

## GETTING READY FOR RECOVERY: RECONCILING MANDATORY TREATMENT WITH THE RECOVERY VISION

MARK R. MUNETZ &  
FREDERICK J. FRESE, III

MARK R. MUNETZ, MD, IS CHIEF CLINICAL OFFICER FOR THE SUMMIT COUNTY ALCOHOL, DRUG ADDICTION, AND MENTAL HEALTH SERVICES BOARD AND DIRECTOR OF COMMUNITY PSYCHIATRY, NORTHEASTERN OHIO UNIVERSITIES COLLEGE OF MEDICINE, ROOTSTOWN, OHIO.

FREDERICK J. FRESE, III, PHD, IS THE COORDINATOR OF THE SUMMIT COUNTY RECOVERY PROJECT AND ASSISTANT CLINICAL PROFESSOR OF PSYCHOLOGY IN PSYCHIATRY AT NORTHEASTERN OHIO UNIVERSITIES COLLEGE OF MEDICINE, ROOTSTOWN, OHIO.

ADDRESS CORRESPONDENCE TO DR. MUNETZ AT THE COUNTY OF SUMMIT ALCOHOL, DRUG ADDICTION, AND MENTAL HEALTH SERVICES BOARD, 100 W. CEDAR STREET, SUITE 300, AKRON, OHIO 44307. PHONE: 330/762-3500. FAX: 330/252-3024. E-MAIL: [mmunetz@neoucom.edu](mailto:mmunetz@neoucom.edu)

*Considering treatment of serious mental illnesses, it might appear that the recovery model would be incompatible with any form of mandatory treatment. The authors suggest that this is not so. With individuals whose psychotic illness substantially impairs decision making, mandatory treatment may offer the best hope of getting well enough for recovery to be possible. It is essential, however, that any program involving involuntary community treatment involves recovering individuals who have themselves experienced a serious mental illness. The authors propose the use of a consumer-run guardianship program and a capacity review panel as two possible ways to achieve such participation.*

A person who "is suffering from a debilitating mental illness, and in need of treatment is neither wholly at liberty or free of stigma."

Chief Justice Warren Burger,  
(*Addington v. Texas*, 1979)

had spent extended periods of time in psychiatric hospitals showed strong evidence of progress towards recovery on long-term follow-up (Harding, Zubin, & Strauss, 1992).

Since those reports there has been considerable attention paid to the concept of recovery from serious mental illness. Anthony contends that people can regain some social function despite having symptoms, limitations, taking medications, and remaining mentally ill (Anthony, 1993). As Anthony writes, "Recovery is described as a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life, even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in

### THE RECOVERY CONCEPT

Historically, schizophrenia has been viewed as a deteriorating disorder from which no one recovered. Kraepelin suggested this by naming the disorder dementia praecox, which he believed was a condition of neural degeneration. With the introduction of psychotropic medications in the mid-1950's, persons with serious mental illness increasingly improved. A series of reports from around the world in the 1980s found that a high proportion of persons who

one's life as one grows beyond the catastrophic effects of mental illness." (1993, p.19).

Fisher has unveiled another vision of recovery that he refers to as the empowering view (Fisher, 1998). He stresses that full recovery is possible for everyone but that does not mean that the person no longer needs supports. Fisher contends that persons labeled with mental illness can carry out important social roles and learn to take control of their own lives.

### **Recovery Versus the "Medical Model"**

Recovery then, as envisioned and described by people who have experienced it, includes self-empowerment, a sense of being in control, of having the capacity for self-healing, maintaining a sense of hope, and abandonment of the victim role. As such, the recovery model is sometimes presented as an alternative to the usual approach to treatment of serious mental illness by what is often called the "medical model." The "medical model," as presented in this way, is highly paternalistic. It is seen as emphasizing illness over health, weaknesses rather than strengths, limitations rather than potential for growth. It is viewed as stamping out hope by implying that biology is destiny, and as emphasizing an external locus of control. This version of the "medical model" describes the physician as a powerful and oppressive figure who at best is acting out of misguided beneficence. The physician in this model is seen as fostering helplessness and chronicity. Extreme critics of the "medical model," following the thinking of Thomas Szasz, hold that mental illnesses do not really exist as biological disorders (Szasz, 1961).

However, many advocates for a recovery approach clearly do accept the reality of illness. Patricia Deegan, a clinical psychologist with schizophrenia, is a strong advocate of the recovery model and

quite critical of traditional mental health systems that she argues foster learned helplessness and dependence. Yet Dr. Deegan, in articulating her vision of the recovery process, talks of her acceptance of having a mental illness. She emphasizes the importance of distinguishing the difference between having an illness (e.g., schizophrenia) and being the illness (e.g., a schizophrenic). "To me it's important to say that I have a disability but that I am not a disabled person" (Deegan, 1993, p. 10). Deegan also emphasizes that recovery is not cure. It is a lifelong process. "Being in recovery means I know I have certain limitations and things I can't do. But rather than letting these limitations be an occasion for despair and giving up, I have learned that in knowing what I can't do, I also open up the possibilities of all I can do" (Deegan, 1993, p. 10). Frese has taken a similar position regarding coping with serious mental illness, but argues that it should be acceptable to acknowledge being "a schizophrenic" (Frese, 1998). He sees this as normalizing in the same way others with a long-term illness refer to themselves as diabetics, or alcoholics and such (Frese, 1998).

Deegan argues that the paternalism of traditional treatment systems creates a "cycle of disempowerment and despair" among those with a serious mental illness. She states that a common view held by mental health professionals is that "People with psychiatric disabilities cannot be self-determining because to be mentally ill means to have lost the capacity for sound reasoning" (Deegan, 1992, p. 12). The recovery model implies that the chances for recovery are optimized when a person is given maximum control over how their condition is to be treated. This approach also suggests that treatments that are resisted are necessarily unhealthy or inappropriate in that they diminish the degree of

control afforded to the person with the disorder.

Many persons who are well recovered from mental illness have enthusiastically embraced these recovery models. Many remember their own terrifying experiences of being forced into hospitals and given various forms of unwelcome, invasive, and often very uncomfortable treatments. They, therefore, view positively models of care that give more deference to their rights to decide what types of treatment, if any, they will receive.

These models also appeal to the general public and policy makers in a nation where individual rights are given the highest of priorities. Lefley has written persuasively how policymakers in particular may embrace a concept that implies that individuals with serious mental disorders may not require the expensive, intrusive treatments previously supported extensively by state and local government (Lefley, 1994).

### **Recovery and Acceptance of Illness**

The recovery concept has a long tradition in the world of alcoholism. Recovery under Alcoholics Anonymous (AA) begins with step 1, which is essentially acceptance of having a problem. The voyage of recovery from alcoholism requires that the individual be ready to accept the need for help. Recovery from a serious mental illness similarly appears to require some level of acceptance of the disorder one is recovering from, or at least a willingness to accept treatment and develop coping strategies. Denying an illness is unlikely to be the way one learns to rise above its limitations. The question of how to understand the nature of the disorder being accepted is where the recovery and medical models may begin to clash. Must an alcoholic accept the AA conceptualization of alcoholism? Must a person with schizophrenia accept this as a medical disorder requiring medical treatment?

There are no simple answers to these questions, but clearly some outspoken individuals with these disorders believe the answers are “no” (Chamberlin, 1978). Yet, in a recent study of the meaning of recovery to 18 mental health consumers, an initial phase of the recovery process was described by the authors as overcoming “stuckness” and included a first step of “acknowledging and accepting illness” (Young & Ensing, 1999).

### THE RIGHT TO REJECT OR REFUSE TREATMENT

Conventional wisdom has held that before many alcoholics are ready for recovery they must first “hit rock bottom.” Based on this concept is the corollary notion that a person with alcoholism cannot be forced into treatment. However, it is not clear that either view is valid. The need to hit rock bottom has not clearly been demonstrated to be a requisite to recovery; and the absolute ineffectiveness of coercive treatment is also very much open to question. Many alcoholics begin their personal recovery under some form of coercion, often the threat of a significant loss: of job, of spouse or children, or of a professional license. Given the considerable risk of morbidity and mortality while waiting and hoping that bottom is hit, there are serious questions about the ethics of not intervening while someone is obviously spiraling downwards (Galon & Liebelt, 1997).

Few advocate that people with a severe mental illness need to hit rock bottom before they can recover. What is often advocated, however, is the right to make choices (including the right to refuse treatment), the right to try and fail, the right to privacy and the parallel right to be left alone. These and similar rights are used as arguments against coercive treatment for serious mental illnesses.

These arguments directly conflict with strong statements in favor of a paternalistic approach to the problem of serious mental disorders like schizophrenia. “Schizophrenia is a terrible illness” (McEvoy, 1998, p. 289) with significant morbidity and mortality. Suicide rates for people with schizophrenia are about 10% (Torrey, 1995, p.271). Victimization, HIV/AIDS, homelessness, violence and incarceration are among the risks facing a person with untreated psychosis. Furthermore there is increasing evidence that the course of psychotic disorders is adversely affected by the failure to treat (Wyatt, 1995). Intermittent non-compliance with treatment may result in a worsening of the underlying disorder. Thus treatment responders early in their course may become treatment non-responders as a function of kindling (Post, Rubinow, & Ballenger, 1986) or other as yet poorly understood neurochemical processes in the central nervous system of the affected individuals. As such, the person given repeated “chances to fail” might find himself or herself in a position where the likelihood of success is greatly diminished.

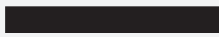

Still, given how much our society values freedom, none of these arguments can alone justify an individual’s loss of autonomy. Despite Deegan’s assertion (1993), the law assumes that a mentally ill person is able to reason soundly, unless they have been judicially determined to be incompetent. Today, civil commitment of persons who have a mental illness is primarily based on dangerousness criteria. In most states, individuals deemed dangerous and confined against their will are considered competent and can refuse medication and other treatment interventions. Only if the individual is found, through appropriate due process, to lack treatment decision-making capacity can his or her stated desires concerning treatment be overridden.

### The Question of Capacity

Deegan is correct; it is wrong to *assume* that a person with a severe mental illness is unable to make his or her own decisions. It is also true, however, that many people with severe mental disorders like schizophrenia have periods when they lack the capacity to make certain decisions. It is increasingly clear that for some consumers, the nature of their illness is such that the very ability to appreciate that they are ill is impaired. In some cases this lack of awareness is temporary and a result of symptomatic illness. In other instances, the lack of awareness appears to be more integrally part of the underlying illness, a manifestation of the underlying brain disorder.

Delusional thinking may be the prototype of a symptom accounting for a failure to appreciate that one is ill. A delusion is a “false belief based on incorrect inference about external reality that is firmly sustained despite what almost everyone else believes and despite what constitutes incontrovertible and obvious proof or evidence to the contrary” (American Psychiatric Association, 1994). It is virtually impossible for a person in the midst of a delusion to understand that their beliefs are in fact the product of a delusion. If this were the case, the delusion would not be a delusion. So, if delusional persons cannot know that they are delusional, how can they possibly appreciate that they need treatment for a condition that they cannot understand they have?

Most observers agree that the degree to which a delusion is fixed is on a continuum. With less intensely held beliefs there is room for an individual to gain understanding that treatment may be helpful. But when delusions are more firmly fixed some individuals hold so fast to their beliefs that they will fiercely fight the notion that they are mentally ill, because acknowledgment of such

  
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would allow for the possibility that their particular belief may, in fact, be false.

Delusions, along with hallucinations and lack of insight have been characterized by Keefe (1998) as related to an underlying cognitive deficit found in people with schizophrenia that manifests as “severe symptoms of confusion between what is part of the self and what is part of the world of external stimuli” (p. 142). Poor insight, hallucinations and Schneiderian delusions are all manifestations of this dysfunction. Keefe calls this deficit *autonoetic agnosia* and compares it to anosognosia.

Anosognosia is a neurologic term describing a common phenomenon in people who have suffered a stroke. A person with anosognosia is apparently unaware or fails to recognize a significant functional deficit. The prototype example of anosognosia occurs with nondominant hemisphere parietal lobe

strokes. In such cases a person with a hemiplegia may completely deny their inability to move the left side of their body.

There is growing evidence that a lack of awareness of illness in people with schizophrenia, what is commonly called lack of insight, has a biological base similar to anosognosia seen in poststroke patients. Several studies demonstrate neuropsychological dysfunction associated with lack of insight in schizophrenia (Lysaker, Bell, Bryson, & Kaplan, 1998; Mohamed, Fleming, Penn, & Spaulding, 1999; Young et al., 1998). These studies report associations between unawareness of illness and deficits in executive function. Several of the researchers suggest an association between impaired insight and frontal lobe dysfunction (Lysaker, et al., 1998; Young et al., 1998). A recent study reported that people with schizophrenia who were relatively unaware of their illness had smaller brain and intracranial volumes compared with both healthy comparison subjects and people with schizophrenia who were aware of their illness (Flashman, McAllister, Andreasen, & Saykin, 2000). These researchers were not able to demonstrate localized brain deficits in this study, and suggest it is still unclear if such unawareness is due to diffuse brain dysfunction or more localized deficits in frontal or parietal regions of the brain (Flashman, et al., 2000).

The recognition of an anosognosia-like biological basis for lack of insight in people with schizophrenia makes it easier to understand an otherwise perplexing and frustrating clinical observation; there appears to be little correlation between treatment response and insight into illness (McEvoy, et al., 1989; McEvoy, 1998). While most people do come to acknowledge their illness over time and particularly after treatment, there are some individuals who do not

appreciate being ill or having been ill, even after they successfully achieve a remission of an acute or chronic psychotic episode, and even after a great deal of time living with the illness. Amador reviews evidence strongly suggesting that this lack of insight is a symptom of a neurobiologic disorder, rather than simply a defensive “denial” of illness (Amador, 2000). Such an understanding may make it easier for consumers, their families, and advocates to understand how to respond to the resultant treatment refusal.

### **The Frequency of Impaired Decision-Making Capacity**

There is some empirical data on the frequency of decision-making incapacity in people with schizophrenia and other serious mental disorders. We know much more about this in people who have an acute illness than in those with longstanding illness. Probably the most carefully conducted study was that of Grisso and Appelbaum (1995). They looked at three groups of hospitalized patients and a community comparison group, and then determined treatment decision-making capacity. They delineated three tests to determine capacity: understanding, reasoning, and appreciation. On any one test approximately 25% of those with schizophrenia lacked capacity, substantially higher than the group with depression or the group with *angina*. The proportion deemed to lack capacity was higher when multiple tests were used, peaking at 52% when all three tests were considered together. These researchers did not reassess capacity following treatment.

While it is clear that some people, perhaps a majority, regain capacity as they respond to treatment, there is a subgroup of unknown size that fails to regain decision-making capacity. It is in this group of individuals where Deegan’s argument becomes problematic. While clinicians must not assume that

a diagnosis of a mental illness implies decision-making impairment, there is a subset of people with severe mental illness who do have such impairments and are unable to make decisions in their own best interest. Interestingly, however, some of these individuals do essentially adhere to the treatment recommended by their physicians and other treaters. Many people who refuse treatment can come to accept, and hopefully respond to treatment by careful attention to the therapeutic alliance (Weiden, Mott & Curcio, 1995). In addition, there is some interesting speculation that the atypical antipsychotic medication clozapine may be more effective than traditional antipsychotics in restoring decision-making capacity (Perkins & Lieberman, 1998). But there is a very visible remaining group who, when left to their own devices, deny their illness and need for treatment. One would hope that this group is small and the lack of capacity is time limited. In reality, however, we have no data as to the size of this group, and it is unfortunately clear that for some the lack of capacity is prolonged despite effective treatment.

### **Impaired Decision-Making Capacity**

It is our thesis that it is inconsistent with a recovery paradigm to abandon incapacitated individuals to remain victims of their serious mental illness. Given the subjective torment of untreated psychosis and the considerable morbidity and mortality as outlined above, a strong argument can be made that giving such individuals the right to refuse treatment is tantamount to abandonment. Instead, clinicians need to be advocates; doing their best to assure that these individuals get the treatment they need so they can then be ready for recovery.

This is not a new argument. Alan Stone, two decades ago, articulated what he called the “myth of advocacy” (Stone,

1979). He pointed out the unwillingness of patient rights advocates to consider the needs of their clients and called for such consideration in their advocacy for those with a mental illness. While this is easily criticized as another example of well-meaning but misguided paternalism when applied to a fully capable person with a psychiatric disorder, it is vitally important for a person who is deemed to lack decision-making ability. This is a group of people who generally have an excellent chance of recovery, if they can receive the treatment they need; and who appear to have little chance of recovery without that treatment being imposed, for however long is necessary. Advocating for the rights of self-determination of such incapacitated individuals is specious advocacy.

### **Mechanisms for Mandatory Treatment**

Different states have different mechanisms to provide community based treatment to this group of consumers who are characterized by persistent lack of decision-making capacity, a severe mental illness that responds well to treatment, persistent treatment refusal and consequently frequent involuntary rehospitalizations (Gerbas, Bonnie & Binder, 2000). In some states the mechanism can be outpatient civil commitment, conservatorship and/or limited guardianship. Is such intervention necessarily aversive and perceived negatively by consumers? While this question is not yet answerable, there are some intriguing data coming from the MacArthur Foundation Research Network on Mental Health and the Law that suggests that court ordered intervention need not be coercive or damaging to a therapeutic alliance. The MacArthur Coercion Study reported by Lidz and associates looked at consumer perceptions of coercion in relation to psychiatric hospitalization (Lidz et al., 1995). They found that perceptions of coercion had less to do with legal status

(“voluntariness”) than with what the researchers call “procedural justice”. Procedural justice consists of being allowed voice (“being able to say what you want”) and being treated with respect, concern, and good faith. Consumers who experience a process characterized by procedural justice feel less coercion even if they become “involuntary” patients (Lidz et al., 1995). Treatment characterized by a mutual, respectful, honest, and concerned relationship is very much the kind of relationship clinicians strive for in establishing and maintaining a therapeutic alliance with their patients.

## A RECOVERY VISION FOR CONSUMERS WHO LACK CAPACITY

The decision to intervene intrusively on an individual's rights should never be made casually. However, clinicians are obligated to inquire about decision-making capacity as part of the informed consent process. For people who have a serious mental illness in need of treatment, who refuse the needed treatment and who are unable to make decisions, clinicians must not abandon their responsibility to help these people get what they need. (The issue of people who lack capacity, but agree to treatment is an important issue but beyond the focus of this paper.) While dangerousness-based civil commitment is certainly an appropriate mechanism to assure safety and to initiate treatment for acutely ill individuals, it does not appear to be the most appropriate approach to the person whose lack of capacity is more prolonged (Goldman, 1996; Munetz, Geller, & Frese, 2000). For such individuals treatment, not confinement, is the major issue. The question of decision-making capacity is largely independent of the question of dangerousness and “commitability.” It

only adds to the stigma of people with mental illness to require dangerousness before allowing one to address the question of decision-making capacity and the need for treatment. Furthermore there are individuals who lack capacity and need treatment, but are not imminently dangerous. There needs to be a clear process for assigning an alternative decision-maker for those consumers determined to lack capacity. Consumers whose incapacity is intermittent would ideally appoint their own proxy decision-maker, such as by executing an advance directive granting a durable power of attorney to an appropriate individual who knows them well. The consumer can work with the proxy, while capable, so that the proxy is aware of the consumer's treatment preferences and can, as much as possible, consent to the treatment the consumer would have wanted (i.e., using a substituted judgment approach) (Appelbaum, 1991).

For the more persistently incapacitated treatment-refusing person a proxy decision-maker will probably have to be appointed by a court through a formal legal process such as conservatorship or limited guardianship (Lamb & Weinberger, 1992). If guardianship is to be used, it is important to promote the idea of a guardian for medical decision-making only, if that is the only area in which decision-making is impaired, as may often be the case. From the perspective of a recovery paradigm, however, we see a significant problem with a legal process that is confined to the medical and legal professions. There is a risk when, even with the best of intentions, paternalistic physicians and judges, with encouragement from concerned family members, make decisions without input from individuals who themselves have experienced a serious mental illness and mandated treatment. We believe, to maximize procedural justice, the process needs to be a partnership between consumers, professionals

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and family members when appropriate. With this in mind we have been considering two ways to involve a recovering consumer in the process of helping someone who may be too ill to make decisions to begin his/her own recovery: an organized consumer-as-guardian program and a capacity review panel (Munetz, Geller & Frese, 2000).

### **A Consumer-as-Guardian Program**

When a person is determined to be incapable of making informed decisions about his or her medical treatment, a guardian can be appointed by the court to make those decisions on the person's behalf. Having a nonprofit agency staffed by persons themselves recovering from a serious mental illness offers several advantages over the usual guardian programs: it relieves family members from taking on a role that can be highly stressful and potentially destructive to family harmony; it provides courts with a viable alternative to court-appointed attorney guardians who are often hard to find and minimally available to serve their wards; it places a person in the guardianship role who has first hand experience with a psychotic

disorder, has likely experienced involuntary treatment and is now in recovery. The inclusion of such a person reduces the likelihood that the treatment team's actions will tend toward misguided paternalism. It is also possible that in some circumstances the consumer guardian may be able to help the consumer accept the proposed treatment or help the treatment team arrive at a treatment plan more acceptable to the consumer. With the help of a consumer guardian, consumer's views are more likely to be heard and appreciated, promoting procedural justice. Having a peer tell a consumer that they need to accept treatment in conjunction with the court's finding is likely to provide a very powerful message. Having a fellow consumer participate in the process of mandating treatment may alleviate concerns of legal rights advocates and could help return the focus of advocacy from one of "right to refuse" to one of "right to be helped." Finally, a consumer guardianship agency offers potential jobs to select consumers with adequate training and coping skills to take on the task.

This proposal also entails substantial challenges. It may be difficult to find consumers who understand the complexity of the issues involved with mandatory treatment and who are able to maintain a dispassionate posture concerning the best interest of the involved individuals. Should such persons be found, it could be a challenge to assure their continued independence so they are not viewed as having been co-opted by the treating professionals. It is likely that being a guardian for a person who does not believe he or she is ill or in need of treatment will be very stressful; guardians will have to be selected carefully, be well supervised, and given small case loads. Ideally the agency would build in "backup" so if a given guardian were temporarily incapacitated others could fulfill the role. Still, we believe this is a model worth pursuing.

## The Capacity Review Panel

Another approach to assure consumer involvement in a mandatory community treatment program is the creation of a capacity review panel, modeled after proposed hospital "ethics committees" (Appelbaum, Lidz & Meisel, 1987). The capacity review panel, as currently conceptualized, would not have formal legal standing but would serve as consultant/advocate to all involved parties as to the appropriateness of the extreme intervention of treatment over an individual's objection. We envision the panel as consisting of three individuals not directly involved with the person whose decision-making capacity has been questioned. The panel could consist of a recovering person who has previously experienced mandatory, or assisted, treatment, a family member of a person with a serious mental illness who has received mandatory treatment and a mental health professional. The panel could review all instances for which ongoing (such as greater than an initial 90 days) mandatory treatment, either through the commitment or guardianship statutes, was being requested. The review would include a face-to-face interview with willing consumers. The panel would issue an advisory opinion to the treating psychiatrist. Should any member of the panel disagree with the appropriateness of the recommendation for court intervention, individual panel members would be encouraged to testify on behalf of the person.

This capacity review panel approach shares many of the same advantages and risks as the consumer guardianship program. The review panel has the additional disadvantage of not having a formal place in the law, so its use would require acceptance by the treatment system and the courts. For this reason we favor the consumer guardian option and hope to pilot its use first.

## CONCLUSIONS

It is increasingly clear that serious mental disorders like schizophrenia are brain disorders, best understood in a biopsychosocial context. While some individuals may recover from such disorders without pharmacologic treatment, this appears to be unusual. There are far more people who repeatedly get ill and deteriorate over time because of persistent refusal to accept treatment. Mental health professionals need to increase their skills to develop working alliances with such individuals to help them accept treatment willingly. At the same time, as some (but by no means all) consumers acknowledge (Frese, 1997), a means to provide treatment over the affected person's objection is necessary to give those people an opportunity to become well enough to begin the recovery process. It is hoped that as consumers continue to do well, there will be less attention paid to the struggle for treatment compliance and more attention paid to skill building, independent living, and other aspects of recovery. It is hoped that over time consumers will come to accept their illness in some fashion and regain decision-making capacity. We do not feel that each consumer has to be able to say, "My name is Fred and I am a 'schizophrenic'" (Frese, 1998). People can recover without buying the same illness model or diagnosis provided by their treaters. But there does need to be some level of personal acceptance of the disorder in order for each individual to start on a real journey of recovery.

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