June 1997

Personal Narrative and the Social Reconstruction of the Lives of Former Psychiatric Patients

Robin M. Gilmartin

Follow this and additional works at: https://scholarworks.wmich.edu/jssw

Part of the Clinical and Medical Social Work Commons, and the Social Work Commons

Recommended Citation
Personal Narrative And The Social Reconstruction Of The Lives Of Former Psychiatric Patients

ROBIN M. GILMARTIN

This study explores ways in which high-functioning former patients integrate the experience of prior psychiatric hospitalization into their lives and find meaning from that event. The narratives of two individuals are presented and discussed in relation to social role theory, social constructionism, and labeling theory. The narratives underscore that the process of integrating and making meaning of important life events such as psychiatric hospitalization occur within a social context. Understanding mental illness and psychiatric hospitalization in familial, social, and political terms was instrumental in helping these individuals to reconstruct personal narratives in order to overcome shame and internalized stigma and to integrate their experiences in meaningful ways.

This paper explores ways in which high-functioning former psychiatric patients integrate the experience of psychiatric hospitalization into their lives and find meaning from that event. In a broader sense, it illustrates the importance of narrative in enabling individuals to reconstruct critical life events so that they can become meaningful experiences. As a non-normative event, psychiatric hospitalization (the critical event of primary focus here) presents problems and challenges for ex-patients because of the fact that mental illness is often stigmatizing, particularly if it results in hospitalization. As such, it may significantly affect how others regard or behave towards the former patient, the former patient’s perceptions of how others regard or treat him or her, and finally the ex-patient’s own self-concept and understanding, all of which may be intricately and complexly connected. Formerly hospitalized individuals must somehow negotiate or redefine themselves within the context of family, social networks, and
society at large in light of this non-normative and stigmatizing event in their lives.

The purpose of this article is to present the personal narratives of two high-functioning former psychiatric patients who reflect on the process of making meaning from their experiences of hospitalization and other related critical life events. Loosely structured interviews provided a forum for these individuals to reflect on how these events shaped their lives and influenced their concept of self and sense of place in the world. Several relevant social theories—social role theory, social constructionism, and labeling theory—are also discussed.

There is a notable absence of existing research on the significance and meaning of institutionalization for ex-patients through personal narratives. While the narratives presented here reflect only the personal experiences of two individuals and are not assumed to be representative of the population of ex-patients, these in-depth accounts may tell us something of the processes of coming to new understandings about a non-normative and often difficult life event. In-depth narratives such as these can aid clinicians in working with former patients who seek therapy later in their lives as well as in helping current patients prepare for discharge. The narratives may also remind us of our resiliency and ability to find meaning in painful events or periods of our lives.

Social Role Theory

Inspired by the work of Mead (1934), who emphasized social interchange and role taking as key to the development of identity and personality, and drawing from Goffman’s (1959; 1961) studies, Sarbin and his colleagues (Sarbin & Allen, 1968; Sarbin & Scheibe, 1983) describe a process whereby the individual’s identity and self-concept derive from social roles and the valuation of such roles. Three dimensions—status, involvement, and valuation—are key with respect to identity vis-a-vis social roles.

One's status within a social structure may be either granted or attained; granted roles (e.g., mental patient) are ascribed while attained roles (e.g., psychiatrist) are those which are achieved. Involvement refers to the degree to which the individual is involved in the role or “plays the part.” When involvement is low, the individual and the role are clearly differentiated. While the
individual's involvement in any given role may vary temporally or situationally, granted roles typically require more total involvement than attained roles which "may be put on and off like cloaks" (Sarbin & Scheibe, 1983, p. 13). According to Goffman, nowhere are granted roles more absolute than in what he termed "total institutions," that is, "a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life" (Goffman, 1961, p. XIII). Cut off from wider society, the individual is not only precluded from assuming other social roles, but his or her identity in the granted role, e.g., mental patient, is secured through a process of acculturation within the total institution. If the individual's stay is sufficiently long in duration, a process of "disculturation," often complicated by social stigma, must occur in order to successfully integrate into life on the outside.

Valuation of social roles bears a close relationship to status and involvement. Importantly, the individual's social identity may be devalued either through a process of derogation or demotion. While demotion is the stripping away of attained status which deprives the individual of previously enjoyed social esteem, derogation involves a devaluation of who the person is by virtue of his granted roles. According to Sarbin and Scheibe:

The most degrading processes are those which combine derogation and demotion. If a person is relieved of all achieved statuses—professional and avocational—and is derogated with respect to all ascribed roles, including sex, age, kinship, and citizenship roles—he or she is reduced to the lowest possible value. (1983, p. 21)

Institutionalization typically involves some degree of derogation and demotion. Even if the individual enters an institution willingly, he or she loses achieved statuses and connected social esteem, as well as certain rights or freedoms ascribed to individuals by virtue of being adults, citizens, or of sound mind. Once released from the institution, individuals may resume or regain their jobs, family roles, and so forth; however, they do so from the standpoint of one whose social identity is most likely changed, whose involvement in roles prior to institutionalization is interrupted, who may need to become "reculturated," and whose status may be greatly diminished.
Having been institutionalized perhaps for months or years, individuals may experience certain losses while away as irrevocable and deeply painful, even if the ex-patient regards his or her institutional stay as time well spent in terms of recovering. For example, in the case of a father who was not present to see his children reach important milestones or an adolescent who was unable to graduate with her high school class. Institutionalization which leads to a prolonged absence from active engagement in normal social roles may also result in an ex-patient feeling unpracticed or uncertain in his or her ability to resume those roles. Problems adjusting to normal roles may be compounded by others either expecting the ex-patient to “pick up where he or she left off” on one hand, or disavowing the ex-patient’s capacity to resume normal roles altogether on the other hand. How ex-patients manage to negotiate their social roles following discharge is certainly vital to their post-hospital functioning. Finding meaning, however, from the experience of institutionalization is likely more involved and complex than the negotiation of social roles, vital and often difficult though that may be.

Social Constructionism

Like social role theory, social constructionism derives from the field of social psychology though it differs from role theory in significant ways. While role theory tends to “assign governing or directive functions” as a psychological basis for human behavior, social constructionism offers a broader understanding of the individual in interaction with the environment (Gergen & Gergen, 1983, p. 256). Rather than simply being defined by social roles, individuals are seen as having a reflexive capacity for self-understanding and an ability to build themselves into the world by creating meaning from experience. Language is the vehicle for finding meaning as words themselves help us to “both name and shape our experiences of the world” (Dean, 1993, p. 129). As the keystone of culture, it is through language that we find meanings collectively, for example, through histories and mythology, and as individuals, through life narratives. Language and culture are inextricably a part of who we are and how we as agents build ourselves into the world. While the individual may actively shape
his or her concept of self and world and place within it, culture is seen as providing a fundamental basis for understanding.

Social constructionism offers a meaningful framework for understanding the narratives of former psychiatric patients because these individuals must find personal meaning and self-definition from their experiences within the context of broader social assumptions and beliefs about mental illness and psychiatric hospitalization. How we structure self-narratives, how we order and relate and prune life events in the act of creating a life story, involves a process which the Gergens (1983) refer to as “social negotiation.” They argue that social negotiation occurs throughout the process of storytelling through anticipation and articulation. When a person tells a story of his or her life, that person is not simply recounting events one by one in sequence, but he or she is actively engaged in a process of interpretation in which meaning is ascribed to events in relation to one another and in a way which seems intelligible and acceptable to narrator and listener. The narrative takes form and is ascribed meaning through an interactive process of discourse between teller and listener (including oneself as listener) within a larger cultural context of meaning (Cohler, 1994). For ex-patients, social negotiation of narratives may be complicated by several factors. First, institutional living itself differs so significantly from life on the “outside” that the ex-patient may experience a sense of two worlds, a fact which may contribute to a feeling of discontinuity. Second, he or she may be reluctant to talk with others for fear of being misunderstood or stigmatized. Such stigmatization may be subtle and insidious or take pernicious forms resulting in loss of friends, job opportunities, or housing. In addition, the ex-patient may lack contact with other ex-patients with whom to share experiences and explore meanings.

Stories of stigmatized or non-dominant groups often go untold. Laird (1989), for example, talks about the fact that in many cultures, including our own, women’s stories have remained largely private as our history consists primarily of the stories of men. In the case of ex-psychiatric patients, the decision to disclose or to do so selectively and judiciously may have more to do with that individual’s “reading” of how others might hear the story than with his or her ability to tell it in a meaningful and cohesive
way. Similar to stories of non-dominant groups within society, individuals may experience events which do not easily fit within the dominant stories of their lives. Those experiences which fall outside of the dominant self-narratives—which Goffman (1961) calls “unique outcomes”—are most challenging or problematic for us. One characteristic response to such unique outcomes is to exclude them from our personal narratives. We do this through the structuring of self-narratives which, according to White and Epston (1990), is “a selective process in which we prune, from our experiences, those events that do not fit with the dominant evolving stories that we and others have about us. Thus over time and of necessity, much of our stock of lived experience goes unstoried and is never ‘told’ or expressed” (pp. 11-12).

Because they are so incongruent with the dominant stories, unique outcomes may represent such personal dissonance that it may be necessary for the individual to keep such events unstructured and unincorporated. Conversely, unique outcomes which remain amorphous and unincorporated may, like a burr under a saddle blanket, prove to become problematic over time. Unique outcomes which remain “unstoried” are often accompanied by pervasive but little understood feelings of guilt or shame and personal narratives with unsettling gaps, somehow unclear or deficient in meaning. In structuring self-narratives, we may find it necessary to prune certain events from our stories; however, it is only through examining unique outcomes that they take form and become available to us as meaningful experience. Somehow the experience of hospitalization must be reconciled with the life story in order to overcome feelings of disjointedness and produce a life narrative with meaning and a sense of continuity. How ex-patients incorporate their experiences must take into account broader social beliefs about mental illness and what it means to have been psychiatrically institutionalized.

Labeling Theory

Labeling theory is a sociocultural model in which mental illness is understood not as individual psychopathology but in terms of social deviancy. Drawing on various empirical studies of psychiatric patients, including Goffman’s (1961) work, Scheff
(1966) made a case that mental illness is, in fact, a label attached to certain individuals who engage in socially deviant behaviors or who are somehow in violation of social norms. Labeling theorists regard mental illness as a social construct with mental health professionals acting as agents of social control in explicating what forms of deviant thoughts and behaviors constitute mental illness. Importantly, Scheff outlined ways in which labeling has particularly dire, self-fulfilling consequences for the individual who, once labeled as mentally ill, is subject to uniformly negative responses from others based on ingrained sociocultural attitudes about mental illness. The behavior of the so-labeled individual conforms to those attitudes and expectations through a process whereby behaviors consistent with those expected are "rewarded" in the individual while behaviors which are inconsistent are "punished," thereby constraining the individual to the role of a mentally ill person. Chronic mental illness is established finally when the individual fully internalizes the role and assumes it as his or her central identity. Chronic mental illness is thus seen as a social role.

One need not reject belief in the existence of psychopathology in favor of the notion of the social construction of mental illness in order to acknowledge the existence and detrimental effects of social stigma on the mentally ill. However, critics of labeling theory have not only tended to hold fast to the notion of psychopathology, but they have also tended to de-emphasize the negative effects of labeling and to question the extent of social stigma. Gove and Fain (1973), for instance, question the extent of social stigma as they found that current and formerly hospitalized psychiatric patients sampled were rarely able to provide concrete examples of social rejection or discrimination. Gove (1982), in a later study, concluded that for the "vast majority of mental patients stigma appears to be transitory and does not appear to pose a severe problem" (p. 280). Other studies (for a summary see Link, Cullen, Frank, & Wozniak, 1987) suggest that any social rejection experienced by the mentally ill is more likely due to odd or deviant behavior they exhibit rather than to the label of mental patient.
While the late 1960s and 1970s saw a preponderance of studies challenging labeling theory, more recent studies have revisited the issue of social rejection of the mentally ill and the negative impact of labeling. Link and colleagues (Link, 1987; Link, Cullen, Frank, & Wozniak, 1987; Link, Cullen, Struening, Shrout, & Dohrenwend, 1989; Link, Mirotznik, & Cullen, 1991) challenge the conclusions of many previous anti-labeling studies, provide new evidence that labels are significant, and, finally, offer a modified theory. Their findings call into question the validity of previous studies which asserted that behavior rather than stigma resulted in social rejection. By “artificially mak[ing] labeling uncorrelated with behavior, [these studies] miss the possibility that labeling may be a more distal cause of rejection” (Link, 1987, p. 110). Internalized negative conceptions about the mentally ill and the expectation and fear of social rejection may lead to the very behaviors (withdrawal, anxiety, depressive symptomatology, etc.) that may cause anyone to be rejected. While modified labeling theorists reject Scheff’s (1966) notion that labeling directly produces mental illness, they acknowledge the ill-effects of labeling in decreasing self-esteem and contributing to behaviors which impair social functioning and place individuals at risk for future onset of illness (Link, 1987).

Overview of Study

A qualitative study was undertaken to explore ways in which high-functioning former psychiatric patients integrate and find meaning in their experiences of hospitalization. The study examined the narratives of five individuals obtained through in-depth interviews using an open-ended interview guide. (Figure 1) The interviews, which were face-to-face, audiotaped, and later transcribed, were each approximately 90 minutes in length. An exploratory study such as this with a small purposive sample seeks depth rather than breadth, that is, richly informative narrative data rather than meaningful quantitative data. This article focuses on only two of the narratives in order to preserve adequate depth. The narratives presented here are those of the two oldest participants. In contrast to the three younger participants, all of whom were in their 20s when interviewed and discharged five to
Interview Guide

1. Could you tell me about your hospitalization(s) and your life since then? How do you think the experience of hospitalization has influenced your life?

2. Has the way you've thought or felt about your hospitalization changed over time from discharge to the present?

3. Has the experience of being hospitalized changed or influenced any [other] specific areas of your life, for example: your values, life goals, the way you relate to family members or others, your spiritual beliefs, choice of careers or any other areas of your life?

4. Has the experience of being hospitalized changed the way you think or feel about yourself or the way you perceive others think or feel about you?

5. In general, do you feel there is a social stigma associated with psychiatric institutionalization? Have you experienced stigma personally and how have you dealt with it?

6. Since [last] discharge, have you sought therapy, pastoral or religious counseling or participated in any self-help groups? How has this been/is this beneficial to you?

7. Is there anything you feel is important for therapists/counselors/pastors/rabbis to know to better understand and work with individuals who are former psychiatric patients?

ten years prior, these individuals were middle-aged having both been discharged approximately 30 years ago. The advantage of presenting their narratives lies in their ability to articulate the changing meanings of their experiences over time.

Both individuals whose narratives are presented here were referred to me by a mental health professional previously informed about the study's purpose and selection criteria. For the purposes of the study, “high-functioning ex-patients” were individuals who were hospitalized for a psychiatric illness for at least three months, who were last discharged for at least four years, and who were determined to function at a level of 70 or higher
with respect to the Global Assessment Functioning (GAF) Scale at the time of the interviews (American Psychiatric Association, 1994). In addition, an implicit criterion called for selection of individuals who regarded hospitalization as a significant life event which they have sought to incorporate somehow into their lives. It was assumed that those who appeared to split off, compartmentalize, or repress the experience would not only be unsuitable participants, but would, in fact, be unlikely to want to participate in the study. This seems to have been the case as each of the individuals provided thoughtful and informative reflections on their experiences.

Each interview began with two broad questions: “Could you tell me about your hospitalization(s) and your life since then?” and “How do you think the experience of hospitalization has influenced your life?” These two questions elicited from participants personal narratives about their experiences, encouraging reflection rather than simply factual recall, and providing them with the opportunity to highlight personal themes rather than those suggested by the interviewer. Subsequent questions addressed specific themes—changes in self-concept, values, relationships, stigma, and so forth—which in many cases emerged naturally in the course of the narratives. The semi-structured interview format seemed successful in striking a balance, that is, in allowing the interviews to develop in ways which seemed natural and conducive to gathering richly descriptive and informative data while at the same time ensuring that certain themes were raised in each interview which helped to facilitate comparisons between respondents.

The two participants were given the pseudonyms of William and Eva. Selected verbatim blocks of narrative presented here are interspersed with relevant information about their lives including histories of psychiatric hospitalization. Again, although the stated purpose of the study was to explore ways in which ex-patients integrate and make meaning from the experience of hospitalization, these participants also reflected on related life events which occurred both prior and subsequent to hospital stays. These accounts demonstrate the importance of reconstructing critical life events through personal narratives in order to integrate these events into the life story in meaningful ways. The task of selecting
which portions of the lengthy narratives to include and what to simply paraphrase was a difficult one. An effort was made to preserve the integrity of the data as much as possible and to include direct quotations which seemed to best illustrate the participants' understanding of the meaning of hospitalization and related events in their lives.

William

William is a 51 year-old married white man who is a Vietnam combat veteran. In high school, he was a strong student, a star athlete, and a gifted public speaker, having won a state speech contest his junior year. He planned to enter college following service in the Marine Corps, after which he aspired to build a successful career in real estate and enter politics. William's parents, who both worked as custodians, shared these aspirations for their only child whose drive and talents suggested these dreams were feasible. During his service in Vietnam as a medic, William experienced his first schizophrenic episode. He spent five months in a naval hospital in 1966 at age 22, heavily medicated and on an acute ward. This was a scarring experience which precluded him from seeking needed mental health services for years following discharge.

For me, the hospital and the time I spent in the hospital was such a horrible experience, was such a nightmare. I was supposed to get transferred to the V.A. hospital in Palo Alto which is the one One Flew Over the Cuckoo's Nest was written about. So the book was out and I knew I wasn't going there. So I figured I was just better off on the streets of America, maybe fumbling, maybe even dying really, than to go back into any kind of psychiatric care. That's why I've become such a dedicated crusader for psychiatric care.

William returned home briefly following his discharge but, feeling isolated and set apart, he soon began drifting from place to place and surviving marginally on his service-connected pension. He lived as a "bush vet," that is, a recluse, in a remote area of the Southwest for a number of years and also lived for months at a time on the streets of San Francisco. During this time, he was a heavy user of various street drugs, especially hallucinogenics. The drugs masked the symptoms of his schizophrenia and he felt less
conspicuous among others who were also high on substances. His means of coping with the stigma of schizophrenia was adaptive though self-limiting.

Over the years, William was involved in a number of political movements—civil rights, anti-war, migrant farm workers, and so forth. In the middle 1980s, he weaned himself off of street drugs and began taking prescribed antipsychotic medications which enabled him to function at a level at which he could attend college. At that time, he also became involved with physically disabled Vietnam veterans. He soon came face to face with his profound sense of shame at having schizophrenia, a fact which he had carefully attempted to hide from others for nearly 20 years. His affiliation with other people with chronic psychiatric illnesses, and eventually his political activism and work within the mental health consumers' movement, began as he was able to come to terms with his internalized stigma and embrace his own cause.

So I went to school. But he [a veteran's affairs counsellor] encouraged me to go to this peer counseling class with people from the independent living movement, people who are in wheelchairs, people who have physical disabilities mainly. And I was in school the fourth day of a five day training and that day I just broke down and cried and said I just can't hide anymore. I can't hide anymore. I'm tired of living in shame. I'm tired of someone discovering that I have schizophrenia, kind of whispering behind my back and making fun of me. . . . I've just had to hide and cover and act like I'm really not this person for so long that I said I don't want to live like that anymore. . . . In my lifetime, I think that . . . I didn't really choose this movement. As a matter of fact, I kind of avoided this movement. I wanted not to have anybody know I was crazy. Until about eight or ten years ago . . . I feel as though I have a moral responsibility to others that are coming out of institutional care who have been more destroyed by it than I was.

With the help of antipsychotic drugs, William's condition is largely stabilized. He is currently the director of consumer affairs for a large deliverer of mental health services with an annual budget of 42 million dollars. In that capacity, he helps develop supportive residential communities for mental health consumers and advocates for mental health care reform. In this work, he encounters broad community resistance.
I know we’re going to be limited by community acceptance in putting up residential facilities. . . . This town’s as good as it gets as far as acceptance but it’s not the promised land. I’ve testified at the city council. I mean people scream at me and follow me. Almost cross burning to keep residences out of the community.

William also commented on the fact that it is not necessarily behavior per se that sets himself and others with psychiatric conditions apart in the eyes of society, but it is the label itself. Behavior is interpreted in light of the label of mental illness.

Maybe I will always be spaced out. Maybe I will always ramble. Maybe I’ll always be unfocused and maybe I’ll never be right on task, you know. . . . It’s weird that if I were a college professor, I would be tolerated as an eccentric but if I’m known as a person with schizophrenia, I’m seen as a person who’s nuts. You see the difference.

As a person with schizophrenia, he also spoke about society’s misconceptions and fear of those with the disease and a failure, in fact, to understand how vulnerable they are to victimization.

With this psych condition I am going to be more spaced out and vulnerable to many of the predators who live in society. In that way, I find that a lot of women and African-Americans identify with that. They’ve been more victimized by these predators. When I speak of predators in society, they know more of what I’m talking about. They’re out there, they’re rampant, and they ain’t us. They’re portrayed in the movies as us. If they are us, they’re people who didn’t get care or even treatment.

William’s first schizophrenic episode profoundly changed his sense of identity and of the world. Building a new identity was a long, difficult process which involved accepting the limitations of his psychiatric condition while at the same time learning to “harness and direct” his creative energy. While reflective of William’s acceptance and discovery related to his schizophrenia rather than his hospitalization, the process he described is instructive to others who have undergone a life changing event.

The military is kind of the ultimate example of some kind of external conformity where somebody decides on what the norms are and everyone has to fit into that. And the psych hospital was the same
way, especially the navy psych hospital. So I felt like I didn't really belong anymore. In other words, after you have a psychiatric break, besides the spaciness of the condition, I just knew I was seeing things differently than other people. In other words, I'm not by any stretch of the imagination the same person I was before my break. I'm different but there are some similarities. I was able to regain my life by building my own identity. Like finding out what I could do and exploring that. Trying to do some singing, doing the writing, trying to figure out who I am, what I can do, and what I enjoy. I mean if I can't go back and be a real estate agent like I wanted to be as a kid, and an all-star football player, you know, and having my own agency, and being this tycoon. I mean what can I do today that I really enjoy with this kind of spaced-outness and this kind of acquired sense of humanity. The psychiatric condition works for and against us and I think that that's one thing we never have put into psychiatric rehab. We always see the tragedy. We always see the loss. You know well "William will never play football again." "William will never do this." But there's a lot of—I hate to use a term like "enlightenment"—but there's a lot of illumination that goes into that. . . . I think we really have to look at that. How can that be, for lack of a better word, harnessed or directed. So that's what I tried to do, to harness and direct this new way of looking at things, this new person, and started to move me forward in an exploratory way. . . . Something happened to me which left me in a different position but not necessarily an inferior position. I finally started to put that together. For years, I beat myself up because of that. But when I started to realize that the new William actually had even more potential than the old William then everything kind of fell into place. As long as I was kind of angry and anguished because I had been a failure or hadn't succeeded in being a military leader of men—which sounds kind of strange but my whole life had been geared to that, right. My whole life had been geared to being some kind of military-political figure. . . . Twenty-eight years of coming out of this. I still have the auditory hallucinations. I still have the external voices that come in until I'm enveloped by them. . . . So I still have all that but I'm able to live in a life that's gentle, outside of mainstream America. . . . If I ever wanted to return to what might be considered normal, I would never be able to do that I don't think. And I don't know if it's healthy to do that. Even for the others . . . it's like saying you broke your arm and now you want to go back and be a baseball pitcher, but they're one out of a thousand. The vast majority would probably be better coaching kids or being a school
teacher or maybe teaching people how to take care of themselves. Sure they’d earn less money and have less fame but that’s part of accepting life. I think life’s more of a learning process.

William talked at length about a profound change in his politics, world view, work life, and philosophy of mental health care as a result of his psychiatric condition and hospitalization.

I had come into the Marines kind of a right-wing young American for freedom—William F. Buckley, Barry Goldwater type of conservative—and it was like at that moment everything I believed in, everything was just gone. . . . They separated me from the unit because all the guys were saying, “Yeah, the doc’s right [he was a medic], we’re just killing farmers over here.” They sent me back to the U.S. and I was hospitalized. . . . The break was actually for me much more transformational than even the hospital because after the break I never did see things the same way. . . . In other words, these guys I idolized as a kid have really once again taken over the country. When I was one of them before my psychiatric break, I felt completely powerful. Like “people on welfare should be shot.” I really believed even that. Euthanasia for people who were in a worse situation than I was. And then this happened to me and then I had to make the adjustments in my life. That’s been the hardest thing I’ve had to do because it’s like losing everything all at once and then having to regain it.

Coming to terms with his psychiatric condition has meant embarking on a path of political and social reform within the mental health consumer movement. A prior sense of self-blame and isolation has given way to a sense of purpose and belonging through a broader understanding. Outside of the mainstream himself, William gained compassion for members of other disenfranchised groups while drawing on their political examples.

In my work with consumers, I used to use traditional psycho-educational approaches. Now I come at it from the perspective of us as a people and our history. That way I’ve learned from the women’s movement, people of color, gays and lesbians. The gay and lesbian papers have articles on identity that I think can be translated to our movement. You talk about stigma. I mean if I were to tell the field of psychiatrists that I’m learning from gays and lesbians. . . . [He laughed.] They’d just be in terror. I garner all this and just try and learn from other people with similar struggles. . . . There’s always
been a sense of shame. Nobody’s ever said well this happened to this one group of people. Maybe we should look at them as a group and see what happened. Just like you were saying, well what was your reaction to the hospital? Well, the reaction to the hospital is that it is the ultimate denial or the ultimate kind of stamping out of ourselves as a people. Our history, right?

William’s experience in the naval hospital and his resultant disenfranchisement from the mental health field for many years have fostered deeply held beliefs which are at the heart of his political activism and vision for mental health care reform.

Our treatment in the past with the hospitalizations has been to shock people back into consciousness, behaviorally shape people rather than to guide the identity of the person that’s there, you know. Find out what the identity of the person is and work with that rather than to shape their behavior. You see the difference. It's a totally different way of doing things. Unfortunately most people say “straighten up and fly right.” We’ve set up this system which doesn’t work. I even attribute a lot of staff burn out to it. There’s no way I’m going to straighten up and fly right... So I would say my whole life has been a kind of reaction to this kind of asylum treatment. I differentiate the world of psychiatry into a time of treatment and a time of care. Before we were in this time of treatment and this treatment was a kind of grisly experimental one-upmanship. . . . So now we’re moving into an era of care. When you care for somebody it’s not like you’re shaping them or anything else. It’s like you’re working beside them as a companion and developing a sense of companionship. . . . [later] There’s this reluctance to have an open discussion about the condition much less about everything else. . . . The secretness and fear of the unknown aggravate the condition. People who have been on back wards for 14 years, consumers we work with say all this. They’re able to sit at the table and say these are my needs, these are my resources, and to plan. It’s not therapy we’re doing. We’re just sitting around having popcorn and talking. . . . People in community mental health are learning just be a regular person. Now the rest of the mental health system is learning these same kind of ideas—no barriers. It’s like we’re on a street corner together kind of mentality. Rather than “I’m the professional, I’m here to help you.” Sal, the case manager. . . . It’s a hard lesson. You pay a lot of money to go to school. What are you going to say after you get all that schooling? “Hey, I’m just hanging out making pizza
here at the house." People want to have some kind of bigger picture of themselves than they’re really going to get out of mental health. Public mental health is going to get a lot funkier, a far cry from setting up a nice private practice somewhere. . . . Drugs and alcohol take behavioral approaches, psychiatric conditions take love and care and hope over time. Society’s not prepared for the length of time it’s going to take. Schools aren’t preparing people for that.

Finally, William reminds us of a simple truth about mental illness. His words are both a call for ongoing, humane care based on societal acceptance of the mentally ill and a statement concerning identity and dignity of those with mental illnesses.

We’re just doing everything now just like hoping it will go away. What I suggest is it’s here to stay, it’s been here for centuries. We are a people, we have a history, and we better build something around that reality rather than someday there will never be mental illness. People with people is going to do more than anything, more than the drugs.

Eva

Eva is a 47 year-old white woman and mother of two who has come to associate her long struggle with drug and alcohol dependence and depression with her history of childhood sexual abuse and a dysfunctional family situation. Eva’s father, a university professor and avowed communist during the McCarthy era, lost his teaching position and abandoned the family when she was young. Eva lived with her physically and sexually abusive mother until age 14. Her older sister, possibly suffering from undiagnosed paranoid schizophrenia, joined with their mother in physically and emotionally tormenting Eva. Later, her family stigmatized her for having been hospitalized, which perpetuated her shame and self-doubt.

I could be dismissed entirely. My mother and sister, who I believe have much more severe psychiatric problems than I do, have never been hospitalized so therefore anything and everything I did became interpreted, not only in hindsight but my current activities, as "Eva the nut." Everything I’ve done subsequent to that, everything I did prior to that became reinterpreted in light of that label. That’s as true today as it was 30 years ago.
Eva left home at age 14 to live on the streets and quickly became involved with illicit drugs and an abusive older man whom she later married. Acknowledging that her way of life and her self identity prior to hospitalization may seem unappealing in many ways, Eva described her rebelliousness as self-preserving and talked about how institutionalization altered her sense of self. After entering a private psychiatric hospital at 16 for observation, she was admitted. Eva believes she was diagnosed in the hospital with depression and an anxiety disorder; her self diagnosis is post-traumatic stress disorder as a result of childhood trauma with related substance dependence. Placed on a ward for adults in recovery from electroshock therapy (though an adolescent and not treated with ECT), adult patients were instructed not to talk to her during the six months she spent on this ward. Everything about this experience confirmed that she was a pariah.

The path that I’d chosen of being homeless, being on drugs, and the criminal activity may have looked dreadful but it didn’t look nearly as dreadful to me as the alternative. When I was dressing up in drag and picking up girls in that part of town, it was like myself as Billy Budd or something. I was definitely out there. But it was a way of claiming an identity. That banded identity or that negative identity that pre-dated the hospital was an affirming one, a life giving one, a life saving one for me. Anger and defiance were necessary to protecting the self. There was something worth protecting. Some reason to live, some sense of justice. . . . The hospital was pivotal. It was a profoundly changing experience. I will never experience myself again as I experienced myself prior to that. As I said, I became much more cautious. That sense of jubilance wasn’t completely destroyed but it was altered . . . the experience of being a person who was so damaged or so toxic that other people weren’t even allowed to carry on even casual conversation with me. That first six months, that experience was fairly shaping in my sense of self. If you know social theory, you know Erving Goffman’s work. I think that’s true. There is a way in which your self is stripped away in a total institution. And a new self emerges. And sometimes that new self is stronger because of the rules structure, or seems stronger because the rules structure gives you some kind of vessel, some kind of framework in which to function. I don’t think the hospital did that for me. I think I was functioning when I went in there and I continued to function after I left, after a fashion. [she laughed]
After six months, she was transferred to an unlocked ward and soon afterward left against medical advice. The following year, she realized that she needed both psychiatric help and protection from her abusive boyfriend and admitted herself to a progressive teaching hospital. She remained in the second hospital for nearly one year until discharge on her 18th birthday. In retrospect, she realized how open she was to receiving help at that time—help coming to terms with earlier trauma, her substance dependence, her bisexuality, and with her need to protect herself and plan for the future. She reports receiving neither the help nor protection she needed.

He [her hospital psychiatrist] totally ignored the battering. He ignored the fact that my mother battered me. He never wanted to talk about that. It was a non-issue with him. I guess he was Freudian. I don’t know what his therapeutic technique was but it did me a lot of harm. I had no choice but to respect him as an authority. I had no one else to turn to. My father abandoned us, my mother was drunk and nuts all the time. There was nobody and nothing. . . . They made me go to group therapy as a condition of my release but it was really a bust. . . . Traditional therapy for trauma survivors, for people like me, sexually abused as children, traditional psychotherapy is just a disaster because it invalidates your experience. The notion that you’re somehow not okay instead of trying to normalize your experience or put it into some kind of context so it can make sense to you. It just casts you further and further out into the darkness. . . . The one thing I wanted to do was go back to school. I had basically stopped going to school in the seventh grade and I really wanted to finish high school. I’d worked enough in factory jobs by that point that I knew I really wanted to go to high school. With all this IQ testing, he told me that according to the IQ tests there was no point in my finishing high school. I’d be lucky if I did some kind of janitorial work. This did not make me hopeful. . . . It was a juncture where I was open, completely open to being helped where I did not get helped. . . . Also in many ways it set me up for a fall. It set me up to get out and not be able to do well because I wasn’t permitted to finish high school. Instead, I was told I had to go to work. I was told I should get married if I was going to be sexually active.

Eva married her boyfriend shortly after discharge from her second hospitalization. Following several years in a troubled marriage which ended in divorce, she raised her two children as a
single mother and continued to struggle with substance dependence and depression. Eva eventually came to understand her problems less in terms of personal failure and shortcomings and more in terms of her familial and social context. During the several years following her discharge in 1965, she became exposed, first through literature, to the women's movement, the anti-psychiatry movement, and the black power movement. She began to understand her life in terms of prescribed roles and applied the concept of internalized oppression to her own internalized stigma of having been hospitalized. In these terms, the specter of stigma that had haunted her could now be understood as discrimination and oppression.

Franz Fanon talks a lot about internalization of oppression so that was my model. I internalized the stigma and I think part of how I stopped doing it was understanding it first through literature and then through the feminist movement. ... That was all very helpful to me in thinking about myself.

While a number of authors were helpful to her, one writer, Tilly Olsen, was pivotal.

When I was 21 or 22, I encountered Tilly Olsen. She wrote a book called *Tell Me A Riddle* which is a wonderful book. That was really my introduction to feminism. That was my epiphany. I mean I had read Betty Friedan's *Feminine Mystique* which is very centered on the experience of middle class women in the 1950s and I hadn't really been able to relate to it very much. *Tell Me A Riddle* was ... I don't think I'd ever cried like that, I cried and cried. There was a lot of relief about feeling like I'd found other people like me. ... What touched me was the fact that we get so chained to a role. The person in the book is a woman, a working class woman with a working class husband who raised a large family. They're an emigrant family of eastern European Jews. It's the story of her final days and her reminiscing. It's the fact that she was so bound by her roles that she was forced to play as a wife, as a mother, as a daughter, as a girl, as a woman, that she never got a chance to develop her humanity. She was this wonderful human being, this full human being. But that was never nourished. That was very astounding to me that other people knew this.

Within this context, Eva's role as a psychiatric patient came into a new perspective.
It was a very jubilant time. I began to see myself as a woman embedded in a social context. When things break down, what happens to you is that men go to prison, women go to mental hospitals. There was an affirmation not of my deviant status, but why my deviant status had occurred. What had happened to me.

Eva was eventually able to obtain her high school equivalency, complete college, and to establish a career in a human services field. She has also been sober for 15 years. Though her own life was changing dramatically for the better, Eva talked about continuing to be haunted by the suicides of fellow patients and the memories of the women who underwent electroshock therapy.

Something I’ve always wanted to write about and I’ve never been able to—maybe someday I will. . . . It seems like every year another fragment comes into place. That first hospitalization I had in the shock therapy joint, they were all women. They were all middle-aged women who had outlived their usefulness. Their husbands were out chasing young chicks, their children had left home, and they were just like Muslims or concentration camp victims in so many ways. Even the way they moved. Drugged, numbed out, an other worldly feel to them. There’s this grieving I’ve never really done about that. Of what it was like to be completely surrounded by my future in some way.

In recent years, Eva has come to recognize herself as a trauma survivor and, through therapy and reading, to understand the role of trauma in her life. She has also come to view her experience in terms of a larger social problem and to work with other trauma survivors. She described first becoming aware that she was a trauma survivor during a work-related seminar.

I went to an all day training on emigrants and one of the populations they talked about was Southeast Asians. A psychiatrist did a slide show with a voice over. During this presentation, I started crying and couldn’t stop. It was very embarrassing. I realized that I was one [trauma survivor]. That a lot of things that he was talking about were things I had lived through. That was the beginning of my researching my life for what had happened to me, who I was, and how I could make sense of that. How I could make that a part of my story instead of the thing that controlled me. I want to be with other people who have had my kind of experiences and work with them. Be a part of them. That’s certainly true with my career. . . . I think
we’re at a very hopeful point in our history where we’re starting to look at trauma therapy and make all kinds of links and connections as implications for the whole social order if you really look at it. It’s a very hopeful thing.

Eva attributes understanding herself in relation to her role as a woman, the dynamics of oppression and internalized oppression, and, more recently, the far-reaching effects of childhood trauma as helping to lift a burden of shame which has enabled her to be more open in disclosing her past to others. As with William, disclosure is a moral imperative for Eva. She stated: “In any situation where I’m able to [disclose], I will because I really think of it as a crusade. People need to know we’re here, that we are fully human, that we have something to offer.” While she clearly acts from her political convictions, Eva is not involved with any consumer-related political organization. This is, as she acknowledged, due to a wariness of institutions or strong ideologies seated in her past.

I was raised by someone who was a communist during McCarthyism and teaching at an Ivy League school and laid off as a result of that. His fanaticism always frightened me. People who got into very rigid fanatical groups, which was kind of like the Mental Patient Liberation Front—you either bought the party line or you didn’t—always scared me. Because I just saw my father as being so nuts and so despicable in so many ways. Someone who could walk off and leave his two children with someone who was so out of control as my mother.

Eva also related the form of her political activism to early childhood fantasies which, born of a sense of helplessness, have now found expression in her adult life.

I used to have very elaborate heroine fantasies. I dreamed about being the heroine and saving a group of people or something. And in fact I’ve tried to live that out in my adult life too. [She laughed.] It’s hard for me to step down from the soap box.

Discussion

The narratives of both individuals seem to underscore that the process of integrating and making meaning of important life events such as psychiatric institutionalization occur within a social context. The theoretical constructs of social role theory were clearly evident in the narratives. In the years following her last
discharge, Eva was able to come to understand her experiences in terms of her role as a woman—"When things break down, what happens to you is that men go to prison, women go to mental hospitals." Having encountered Goffman's writings in her search for meaning, she reflected on how her roles as a young woman were "stripped away in a total institution" and talked about the gradual emergence of a positive self-identity through achievement of attained roles (college graduate, worker, activist). For William, having schizophrenia has been more central in his life than having been hospitalized, though he certainly described both as pivotal. He described how the onset of his schizophrenia robbed him of the positive roles he enjoyed as a young man—star athlete, strong student, Marine—along with the promise that these roles seemed to hold for his future. At the same time, he was derogated to a new, unwanted role as a chronically mentally ill man. In that stigmatized role, William described battling privately with his shame for 20 years and the process of confronting the shame and coming to accept himself. He was able to redefine the battle in terms of consumers' rights and to embrace a new role as social activist.

The issue of social stigmatization is prominent in both narratives. It is interesting to reflect on the debate concerning the effects of labeling in light of these narratives. First, contrary to traditional labeling theory (Scheff, 1966), neither participant indicated that labeling in and of itself resulted in mental illness though both indicated that the hospital treatment they received failed to normalize or validate or help them adapt to their experiences (childhood sexual abuse, adolescent struggles related to sexuality, and schizophrenia), thereby contributing to depression, substance abuse, low self-esteem, and so forth. In this sense, their narratives appear to support Link's (1987) modified labeling theory. Second, contrary to some labeling theory critics (see summary in Link, Cullen, Frank, & Wozniak, 1987), who believe that behavior plays a greater role than social stigma in the rejection of the mentally ill, in William's experience behavior is, in fact, interpreted in light of the label of mental illness. As he stated: "It's weird that if I were a college professor, I would be tolerated as an eccentric but if I'm known as a person with schizophrenia, I'm seen as a person who's nuts."

Finally, social constructionism provides a framework for understanding and appreciating the narratives. Eva and William's
reflexive capacity for self-understanding within a social context is evident in their ability to find new meanings from their experiences of mental illness and institutionalization. Both found alternative social perspectives and political involvement instrumental in gaining a new understanding about what happened to them and in “restorying” their lives. Involvement in the women’s movement helped Eva to place her life experiences within a social context while reading literature about oppression helped her to reframe her internalized stigmatization of psychiatric institutionalization. In reference to coming to terms with her trauma history, Eva emphasized a process important for both participants, that is, making sense of life events through dialogue and affiliation with others with similar struggles: “That was the beginning of my researching my life for what had happened to me, who I was, and how I could make sense of that. How I could make that part of my story instead of the thing that controlled me. I want to be with other people who have had my kind of experiences and work with them. Be part of them.”

The fact that William spent 20 years of his life carefully hiding his disease from others and masking the symptoms from himself through drug use is indicative of the fact that schizophrenia is stigmatizing, sudden in onset, and dramatic in its effects, making it particularly difficult to contextualize. He powerfully characterized its impact and the difficult task of coming to terms with this “unique outcome” (Goffman, 1961): “And then this happened to me and then I had to make the adjustments in my life. That’s been the hardest thing I’ve had to do because it’s like losing everything all at once and then having to regain it.” The process he described, however, was not so much about regaining what was lost as about reconstituting his life—“So that’s what I tried to do, to harness and direct this new way of looking at things, this new person, and started to move forward in an exploratory way.” As he was able to come to accept and appreciate this new person, he could then draw on his illness and the negative experience of hospitalization as an impetus for his work.

Implications for Practice

While other ex-patients may not integrate the experience of prior psychiatric institutionalization into their lives and find
meaning from that event in ways similar to these two participants, for example, through social perspectives or political activism, the process of contextualizing the event and gaining new understandings about it through dialogue appear vital. The narratives presented here suggest that social stigma has insidious and powerful effects on ex-patients. Because the event of prior psychiatric hospitalization is often shrouded in secrecy as a result of broad social stigma and resultant feelings of personal shame, ex-patients may not seek out or readily find others with whom to explore alternative meanings. In this sense, stigma not only contributes to shame but impedes ex-patients in overcoming it. Practitioners working with ex-patients may facilitate their clients in drawing on the experiences of others by reading and recommending pertinent literature, for example, related literature about oppression and internalized oppression, facilitating groups for ex-patients, or referring clients to informal groups in the community. Use of bibliotherapy (Hynes & Hynes-Berry, 1994), writing and narrative therapy (White & Epston, 1990), and poetry therapy (Mazza, 1993) can all be used to help individuals reconstruct critical life events such as psychiatric hospitalization. How groups and individual work are able to help individuals overcome shame and shape meaning from their experiences of psychiatric hospitalization represents an area for future research. The value of this research will be in aiding ex-patients and the practitioners who serve them in finding a framework for the experience of prior psychiatric hospitalization so that the event is not simply a "unique outcome" (Goffman, 1961) but can be integrated into the life narrative in a meaningful way which eliminates shame and promotes self-growth.

References


Endnote: I am grateful to Joan Laird and to Dr. Benjamin Druss for their input and support.