A magazine for professionals serving children and youth with behavioral needs.

Midwest Symposium for Leadership in Behavior Disorders
The Multiple Worlds of Mental Illness and Stigma: Is it us? Is it them? Or is it both?

By Carl R. Smith
In 1972, I began my Ph.D. program at the University of Iowa. I was a newbie to Iowa and intended to complete my program in 3 to 4 years and then start my career in behavioral disorders in a somewhat warmer climate. I soon encountered these perspectives.

- Thomas Szasz argued that mental illness is a myth and criticized the moral and scientific foundations of psychiatry. He argued that mental illness was just normal problems in living, not “illness” and that “madness” was manufactured (Szasz, 1961).

- Erving Goffman, a sociologist, documented the regimented and carefully controlled existence of those who were unfortunate enough to be identified as a person with mental illness in psychiatric institutions in his book Asylums: Essays on the Social Situation of Mental Patients and Other Inmates (1961).

- D.L. Rosenhan questioned whether experts in mental health could truly distinguish between patients needing care in mental health settings from others who he called “pseudopatients,” people who represented themselves as mentally ill but who were actually normal people (1973).

- Bill Rhodes posed the question whether the students served as emotionally disturbed in special education were actually better described as emotionally disturbing to others (1963). Various theorists, labeled as counter-theorists, carried this banner forward. Rhodes went on to champion the notion of “celebrate deviance” asserting that our society would be in significant danger if deviance were eliminated.

These seemingly incompatible perspectives presented a challenge for me. On the one hand, mental illness was a creation of our society as a means of coping with behavior that others perceived as unacceptable. On the other hand the behaviors noted above seemed to fall out of the range of normal behavior.

My road towards understanding these challenging thinkers and developing a career in special education then took a sudden and dramatic turn. As I remember, I started having significant problems with sleep. I also began having significant problems in my thought and interpretive competencies. Along with this I became much more assertive in my advocacy work on behalf of the students I worked with and became suspicious that I would suffer consequences from faculty because of such advocacy. Realizing the dangers of such thinking I began to understand that I probably would benefit from some type of mental health help.

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**My mental illness experience was a secret to hide most of my adult life.**

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But I also saw what had happened on the national scene when Thomas Eagleton, Senator from Missouri had been chosen in 1972 as George McGovern’s running mate but was later removed from this opportunity because of his mental health treatment. For me this signaled the unacceptability of receiving any type of mental health treatment as that would likely plague me for my entire life and thus I did not seek such help. I also did not accept help from a good friend to have me meet with the admitting physician at the University Psychiatric Hospital.

This strategy did not work well for me, as I nevertheless ended up being hospitalized for most of the Spring of 1973. When finally admitted, I was diagnosed with various conditions ranging across
primary affective disorder, acute atypical psychosis, acute schizophrenia-form psychosis, paranoid state in remission, and reactive agitated depression in remission. Thus, I went from being a promising, up and coming doctoral student to a psychiatric patient with several of the identified conditions described in DSM II (the current version at the time). I was –

- A patient who thought he was being constantly observed even by the television.
- A patient who thought another patient was actually his doctor.
- A patient looking totally drained after being locked in a time-out room for eight hours, which apparently had followed the patient being restrained.
- A patient who could not sit still and had to continually walk.
- A patient who was so medicated that he drooled and could barely stay awake.

During that time I was prescribed the most commonly used interventions of medications for addressing psychotic behavior, Thorazine, described by some as “a chemical lobotomy” and Stelazine. While these medications were hailed as significant strides in the practices of psychiatry from earlier methods of prefrontal lobotomies there were side effects to cope with. As a side effect of these drugs I became almost robotic in my movements. As a result I was also given Artane to offset these side effects of the first two.

At other times, I became noncompliant and aggressive; behaviors that were not typical for me. In dealing with this, the hospital staff restrained and secluded me in what was named the quiet room for up to eight hours at a time as a primary intervention. The only interaction with others during this extended time-out were the nurses bringing in my medications.

In viewing the impact of this experience in my life since, I have several thoughts. First, my mental illness experience was a secret to hide most of my adult life. And there is certainly a foundation for doing so. A close friend advised me to not share my story. She was particularly concerned that this sharing would lead to adverse effects on my chances of advancing professionally. Fortunately, this same good friend recently advised me of the value of sharing my story with others as one example of moving beyond this experience and doing well professionally.

Secondly, there were also other possible outcomes outside of the hospital that would have had a significant impact on my chances of recovery. First would have been the ending of my assistantship with the university and possibly being excluded from my program in special education. Rather than this, I received total support from the university faculty. They did so even though my behavior leading up to the hospitalization could have easily led this faculty to determine that I was a threat to them individually or to the program considering my paranoid thought processes leading up to my hospitalization. This could have also led to my exclusion from my intended program. Think about how this plays out with current media and the focus on the danger of violence often associated with persons with serious mental illness; an additional dynamic of mental illness and stigma.

A final thought that has emerged through my journey is that I was extraordinarily fortunate to be where I was when my serious mental illness happened. I was new to a state, only having lived in Iowa for six months. The student insurance policy
I took out only provided for less serious concerns. Despite this status, all of my hospital stay was covered by what is known as “state papers.” I have tried to get the actual costs of this treatment and hospitalization but found out that county records, where these would be stored, did not extend back that far. In what was probably my first “outing experience” of sharing my mental illness I shared my experience with the Iowa Mental Health and Disabilities Commission and questioned whether such support would be consistently provided to a student in Iowa in a similar situation today. My fellow Commission members agreed to reconsider the assumption that such a student would receive the same treatment today, I believe this contributed in further considerations of reforms needed in our mental health system.

**Lessons Learned**

First, I think that we need to make our stories public. I hope this article contributes to the collection of stories of the many individuals who have faced mental health challenges and went on to lead productive, self-satisfying lives. At least two studies (Corrigan & O'Shaughnessy, 2007; Mann & Himelein, 2008) suggest that the stories told by persons who have experienced mental illness may have a profound effect in reducing the impact of stigma.

Secondly, think about the circumstances under which we are most frequently exposed to the lives of persons facing mental health challenges. How frequently are these diagnoses associated with highly deviant, aggressive, or destructive behaviors? As Leys (2010) points out, serious mental health conditions such as schizophrenia are commonly associated with violence and crime when in reality most individuals with this condition lead “quiet, unremarkable lives” (p. A1).

Another related dynamic is the influence of whether we believe an individual with mental illness can control their behavior. On the positive side, some of us, who believe such behavior is beyond the control for the individual, may be more forgiving. Others may be more pessimistic regarding possible recovery from these conditions if they believe the behavior is beyond the control of the individual (Corrigan et al., 2005).

We also have differing judgments of other people’s behavior in contrast to our own. As Aronson (2000) states:

> . . . whenever we observe someone’s negative or nasty behavior, we are prone to assume that the behavior is caused by the kind of person they are, rather than the kind of situation they are in. Interestingly, we are almost always more generous in interpreting the reasons behind our own behavior - primarily because each of us is more familiar with the situational pressures under which we are operating. (p. 22)

Contrast this perspective with the role models we need of leaders and caring individuals, particularly in these times where blaming often seems to have replaced attempts at understanding.
There are not clear defining lines separating most forms of mental illness from normal behavior. We all may experience certain behavioral manifestations in areas such as depression or anxiety that may be tolerable at certain times and at other times take us over a threshold and shut down our ability to cope and function competently. As Smoller (2012) notes, "By the latest accounting, more than half of all Americans meet criteria for a psychiatric disorder at some time in their lives" (p. 13).

It is also important to note that my journey beyond the early hospital experience has not always been smooth. There were times when I was faced with anxiety and panic attacks related to public speaking and phobias triggered by airplane travel or crossing bridges. The criteria or measure of seriousness is the ultimate challenge of whether these have a functional impact on my life. They did and through some pretty good talking cures and medication these were dealt with. I still take a small dose of antidepressant to cope with what seems to be a common malady for people of my age.

This leads to the meaning of the title I chose for this article and what I believe will be one of the most significant barriers we face in reducing stigma. Until the time that most people perceive mental illness as being a part of all of our lives and not just them, we will see this stigma persist. To capture the theme of us means that we realize that mental illness will affect all of us, particularly as we think of all the people in our extended family. As Pete Earley (2006) reminds us, we lock up the mentally ill because they frighten us and we believe there is something that caused this insanity. To believe otherwise, Earley notes would open the possibility that this could happen to us. As he contends, "... that is such a frightening thought that we quietly search for explanations to prove that the mentally ill really aren't like us and they somehow deserve the torment they suffer" (pp. 121-122). To truly impact the stigma of mental illness, for children, adolescents, or adults, we can and must do better. We must adopt an approach that embraces a caring and understanding world of mental illness and belief in the power of recovery.

References


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Carl R. Smith, Professor Emeritus, Iowa State University, Ames, Iowa, csmith@iastate.edu

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