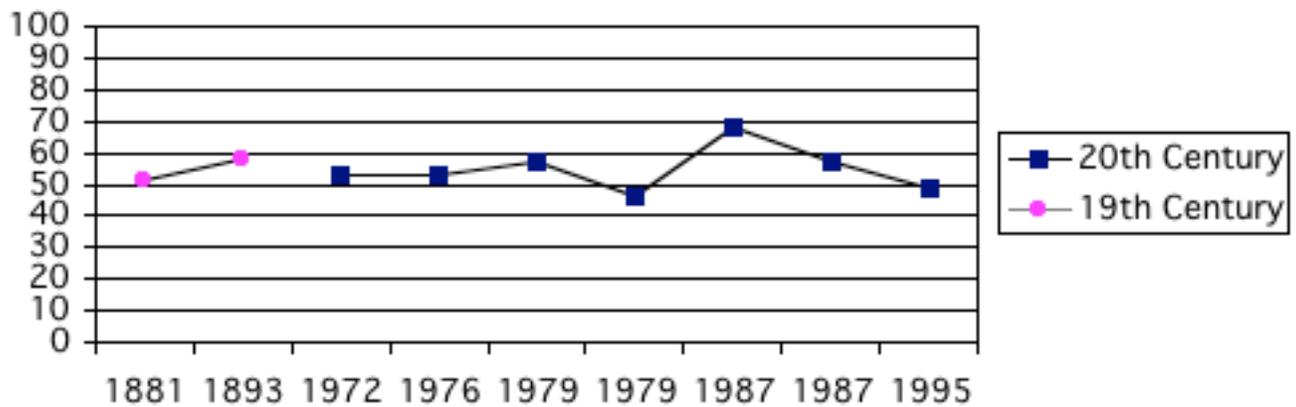
Resilience and Recovery

People with psychiatric disabilities are resilient and the majority of us recover. Despite the enduring legacy of pessimism about outcomes, worldwide longitudinal studies on recovery have consistently found that half to two thirds of people diagnosed with schizophrenia significantly improve or recover (Harding & Zahniser, 1994). In seven worldwide longitudinal studies on recovery from schizophrenia (Bleuler, 1972; Ciompi & Muller 1976; Huber et al. 1979; Ciompi 1980; Tsuang et al. 1979; Harding et al., 1987; Ogawa et al 1987; DeSisto et al 1995) recovery has been found to include living and working in the community in a fashion similar to that of other community members, being free of psychiatric symptoms, using or not using psychiatric services including psychiatric medications, having a network of friends and family, and living in fully integrated housing. Recovery does not mean stabilization, maintenance or sitting in a drugged stupor, smoking cigarettes and drinking coffee.

Positive recovery rates are not confined to modern times. Grob (1966) reports on one of the largest longitudinal studies of recovery in the world literature. It was

conducted between 1881 – 1893 at Worcester State Hospital in Massachusetts. Surveying the status of 1,157 people discharged as recovered since 1840, the researchers found that 58% remained well for the rest of their lives, some as long as 40 years after discharge. The same researchers found that 51% of those discharged as recovered *prior* to 1840 remained well and never returned to the hospital. Table 1 illustrates the clustering of these empirically established recovery rates over two centuries.

Table 1
Rates of Recovery 1881 - 1995



Deegan (2002) suggests using a consumer/survivor-centric interpretation to understand the clustering of these recovery rates. Rather than crediting modern (or not so modern) treatment methods for these successful recovery rates,

Deegan suggests we recognize and explore the fundamental resilience of people with psychiatric disabilities.

In her comprehensive review of the literature on recovery and resilience, Ridgway (2004) notes that although there is no single, accepted operational definition of resilience, the concept refers to the capacity of people who are faced with adversity, to adapt, cope, rebound, withstand, grow, survive and even thrive (p.10). Importantly, resilience does not refer to a magical state of invulnerability. Ridgway (2004) notes the capacity for resilience does not end when one has a psychiatric disability. She concludes that recovery and resilience are two sides of a multi-faceted phenomenon and that, "The dynamic, complex self-righting capacities that we call resilience and recovery are advanced when people have hope, a sense of meaning and purpose and a spiritual life."(p.3)

The concepts of recovery and resilience shift clinicians' attention away from disease processes and onto the whole person. Clinicians become less concerned with charting pathological processes and more interested in understanding and enhancing the innate self-righting potential of each person who comes for help. The focus becomes salutogenesis or the origins of health, rather than pathogenesis or the origins of sickness (Antonovsky1979; Hollnagel & Malterud, 1995).

In order to understand the resilient and resourceful person who comes for help, clinicians must be willing to explore the subjective experience of the client.

Strauss (1989, p.179) notes that:

We in the mental health field do not listen to what patients experience as well as we think. There are many things that patients are trying to tell us about their subjective experiences that we systematically fail to hear.

In the following sections we will listen to what mental health clients are teaching us about resilience, recovery and how clinicians can be of help.

Personal Medicine

Joe¹ is 41 years old and has been diagnosed with bi-polar disorder. During an interview Joe explained what he had learned about the difference between pill medicine and personal medicine:

I think medication is a *part* of the whole solution. I don't think it's *the* solution...I think there's a lot of other things that is medication that's not really considered medication. There's things that you can do that does change what your body does and it may not be medicine...I still think that one of the best mood stabilizers there is in life – maybe not for everyone – but for me, is math. That stimulates your intellectual process.

Joe does not look to pill-medicine for his recovery. He has learned that pill-medicine alone is not the solution. Recovery means changing our lives, not our

¹ Verbatim quotes from interviews conducted by the author. Names have been changed to protect confidentiality. Quotes used with permission.

biochemistry. Joe has found that math is an effective mood stabilizer for him. Math is something that stimulates his intellect and makes him feel alive and well. It calms him, gives him a sense of mastery and eventually lead him back to school to finish his education. Math is strong personal medicine for Joe and is integral to his recovery.

Each individual has his/her unique personal medicine. Nadene, diagnosed and treated for schizophrenia since childhood, found that singing was powerful personal medicine. After years of institutionalization, she joined a gospel singing group and found new meaning and purpose in her life that ended her cycle of recidivism:

And I sung for a living for five years...We were real good I must say...And I was the lead singer...God I loved it...Oh man. It's like I'm in heaven myself you know? And I like to make people happy. You know, and I would sing and, or, the group would sing. And they would love us and stuff like that and in return I would love what I was doing you know? I still sing every once in a while. Yeah. But that feeling was, it was like I was floating.

Nancy, who is 29 years old and diagnosed with schizophrenia, reported that her personal medicine includes being a good mother as well and volunteering in the community:

I love being a mother. I love spending time with (my kids). I love playing with them. I love teaching them. I love putting them to bed. I love hearing them argue, 'It's not bedtime. I don't want to go to sleep.' I mean I love it all. I love the hard times. I love the good times...Being a mom is very important to me. And being a good person in the community, like volunteering like we do. My husband and I volunteer. Doing that is very important to me.

Personal medicine sometimes includes being involved in activities that are stressful. In other words, recovery does not occur by learning to avoid all of life's stresses and many people have found the professional's advice to "avoid stress" to be unhelpful. For instance in her first person account of recovery from schizophrenia, Marcia Lovejoy (1982) says that her psychiatrist advised her not to return to school and to regard herself as retired although she was only in her early 20's:

When I inquired about returning to school, he cautioned me to dismiss the idea of ever returning to academic pressures. He said I should realize that I was ill and had to take things easy. I asked about looking for work, and he stressed that this too was out of the question for me. Maybe in a few months a volunteer job might be a possibility. He cautioned me not to think about any of these things right now, and just to regard myself as retired and needing a long, long rest. (p. 606)

Many people find that boredom, even when prescribed by a physician, is stressful (Deegan, 1988). The stress of boredom can work against recovery. Achieving valued social roles such as college student, parent, and worker may be stressful, but that stress is different than the type of futile stress involved in boredom. Tamika makes this point when she says that for her, going to school was powerful personal medicine even though it was stressful. The stress associated with being a university student was bearable because it had a purpose to it:

It's stressful but it's kind of just good stress you know. I mean there's a purpose to it. A good purpose. And I think that's why I still do it. It's, it keeps me from thinking about other things. Going to other sources (street drugs) on how to relieve my stress.

In a similar way Nadene finds that work is powerful personal medicine. Working full time can be hectic and stressful but ultimately fills her life with purpose, keeps her depression at bay and keeps her out of the hospital:

If I wasn't working my job I'd end up in a hospital or something like that. Depressed all the time. But since I'm working, I'm full time and I'm going, going, going. I just love it you know...It's keeping me from being in the hospital.

Mathematics, singing, parenting, volunteering in the community, going to college and working are all forms of personal medicine. Personal medicine refers to

those things that give life meaning and that make life worth living. Personal medicines are the things that build our sense of self-esteem, mastery, and confidence. Personal medicines are the things we do that soothe and comfort us, as well as the things we do that challenge, intrigue and engage us.

Sometimes mental health treatment interferes with people's personal-medicine. For example, Nancy – the young mother quoted above – became severely depressed and sought treatment. However, the medications she received interfered with her ability to be a good mother, resulting in an iatrogenic trap from which she found it difficult to escape:

I was on Depakote and I was tired. I was moody. They put me on it to help my depression. I got more depressed. I started sleeping all the time. I gained a lot of weight. I wanted to end life because I had so much pain. I couldn't do anything. I was in bed. My house cleaning wasn't getting done. I did not feel I was a good mother because I did not have the drive to take care of my kids. I took them to daycare because I just had to sleep. So I got them a babysitter and I slept and slept and slept on that medication. So I quit taking it at times. And I would then do better, lose the weight, get better and then I would hear voices and hallucinate and need help and tell the doctor that. I would get back on medication, gain weight again, get depressed, get big again.

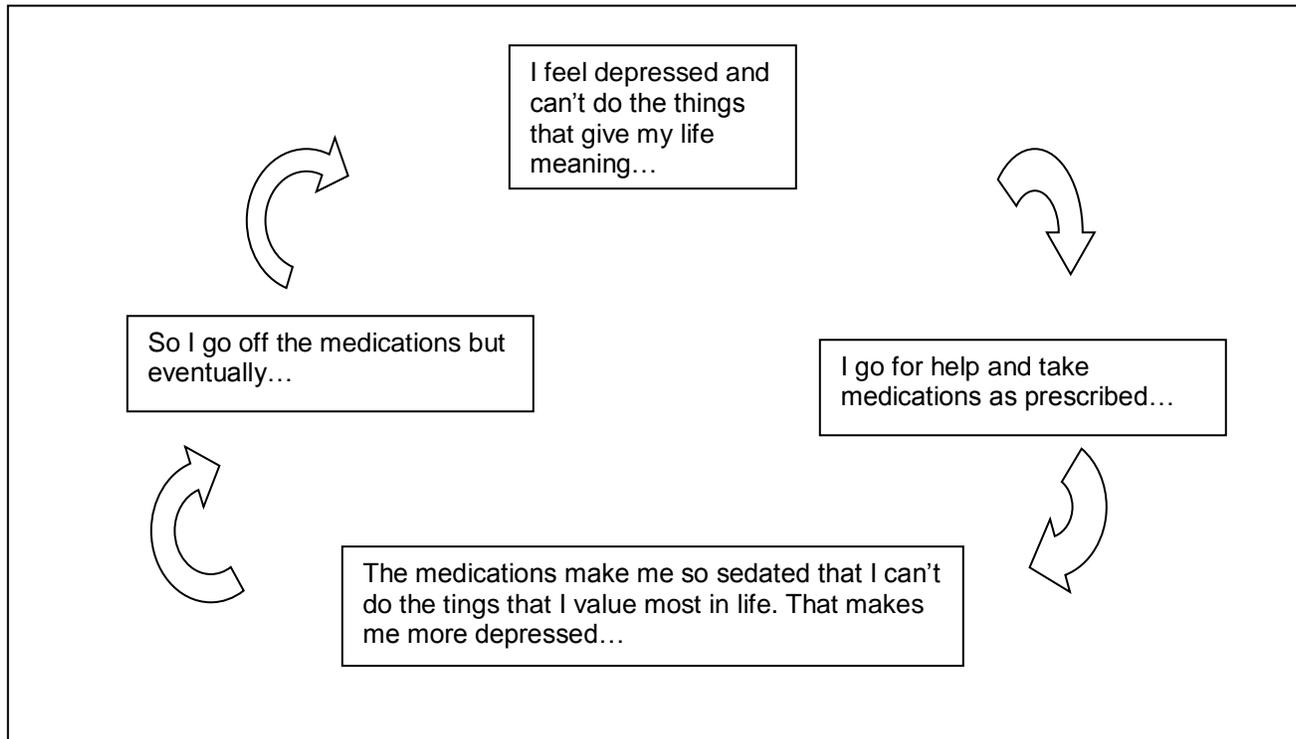
The medications made it impossible for Nancy to care for her children. However, being a good mother was powerful personal-medicine and was just as important as any mental health treatment she received. Clearly, professional treatment interfered with the things that made life worth living for Nancy.

From the perspective of a person-centered, recovery-oriented approach, Nancy's treatment was a failure. It was a failure because her clinicians did not enhance and support Nancy's personal medicine and her own self-righting capacity. The treatment failed because it focused more on symptom abatement than on the client in the context of her life. It should not be surprising then, that Nancy rejected the treatment. She was not willing to sacrifice her role as mother. She was not willing to sacrifice her personal medicine in order to be compliant with prescribed medicine. Predictably, Nancy became non-complaint with the prescribed medication. This was not a crazy choice. In fact, it could be argued that it was a life affirming choice originating from her determination to live *her* life and preserve those things that give her life meaning.

When Nancy went off her prescribed medications she found herself entrapped in a downward spiral that is illustrated below:

Diagram 1

When Treatment Interferes With Personal Medicine



What Nancy required, and eventually found, were mental health clinicians who recognized and joined with the priority of her desire to be a good mother. These recovery-oriented clinicians collaborated with her to preserve her valued social role *and* to find help for her depression. Here is Nancy's description of her recovery oriented practitioner:

She's a nurse practitioner. She's better to work with than the doctors we have. She listens to us and she seems like she's up on all the medication. She knows a lot about everything like thyroids and everyting and she just listens to you. She wants you to be the best person you can be so she

tries to get medication for that. Not something that's just going to, as I call it, zombify you out and get rid of the symptoms. She wants to get rid of the symptoms but also wants you to live. So if you can talk to somebody like that, it's a lot better...And I also go to DBT. I love it. I love it. It is teaching you skills that you need to live. It offers hope. It's re-teaching your brain to take care of yourself better and healthier...(Also another therapist that helps with) Parenting. Just helping me with parenting things.

As Nancy's experience teaches us, symptom abatement at the cost of losing the things that make life worth living is unacceptable. The effective clinicians were the ones who recognized Nancy's personal medicine, supported her in maintaining her valued role as mother, and helped her address her depression. Treatment must work to enhance clients' personal medicine. That is the recovery-oriented approach.

Sometimes clinicians interpret a client's personal medicine as part of a psychiatric disorder. For example, Kim is 46 years old and has had a variety of psychiatric diagnoses over many years including major depression, schizophrenia and bi-polar disorder. Although Kim took an antidepressant without complaint because she valued its effect, she only sporadically took a neuroleptic that was prescribed for her. The reason for her non-compliance? She felt the medication was drugging a valued part of her, rather than treating a disorder:

I can get into some mania, which for me, I don't know if it is a bad or a good thing. I don't really see it as mania. I see it as part of me. I just see that as an extension of me when I am full of energy. I am able to do things. My kids, well, my young people, they find it was a great thing because there was mom that could run around them, be helpful and go shopping, and do these wonderful things. It was pointed out to me from a medical point of view that 'That's not normal.' To be, to have so much energy. That if I am talking a lot. But if you knew my family, we all talk a lot. We all move fast. And so it was hard for me to struggle with this. To know which is part of me, Kim. Kim's personality. The way I am and the way God created me. Which is this piece that is part of the mental illness disease? This is the me that I know but then there's somebody else calling it a disease, a problem. Well, for me, sometimes this problem has got me through a lot!

If we view Kim in the context of her life, we learn she is a single mother with three children. She must work hard to support her family. It takes a lot of energy and stamina to keep up with her responsibilities. Kim views her high level of energy to be a type of personal medicine. She experiences her energy as a strength and an asset. In fact, Kim attributes her stamina and energy with having helped her through difficult times. For Kim, her energy is not a symptom of a disorder. It is a self-assessed health resource (Malterud & Hollnagel, 1997). Kim's clinician on the other hand, views her energy as part of a psychiatric disorder. He

prescribes neuroleptics to treat what he perceives as hypomania. Kim refuses to take the drug and the clinician labels her non-compliant and treatment resistant. How can this clinical impasse be resolved?

Malterud and Hollnagel (1997) suggest that the impasse can be resolved when the clinician uses it as an opportunity to further understand the client's life context and strengths. They have found that such impasses are not uncommon in general medical practice. Patient's self-assessed health resources sometimes contradict commonly held clinical/medical understandings. They define self-assessed personal health resources as "the individual's subjective experience and perception of qualities or strategies which she thinks maintain her health, irrespective of empirical evidence about health effects" (p. 15). Such differences in viewpoints can be an opportunity for the clinician to explore the client's resilience and life-context. Rather than asserting the primacy of the clinical/medical viewpoint, Kim's clinician could have used this difference to explore other ways she manages the stressors and challenges of her life.

In a recovery-oriented approach clinicians must listen to what we have to say and inquire about our personal medicine. Some of the questions that clinicians might use to explore our personal medicine are:

- What are the things you enjoy doing most during the day or week?
- What are things you value in life?
- What are the things that give you a sense of purpose and meaning?

- What are your plans for your future?
- When have you been happiest in the past?

In a recovery-oriented approach, the focus is on clients in the context of their lives. The measure of success is not simply an absence of symptoms or reduction in inpatient admissions. In a recovery-oriented approach, success is also measured by how well we are able to pursue the things that give our lives purpose and meaning. Success is measured by how we maintain and even expand the social roles we value e.g., parenting, working, solving math problems, friendship, marriage, etc.

In order to view us in the context of our lives and to value our personal medicine, clinicians must learn the difference between disorder and the experience of distress. This important distinction has been extensively studied in the broader field of patient-centered medicine (Stewart et al., 2003). Clinicians are trained to observe signs and symptoms, formulate diagnoses and treat disorders. However, as the following quote from a physician demonstrates, it is possible to treat a disorder but fail to help the patient.

The big lesson for me was learning the difference between treating the disease and treating the human being. It's not always the same thing. There are times you can kill the person – in a sense, killing their spirit – by insisting that something be done a certain way. (Herwaldt, 2001, p.21)

Disorder and disease are abstractions and constructs and should not be confused with the lived-experience of clients. A person is never a disorder. We are always more than our diagnosis. The clinician's understanding is not complete until he/she understands the client's experience of the disorder as well as his/her life context, personal medicine and self-assessed health resources (Malterud & Hollnagel, 1997). In a sense, the clinician must learn to "unsee" the diagnosis in order to meet the *person* who comes seeking help. Perhaps the great artist Monet knew something of the discipline of "unseeing" that allowed him to shed the tired categories of perception and labeling, in order to see the world anew:

"It was Monet, the painter, who said that in order to see, we must forget the name of the thing we are looking at." (Patterson, 1979, p.10)

Recovery-oriented practitioners will strive to be like Monet. Forgetting the diagnosis and unseeing the signs and symptoms, a new view of a whole, resilient human being, framed by the multi-colored hues of life context, will emerge. This is the person that holds the key to recovery. This is the person the clinician must learn to partner with.

Self-Directed Recovery

The image of the passively afflicted and helpless mental patient is prevalent in the general public, as well as in the mental healthcare professions (Strauss, Harding, Hafez & Lieberman, 1987). Such misconceptions are disabling to us

because they decrease professional and societal expectations about who we are and what we can accomplish. Lowered expectations, in turn, result in fewer opportunities to access programs, services and resources through which to improve our lives. Thus, a systemically-based, self-fulfilling prophecy is established (Deegan, 1992).

One of the most significant, but often ignored, challenges to this view are the stories told by ex-patients about their experiences. There are over 300 first-person accounts of madness published in English, with the oldest written in 1436² (Hornstein, 2002). These first person accounts comprise an “evidence-base” that defies the misconception that we are passively afflicted, weak, and helpless. Instead, the collective image that arises from these accounts is of a people who are strong, tenacious and, above all, resilient. We shall examine one of these accounts from the 19th century and compare it to the resilient, self-directed recovery used by people with psychiatric disabilities in contemporary times. Through comparison of historical and contemporary accounts of self-directed recovery and coping, we will demonstrate that there are broad similarities in how people go about recovering from major mental disorders irregardless of an era’s preferred treatment modalities. We will then examine what clinicians can do to support self-directed recovery in the clients they serve.

² The Book of Margery Kemp was rendered into modern English by W. Butler-Bowdon. New York: Devin-Adair, 1944.

John Perceval wrote his account of madness and recovery in the first half of the 19th century (Perceval, 1838,1840; Bateson, 1974). In his late twenties, Perceval began to see visions and hear voices that often commanded him to do contradictory things. Eventually, he was placed in two madhouses and treated by “lunatic doctors” over the course of nearly four years (Peterson, 1982). Despite cruel and inhumane conditions, as well as his severe and protracted periods of distress and disorganization, Perceval discovered a number of strategies to help himself get well. One of the most fundamental was adopting the discipline of self-observation:

During the progress of my recovery there, I kept watching minutely all my experiences, and my conduct, and that of other patients, comparing their cases with my own and drawing such conclusions as in those painful circumstances I was able...Keeping my mind continually intent upon unraveling and understanding the mysterious influence I was under...
(Perceval/Bateson 1838/1840, p.270,271)

Perceval’s disciplined self-observation and observation of peers, with the goal of learning to control or eliminate symptoms, is widely used by people with psychiatric disabilities in contemporary times. When Mary Ellen Copeland (1994) was diagnosed with bi-polar disorder, she asked her doctor how people with the disorder get by on a day-to-day basis. He was unable to answer this question and so she set out to answer it for herself. Through close observation of her own experience, and by studying the experiences of peers, Copeland not only

achieved her own recovery, but was able to develop the Wellness Recovery Action Plan (1997) for others to use. Not unlike Perceval's discovery 150 years earlier, the WRAP self-care plan relies heavily on disciplined self-observation and provides opportunities to learn from peers.

The Wellness Recovery Action Program is a structured system for monitoring uncomfortable and distressing symptoms and, through planned responses, reducing, modifying or eliminating those symptoms. (p.3)

Through close observation Perceval was able to determine that when he was upset his breathing became rapid, uneven and panicked. By learning to control his breathing and taking deep, sustained breaths, he was able to change his thinking and mood. Interestingly, some of his spirit voices advised him on the details of how to control his breath:

Moreover I have remarked, that when my mind is most disturbed, I breathe at that time violently and rapidly, and with difficulty through the nostrils...The spirits also which I conceived to speak to me, used to direct me to control my breath, and 'to breath gently up one nostril down another.' I have often found too, that when I am depressed or agitated by any passion, a deep-drawn breath will change the whole complexion of my thought and the tenor of my desires. (Perceval/Bateson, p.274)

When distressed, Perceval learned to attend to his breathing and even mastered a technique of gently breathing up one nostril and down another. In

contemporary times this practice of mindful breathing continues to be discovered by people with psychiatric disabilities. For instance Virginia Wentworth (1994) was diagnosed with bi-polar disorder, hospitalized a number of times and treated with medications for many years. As part of her recovery she began to meditate for 20 minutes a day. At one point she had another manic episode and was again hospitalized. When reflecting on her experience she wrote:

In retrospect, I think the most important contributor to my mania was that I hadn't maintained my daily meditation program in the four weeks prior to escalation. During that period even when I did meditate I didn't breathe deeply and slowly enough. I wasn't relaxing tensions I was storing them. My whole system, my physiology escalating, my blood pressure got dangerously high and I got the flu. I had difficulty sleeping and I was tired. I know now that I need to be consistent and disciplined in my meditation practice doing it daily for a least twenty minutes if I am to stay relaxed.

(p.87)

Similarly, Edward Knight (2004), diagnosed with paranoid schizophrenia and hospitalized, discussed how his recovery depended on moving beyond total reliance on experts, and learning to be self-directed in his recovery. Like John Perceval, part of his path to self-directed recovery was learning to self-direct his breathing to control his distress:

I discovered that I could use my concentration abilities to re-focus my attention away from anxiety, negative emotions and fearful images. I paid

attention to the tree, or to my breath going in and out of my nose, and in this way rode out the panic and spaciness. (p.8)

Perceval was often tormented by voices which he sometimes referred to as spirits. Although he was initially overwhelmed by the spirits and felt powerless to resist their commands, he eventually discovered strategies that lead him to believe that the voices were not all-powerful. In other words, over time Perceval learned that he could shift his attention away from the voices. He also learned that he sometimes slipped into a listening-attitude (Arieti, 1974) that actually made it easier to summon and hear voices. He wrote:

Here is what I discovered one day, when I thought I was attending to a voice that was speaking to me, that, my mind being suddenly directed to outward objects, - the sound remained but the voice was gone; the sound proceeded from a neighbouring room or from a draft of air through the window or doorway. I found, moreover, if I threw myself back into the same state of absence of mind, that the voice returned...I found that although these voices usually came to me without thought on my art, I had sometimes a power, to a certain extent, to choose what I would hear. (Perceval/Bateson, p. 294)

Romme & Escher (1989) have developed an emancipatory approach to working with people who hear distressing voices. The approach builds on their finding that voice hearers often develop a wide variety of strategies to cope with distressing voices. Many people develop these coping strategies and never come

to the attention of mental health professionals. Like Perceval, contemporary voice hearers discover many ways to cope: ignoring voices, accepting voices, telling voices to go away, understanding voices, learning what triggers voices, distinguishing between helpful and tormenting voices, and planning to listen to voices at predetermined times during the day. In 1987, voice hearers organized their own support groups to decrease the loneliness and isolation caused by a society that is intolerant of their unique experiences³. The Hearing Voices Network, based primarily in the United Kingdom and the Netherlands, has held a number of international conferences, written books and articles and continues to provide self-help and peer-support to voice hearers (Baker, 1992).

As Perceval recovered, he began to differentiate tormenting spirits from other ones that brought him important information about what he must do to recover. For instance he reports:

Now the voices I used to hear during my illness at Dr. Fox's told me...'keep my head and heart together,' not to let 'my head go wandering from my heart,' – that 'if I kept my head an heart together,' I should do well. (Perceval/Bateson p.272)

At first Perceval did not understand what this meant. However, in time he discovered:

³ To learn more about the voice hearers network go to <http://www.hearing-voices.org>

But know I conceive that the voices when they told me to keep my head and heart together, meant me to think on what I was in need of or desired; of those subjects or objects my heart and health dictated to me, since the head may be occupied on subjects which are repulsive to the heart, or out of time, and out of place, and out of character; as if a parent who had a family of children craving for food, were to go idling to a fair to look at puppet shows... (Perceval/Bateson, p. 272)

With a few notable exceptions (Perry, 1976; Podvoll, 1990; Romme & Esher 1993; Watson, 1998) contemporary understandings of major mental disorders, especially psychotic disorders fail to take account of experiences like the one described above by Perceval. For Perceval psychosis was not simply an epiphenomenon of wildly disordered neurochemistry. Perceval's psychosis was not all non-sense. From within the cacophony of tormenting spirits another type of voice emerged – a helpful voice. In time Perceval learned that these voices had something of value to teach him. To paraphrase, the helpful voices told Perceval: 1. Keep your heart and your head together and you will do well; 2. Don't let your head go wandering off from your heart or you will be out of touch with what you really desire and need; 3. What you really need is what your heart and health dictate; and 4. Keep your head focused on that, rather than on repulsive subjects that are out of character for you. This is undoubtedly sage advice! Slowly Perceval began to incorporate the teachings of the helpful voices into his self-directed recovery.

In contemporary times some people with psychiatric disabilities continue to find that not all voices are tormenting. Some are helpful, provide encouragement, provide direction, provide companionship and/or provide good advice. This is illustrated in a transcript from a voice hearer provided by Romme & Escher (1989, p. 211):

In this period of trying to ignore the voices, to my surprise there were two voices that wanted to help me. My first reaction was to send them away, because this whole story was getting on my nerves, but they insisted that I needed them and to be honest, I realized this was true. The voices taught me how to watch, hear and feel...At first we jerked along. I wasn't used to thinking in symbols at all, but I could immediately apply what they taught me and as a result I began to feel better.

Perceval was able to apply what he was learning so that his thoughts did not have free reign to wander off and entertain powerful delusions. Through determined self-observation he began to find contradictions between what his delusional voices told him, and what actually happened. For instance early on in his stay at the madhouse, his spirits were ordering him to do a variety of things and if he disobeyed, he was told he would be struck by a lightning bolt. In an act of courage Perceval defied the commanding voices, only to find that the thunderbolt struck harmlessly by his side:

A kind of confidence of mind came in me the evening after I had been threatened (by voices), and saw the thunderbolt fall harmlessly by my side...nothing ensuing, confidence again came in me, and this night a change took place in the tone of the voices. (Perceval, p. 54; Podvoll 1990 p. 40)

It is important to note that although insight into the contradictions posed by the spirits came suddenly at times, Perceval often slipped back into unwavering belief in them. "My recovery was very gradual, but its periods remarkable." (Perceval p. 142). However with determined persistence over a period of four years and by repeatedly noting the contradictions and false claims made by the spirits, Perceval freed himself from the grip of his delusions.

A century and a half after Perceval, Chapman (1994) found a similar solution to ridding himself of his delusions. Chapman was diagnosed with paranoid schizophrenia at the age of 20 years old. Like Perceval, Chapman's recovery did not occur through a sudden burst of insight:

My recovery would come gradually as I changed my view about my false beliefs... With a motivation to overcome ill-thinking and false beliefs I learned to recognize and change a bizarre world which had taken a bold and unreserved place in the front rows of my mind. I began my three phases of recovery – *Recognize and Identify*, *Counter-argue*, and *Replace* delusions. (p. 7)

Chapman used the same type of rigorous self-observation as Perceval in order to discern discrepancies between what his voices told him, and what in fact happened. He called his method, the “opposite principle”:

Through a period of years, I was coming to realize that there was a method to my madness. By this I mean every time I compared reality to a delusion, I found reality to be the very opposite of what the delusional idea was making me believe. It became apparent to me that reality was something to be considered. This pet theory of mine was one I referred to as the ‘opposite principle’...I became, in a manner of speaking, a detective unto myself. (p.6)

Similarly, John Nash, the Nobel Prize winner whose life was depicted in the film *A Beautiful Mind*, reports using similar strategies to free himself of delusions. This quote is taken from an interview with him on National Public Radio (2002):

I don't really remember the chronology very well, exactly when I moved from one type of thinking to another. I began arguing with the concept of the voices. And ultimately I began rejecting them and deciding not to listen... **Harold Kuhn:** I said, ‘John, how in the devil have you recovered?’ He said, ‘I willed it. I decided I was going to think rationally.’

Deciding to think rationally, arguing with voices, becoming a detective unto oneself, disciplined self-observation, learning from the wise voices, learning to

divert attention from distressing voices, avoiding the listening attitude, keeping the mind tethered to the heart, mindful breathing and meditation, and observing the contradictions in what delusional voices predict – these are just some of the strategies developed by resilient people as part of their self-directed recovery. People diagnosed with major mental disorders have been discovering and using these strategies over centuries with or without guidance or direction from professionals. The point here is not that professionals are of no use. Rather the point is that professionals need to reformulate their understanding of the innate resilience and capacity for self-directed healing of people with psychiatric disabilities. The goal is for clinicians to partner with and support self-directed recovery.

Clinicians are most often trained in a disease-deficit model. This training emphasizes observing what is wrong and problematic: he is low functioning; she has flat affect; he has not worked in fifteen years; he is decompensating; she is rapid cycling; she has not returned to baseline; etc. The emphasis on deficits and problems can be so absolute that Strauss (1989) reports during a research interview a woman diagnosed with schizophrenia asked him, “Why don’t you ever ask what I do to help myself?” (p. 182).

When researchers have taken the time to ask people with psychiatric disabilities what they do to cope, they have often been astonished at the number and diversity of self-care strategies reported. For instance, Vaughan Carr (1988) set

out to have 200 people complete a survey on coping strategies. All of the research participants were diagnosed with schizophrenia and were living in the community. The average duration of illness of the research participants was 13.5 years. To the researcher's surprise, in addition to completing the questionnaire, 92 of the research participants went on to volunteer an additional 350 coping strategies that they used that hadn't been mentioned on the questionnaire. Carr grouped these coping strategies into five categories that included behavior control, cognitive control, socialization, medical and symptomatic. He concludes:

From the foregoing it should appear obvious that schizophrenic patients are not simply passive victims of their illness. On the contrary, these results...suggest that in schizophrenia patients can play an active role in the management of their illness, particularly in the containment of its symptoms...The experience of schizophrenia is evidently a learning process in which patients make active attempts to master the illness and not have it dominate them. (Carr 1988, p.350)

We would take Carr's insight a step further and argue that not only can people with psychiatric disabilities play a role in the management of disorder and the containment of symptoms, but they can also self-direct their recovery. We have been doing it for centuries.

In order to ally themselves with the resilient, self-righting capacity of clients, mental health professionals should first ask us, "What do you already do that

helps with this distress?” Secondly, having determined what we are already doing to help ourselves – what has worked and what has not worked – the professional can ask, “How may I be of help?” Rapp (1998) has called this way of working with clients, The Strengths Approach which he defines as follows: “The strengths model then is about providing a new perception. It allows us to see possibilities rather than problems, options rather than constraints, wellness rather than sickness” (Rapp 1998,p. 24).

A third suggestion is for professionals to read first-person accounts of recovery. Suggested resources include Lovejoy (1982), Deegan (1988), Leete (1989), Spaniol & Koehler (1994) and Ridgway (2001). Reading these accounts can bolster the resolve of clinicians to see people with psychiatric disabilities as resilient, despite the resistance with which these ideas are met by some colleagues (Harding, 2004). In addition, these first-person accounts contain a wealth of simple, inexpensive and concrete strategies that people use to direct their own recovery. For instance, Table 1 lists 24 self-care strategies found in Esso Leete’s (1989) article about her recovery from schizophrenia.

Table 1

24 Self Care Strategies Used by a Woman in Recovery from Schizophrenia

1. Change priorities to allow self-care to be prioritized
2. Change attitudes to be more accepting of others and less judgmental
3. Plan how to use time
4. Structure a predictable schedule
5. Work/employment
6. Reduce distractions to increase concentration
7. Force self to look up to approximate eye contact with others
8. Socialize with people with similar experiences
9. Withdraw in situations of stimulus overwhelm
10. Attend to feelings
11. Choose to face the door with back to wall in order to cope with paranoia
12. Avoid talking to voices when others are around
13. Reality check with others when suspicious or afraid
14. Recognize and confront paranoid fears
15. Attend peer-run support group
16. Maintain relationships with at least one person that can be trusted
17. Make lists to help with concentration and memory
18. Request clear, simple, unambiguous communication
19. Keep busy and keep the day structured
20. Pacing, curling-up and rocking to relieve stress
21. Physical exercise, reading or watching a movie
22. Keep physical environment organized
23. Set small goals and break tasks down into steps
24. Prepare mentally for situations and anticipate problems

A fourth suggestion is for clinicians to become familiar with and use resources that have been written or co-written by people with psychiatric disabilities. These include: Pathways to Recovery: A strengths recovery self-help workbook (Ridgway, McDiarmid, Davidson & Bayes, 2002), Living without depression & Major Depression (Copeland, 1994); Working With Self Harm: Victim to Victor (Smith, 1998) and The OCD Workbook: Your Guide to Breaking Free from Obsessive-Compulsive Disorder (Hyman & Pedrick, 1999). These workbooks

offer a wealth of practical self-care strategies and exercises that can be done alone, with peers and/or with the clinician in individual or group settings.

Finally, unlike in Perceval's day, today's clinician can draw on a solid evidence-base confirming the efficacy of cognitive-behavioral strategies in the treatment of psychiatric disorders, including psychotic disorders such as schizophrenia (Mueser, Corrigan, Hilton, Tanzman, et al., 2002). It is fascinating to note that some of these cognitive behavioral strategies are similar to those discovered by people like Perceval in their own self-directed recovery. Just as women, in their role as primary caretakers of families, have evolved a wealth of "experience based evidence" that has only recently been substantiated by evidence based medicine (Anderson, 2004), so too do the empirical findings of the efficacy of cognitive behavioral treatment echo the collective wisdom of people with psychiatric disabilities with regards to "what works". Table 2 summarizes some of the convergences between what Perceval discovered in his own self-directed recovery and modern cognitive behavioral techniques in the treatment of psychotic disorders.

Table 2

Comparison of Self-Directed Care Strategies Used by John Perceval (1840) and
Modern Cognitive-Behavioral Approaches

Perceval's Self Directed Recovery	Cognitive Behavioral Techniques
Disciplined self observation	Behavioral assessment Beck 1984; Bradshaw & Roseborough, 2004
Mindful breathing	Meditation and progressive relaxation Beck 1984; Bradshaw & Roseborough, 2004
Distraction from voices	Distraction technique Haddock, McCarron, Tarrier et al. 1996
Avoidance of "absence of mind" which results in voice hearing	Avoidance of the listening attitude through behavioral assessment Arieti, 1974
Observing what delusions predict and what actually happens	Reality testing and verbal challenge Jensen & Kane, 1996

A fifth suggestion to support client's self-directed recovery is for clinicians to teach and support us in the use of empirically proven coping strategies. In a recovery-oriented approach the clinical consult can become the place of convergence between our self-directed recovery strategies and empirically informed coping strategies. Table 2 illustrates that convergence. It is not enough to rely on medications alone because at least 50% of people adhering to pharmacological treatment for schizophrenia continue to experience persistent and distressing psychotic symptoms (Dickerson, 2000). Nor is "business as

usual” enough. Eight controlled studies of time-limited cognitive-behavioral therapy for psychosis have consistently shown that it “is more effective than supportive counseling or standard care in reducing the severity of psychotic symptoms” (Mueser, Corrigan, Hilton, Tanzman, et al., 2002, p. 1280). Cognitive behavioral approaches have also been found to help people with depression (Beck, Rush, Shaw & Emery, 1979), panic, phobic and anxiety disorders (Beck, Emery, & Greenberg, 1985) and obsessive-compulsive disorder in adults, adolescents and children (March & Mullen, 1998). Cognitive-behavioral approaches have been found to meet the criteria of current evidence-based practice and is a vital component of the illness self-management toolkit (Mueser, Corrigan, Hilton, Tanzman, et al., 2002).

The final recommendation for clinicians to support and enhance client’s self-directed recovery, is for them to develop what Russinova (1999) calls hope-inspiring competence. Through a literature review Russinova (1999) was able to translate these competences into 29 hope-inspiring strategies for clinicians that include: believing in the person’s potential and strength, a willingness to listen to a person’s experience non-judgmentally, helping people learn from failures and to recall previous achievements, helping a person to set and reach concrete goals, helping a person connect to successful role-models, supporting people in getting jobs, maintaining employment and securing housing, supporting a person in their spiritual beliefs, using humor, and being available to people when they are in crisis.

One of the best ways for clinicians to remain hopeful is to continue to be surprised and inspired by the fundamental resilience and self-righting capacity of people with psychiatric disabilities. Clinicians do not have to do all the work! People with psychiatric disabilities have been hard at work directing their own recovery for centuries. Clinicians must be vigilant and watch for signs of turning points and ways to partner with self-directed recovery.

Peer Support

Many people with psychiatric disabilities seek out peers as part of their self-directed recovery process. In peer support, individual resilience is magnified and enhanced. Each person brings his/her own compassion and wisdom born of their experience. The collective pooling of these individual resiliencies becomes greater than the sum of the individual parts. The peer support group becomes a self-generative wellspring of care, new ideas, shared learning and novel approaches to overcoming adversity and forging a new life. When people with psychiatric disabilities join together in a culture of support, we discover that in helping our peers, we are healing ourselves.

The dictionary defines a peer as “one that is of equal standing with another.” Unlike the hierarchical relationships that clinicians develop with clients, peer relationships are characterized by horizontal mutuality that has sometimes been characterized as “reaching across” (Zinman, Harp & Budd, 1987). Clay (2004)

reports that peer run organizations share certain “common ingredients” that include: program structures that are consumer operated and controlled; environments that are informal, safe and accessible; common belief systems; opportunities for education, advocacy, crisis prevention, peer mentoring, telling our stories, consciousness raising, self-management/problem solving strategies; and empowerment orientation including acceptance and respect for diversity, system advocacy and community education.

Two important components of peer support are the peer principle and the helper’s principle. The peer principle is characterized by “equality, along with mutual acceptance and unconditional respect” (Clay, 2004, p. 16). Peers share a common experience that forms the basis of their relationship. A related component, the helper’s principle, states that in helping others, we help ourselves: “Consumers believe that working for the recovery of others, especially one’s peers, facilitates personal recovery for both” (Clay 2004, p.16).

Peer support among people with psychiatric disabilities has a long history. Informal peer support has been occurring between people in madhouses, asylums, and inpatient units for centuries (Deegan, 2002). The first organized peer support and advocacy organization run by and for people diagnosed with mental illness was called the Alleged Lunatics Friends Society (Hervey, 1986). It was established in England in 1845 and continued for 18 years before disbanding in 1863. The Society was founded by none other than John Thomas

Perceval, the man whose self-directed recovery we studied earlier in this paper. After achieving his freedom from the madhouse, he began recruiting ex-patients to campaign for “lunacy reform” and to assist people who were unjustly confined in asylums.

The Alleged Lunatics Friend Society met regularly, held public lectures, visited people in asylums, advocated for their release, published their poetry, brought lawsuits on their behalf, monitored the Lunacy Commission’s compliance with regulations, and drafted progressive legislation in Parliament. The Society’s platform of demands included putting an end to involuntary confinement, training and licensing attendants, ending brutality in madhouses, and promoting the rights of inmates including the right to receive mail unopened.

In a sense, the work of The Alleged Lunatics Friends Society became a blueprint for future peer-run organizations, albeit most modern mental health consumers do not even know it existed. The pairing of systems advocacy with mutual support has been repeated many times in the start-up of new peer run programs (Chamberlin 1984, 1990; Campbell, 2004). This pairing of systems advocacy with mutual support reflects a defining characteristic of the experience that unites most people diagnosed with mental illness. Most of us emerge from mental health treatment with some sense of outrage or indignation. Listen to the similarities across the centuries:

I was never told, such and such things we are going to do; we think it advisable to administer such and such medicine, in this or that manner; I was never asked, Do you want any thing? Do wish for, prefer any thing? Have you any objection to this or to that?...I did not find the respect paid even to a child...I was not, however, once addressed by argument, expostulation, or persuasion. The persons round me consulted, directed, chose, ordered, and force was the unica and ultima ratio applied to me. (Perceval/Bateson, p.120-121)

I can report my thoughts, but they may be seen as delusions. I can recite experiences, but they may be interpreted as fantasies. To be a patient or even an ex-client is to be discounted. (Leete, 1989, p. 199)

The outrage and indignation of being treated as if we do not exist, as if what we have to say is not worth listening to is *the* defining characteristic of the experience of being a mental patient. Being stripped of our voice such that even when we scream – “Let me out”, the response is to tighten the leather straps holding us in restraints - this is the type of death-making experience most of us understand. Many of us call ourselves survivors precisely because we have reclaimed our voice and use it to assert that we are, above all human beings. That is why so many of us emerge from mental hospitals wounded, but not defeated, and like Perceval, proceed to gather together with our peers to support each other and to advocate for systems change.

Today there are hundreds of peer support and advocacy programs in the United States. Two reviews of the literature have concluded that there is preliminary empirical evidence to support the effectiveness of peer-run support services (Campbell, 2004; Davidson, Chinman et al., 1999; Solomon & Draine, 2001). Nonrandomized control group studies have shown that peer support services decrease hospitalization and improve psychiatric symptoms (Galanter, 1988). Peer support services provide important opportunities for socialization and are associated with people having larger social support networks (Carpinello, Knight & Janis, 1992). Double Trouble in Recovery peer support groups have been found to significantly reduce symptoms, the use of crisis services and substance abuse (Magura, Laudet, Mahmood, Rosenblum, Vogel, & Knight, 2003). We are awaiting the results of a national multi-program study of consumer-operated service programs funded by the Substance Abuse Mental Health Services Administration (SAMHSA). The researchers report, "...baseline studies offer promising indications that further analysis of the data will reveal positive outcomes, particularly in the domains of well-being and cost effectiveness" (Clay, 2004, p. 219).

Peer support programs and services are on the rise. The final report of the President's New Freedom Commission (2003) details what a transformed mental health system will be. Recovery is its guiding vision and peer services are recognized as one of the vital ingredients of such a system: "Consumers who work as providers help expand the range and availability of services and

supports that professionals offer. Studies show that consumer-run services and consumer-providers can broaden access to peer support, engage more individuals in traditional mental health services, and serve as a resource in the recovery of people with a psychiatric diagnosis” (p.37).

Mental health professionals have a role to play in relation to the emerging role of peer support services. First, professionals should be knowledgeable about the research supporting the efficacy of peer support and encourage clients to use it. Secondly, professionals should be knowledgeable about the full range of local peer support programs and make such information available in user-friendly formats. Remember that people with psychiatric disabilities often share a lot in common with other groups as well. Peer support, education and advocacy groups that focus on issues related to poverty, public transportation, smoking cessation, physical health concerns, substance abuse, bereavement, aging, rape, women’s issues, etc. are important to include in a listing of community-based supports. Each state has at least one Independent Living Center that is/are cross-disability organizations run by people with all types of disabilities. These centers offer free self-advocacy skills training, education and advocacy opportunities for anyone with a disability, including youth.

A third important role that professionals can play in relation to peer support groups, is to provide resources to them. Peer run organizations usually run on very small budgets and are cash strapped (Clay, 2004). Transportation,

supplies, and donations are concrete ways that mental health centers can support peer run services. Other important contributions include resource sharing and technical assistance. Let a group use your fax machine or printer if they don't have one. Help a peer run program with grant writing, budgeting, by-laws, application for non-profit status or board development.

Conclusion

People with psychiatric disabilities are resilient and have been involved in self-directed recovery across the centuries. Working from a person-centered recovery model, mental health professionals can learn to partner with a client's strengths. Although the clinician can't instruct a client in how to recover, the clinician can be a valuable advisor, consultant, and resource person in an individual's journey of recovery.

The recovery model does not make the role of the mental health professional obsolete. Mental health clinicians can learn to help clients discern self-assessed health resources and personal medicine, and support the achievement of meaningful activities and valued social roles in the recovery process. Mental health clinicians can learn to align their knowledge and skills with clients own self-directed recovery, always making sure to ask clients what they already do to help themselves with their distress and then teaching clients cognitive behavioral strategies when applicable. Finally, mental health clinicians can provide technical assistance, referral and tangible resources to peer support programs

which, though often the last funded and the first cut, have been empirically demonstrated to offer significant support for people in recovery.

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