

Stigma: A Barrier to Treatment

by C. Jay Fox, Ph.D.

Sister Williams has given us information on the nature and prevalence of some of the serious and persistent mental illnesses. [See her talk on this website entitled “What is Mental Illness.”] I would now like to talk to you about ways in which stigma is a barrier to treatment. I come to you this evening wearing many hats, the most important of which is having the lived experience of a sister who, before she died, suffered for 45 years with schizophrenia. Earlier I had worked with students with mental illness at BYU-Hawaii as a vice president and dean of students and as a bishop to two different BYU student wards in Provo. I wish I had known then what I know now about serious and persistent mental illness. In the relatively short time we have tonight all I can hope to do is to introduce you to some basic principles and resources.

Much of what we as Latter-day Saints and as Americans know about mental illness is colored by stigma. If you look at your hand out, you will see a definition of stigma: “A negative label that we place on the mentally ill. From the dictionary: **stigma 1.** a mark of disgrace or infamy; a stain or reproach, as on one’s reputation.” (*Random House Dictionary of the English Language*, 2nd ed. unabridged)

What Does Stigma Lead To? According to the Surgeon General,

Stigmatization of people with mental disorders has persisted throughout history. It is manifested by bias, distrust, stereotyping, fear, embarrassment, anger, and/or avoidance. Stigma leads others to avoid living, socializing or working with, renting to, or employing people with mental disorders, especially severe disorders such as schizophrenia (Penn & Martin, 1998; Corrigan & Penn, 1999). It reduces patients’ access to resources and opportunities (e.g., housing, jobs) and leads to low self-esteem, isolation, and hopelessness. It deters the public from seeking, and wanting to pay for, care. In its most overt and egregious form, stigma results in outright discrimination and abuse. More tragically, it deprives people of their dignity and interferes with their full participation in society.” (The Roots of Stigma.” *Mental Health: A Report of the Surgeon General*.

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Although all disabilities present their own challenges and carry their own kinds of stigma, the Surgeon General’s report reminds us that

The stigma that envelops mental illness deters people from seeking treatment. . . .Stigma impedes people from seeking help for fear that the confidentiality of their diagnosis or treatment will be breached. It gives insurers—in the public sector as well as the private—tacit permission to restrict coverage for mental health services in ways that would not be tolerated for other illnesses. (Overcome Stigma. *Mental Health: A Report of the Surgeon General*.

<http://www.surgeongeneral.gov/library/mentalhealth/chapter8/sec1.html>

As members of the Church, stigma can prevent us from full compassionate service toward those

with mental illness.

Unfortunately, many of our perceptions and misconceptions about mental illness come to us from the media. As a professor at BYU and a teacher of literature and film, I have been researching for several years how the media can shape our values, attitudes, and behavior. Edward Hanin, M.D., chairperson of the American Psychiatric Association Joint Commission on Public Affairs summarizes media representations of those with mental illness this way:

Unfortunately, these depictions are too often distorted, outmoded, or just plain wrong. They perpetuate stigma and add to human suffering. Mentally ill people are portrayed as homicidal maniacs, when in truth they are more often the *victims* of violence. They are portrayed as isolated rogues and outcasts, living on the fringes of society. Most often, though, they are friends, co-workers or loved ones, even high government officials, hiding their pain and confusion and suffering in shame and silence. They are pictured as buffoons and fools, laughing at jokes no one else understands. Yet mental illnesses have nothing to do with intelligence. Sometimes a mentally ill person will be depicted as the quintessential free spirit—someone who’s not really ‘sick,’ just out of step, instead of one whose suffering is sometimes so great that suicide appears to be the only escape. Why is the real picture of mental illnesses not more widely known? Part of the reason is stigma. People fear mental illnesses, fear the people who have them, and fear seeking treatment if they suspect they are ill. They are afraid of the labels: *crazy, schizo, nutcase, psycho, wacko, mad-dog killer.*” (5) *Mental Illnesses Awareness Guide for Image Makers*. American Psychiatric Association, 1993.

Elder M. Russell Ballard in Oct. 2003 General Conference called us to action to speak out: “The time has come when members of the Church need to speak out and join with the many other concerned people in opposition to the offensive, destructive, and mean spirited media influence that is sweeping over the earth” (*Ensign*, Nov. 03, p. 17). Misconceptions about mental illness, often fostered by the media, can influence how we treat those who suffer from these illnesses and their families in our wards, stakes, neighborhoods. We need to start with empathy. By empathy, I mean “the intimate comprehension of another person’s feelings without imposing our own judgment” (Joyce Burland) .

Elder Morrison helps nurture that empathy by educating us on some of the misconceptions surrounding mental illness. His entire talk “Myths and Misconceptions about Mental Illness,” which he gave at a regional welfare conference, is in your packet. It is also in his new book *Valley of Sorrow: A Layman’s Guide to Mental Illness* (Deseret Book, 2003). I invite you to read the entire talk. [Another version, “Mental Illness and Families,” can also be accessed from this website.] I would like to comment briefly on some of the misconceptions. Remember that he says, “By mental illness I do not mean the temporary, transient social and emotional concerns experienced as part of the normal wear and tear of living. Included in that category would be the temporary depression associated with the death of a loved one, or the anxiety felt when starting a new job.” No, he is talking about serious and persistent mental illness as explained by Sister Williams. Let us see a short clip from a new series, *Living Essentials* being produced by BYU Broadcasting. [Clip was shown from DVD in which Elder

Morrison explains two misconceptions: “All mental illness is caused by sin.” and “All we need are priesthood blessings.”] (from *Living Essentials: Social and Emotional Strength DVD* This DVD is part of a BYU “Living Essentials” series on most aspects of personal welfare. The two disks in this part include “Social and Emotional Strength: An Introduction,” “Dealing with Depression,” “Understanding Mental Illness,” “Dealing with Abuse,” “Interpersonal Communication,” “Grief and Loss,” and “Dealing with Substance Abuse.” For descriptions of each program and transcripts, visit www.byubroadcasting.org/livingessentials or order from www.creativeworks.byu.edu ISBN 0-8425-2582-3 KB232)

I will now comment on some of the other misconceptions that Elder Morrison identifies:

Someone is to Blame for Mental Illness

According to Elder Morrison,

Many victims of mental illness wear themselves out emotionally by repetitive futile attempts to remember something they, their parents, or someone else might have done that resulted in the terrible suffering they are forced to endure. Some blame their problem on demonic possession. While there is no doubt that such has occurred in very rare instances, let us take care not to give the devil credit for everything that goes awry in the world! Generally speaking, the mentally ill do not need exorcism; they require therapy and the hands of skilled health care providers; and love, care and support from everyone else. [. . .] Ascribing blame for mental illness causes unnecessary suffering for all concerned and takes time and energy which would better be used to increase understanding of what actually is happening—to get a complete assessment and proper diagnosis of the illness involved, understand the causations—often ultimately, changes in brain chemistry—get proper medication which will help control the disorder by reversing those chemical changes and learn behavioral and cognitive techniques that are part of the healing process.

A visual that has been helpful to me is to look at two interlocking circles, on one side are those who have a serious and persistent mental illness; on the other we can list those who have committed serious sin, been abused, used harmful drugs, etc. True there can be an area in which someone who has committed serious sin also has mental illness—where the two circles interlock. But there are also vast numbers who have mental illness who have not committed serious sin and vast numbers who have committed serious sin who do not have a mental illness—where the two circles do not interlock. Our judgments here can often be faulty.

We do know that there is a genetic component in these illnesses. We know that about one percent of the general population has schizophrenia. The fact that my sister had the illness increases my chances to 10 percent—of course on the positive side, I have a 90 percent chance of not getting the illness. We have similar risk statistics for all of these illnesses.

Mentally-ill Persons Just Lack Will-Power

Elder Morrison explains: “The facts are that seriously mentally ill persons simply cannot, through an exercise of will, get out of the predicament they are in. They need help, encouragement, understanding and love. [. . .]We don't say to persons with heart disease or

cancer, ‘just grow up and get over it.’ Neither should we treat the mentally ill in such an uncompassionate and unhelpful way.” One of the biggest challenges we have as family members and even as professionals is to sort out what a mentally ill person can will and what he or she cannot will. My sister was never able to will herself out of hearing voices, which is a common symptom of schizophrenia. Doctors tried to control them through medication and the most we could do is try to help her control how she responded to the voices when she heard them.

Mentally-ill Persons are Dangerous and Should be Locked up

Again the media contribute much to the misconception that all those with mental illness are violent. When we hear of a shooting at the Triad Center or the Family History Center in Salt Lake, we erroneously conclude that all the mentally ill are dangerous. Make no mistake about it, violence can accompany a mental illness, but the majority of the mentally ill are not violent and are often the victims of violence. One of my biggest concerns—and I serve on the Provo School District’s HOPE Committee for Suicide Prevention—is that those with mental illness will harm themselves. We should learn the warning signs of potential suicide and know how to help, particularly when the person has a mental illness.

Whatever the Cause. Mental Illness is Untreatable

Treatment can work when it takes into account the Biological, Psychological, Spiritual, and Sociological components in these illnesses. U.S. Surgeon General Satcher reminded us in 1999 that

the mind and body are inseparable. [. . .] everyday language tends to encourage a misperception that “mental health” or “mental illness” is unrelated to “physical health” or “physical illness.” In fact the two are inseparable. Seventeen-century philosopher Rene Descartes conceptualized the distinction between the mind and the body. He viewed the “mind” as completely separable from the “body” (or “matter” in general). [. . .] This partitioning ushered in a separation between so-called “mental” and “physical” health, despite advances in the 20th century that proved the interrelationships between mental and physical health (Cohen & Herbert, 1996; Baum & Posluszny, 1999).

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What research in the 1990s—the “decade of the brain”—helped us see is that the body does not stop at the neck. The brain is an organ of the body and can malfunction as can any other organ of the body.

I really believe that as Latter-day Saints, we need to understand that a holistic approach to treatment is the answer. These are reflected in the handout you have. [See BioPsychoSocial Spectrum Handout below.] As you will note, there is danger in leaving out any one of these domains. Once we realize that someone may be suffering, we may find that that person is in denial and will resent our inference that they may be ill and will resist treatment. At such times, the person with the illness and their family members or other loved ones need our support and love. Coping with mental illness requires as much, and perhaps more, patience as any illness we may encounter in this life.

A first step for someone willing to receive help is a family doctor. The expertise and

comfortability in prescribing anti-psychotic medication will vary from physician to physician. LDS Family Services is another option, especially for those illnesses helped by psychological treatment. Community mental health centers provide an array of services, but are often limited to those who qualify for Medicaid.

Many times a psychiatrist is needed. Although they are medical doctors, they suffer from their own kind of stigma. A prominent psychiatrist in the state told me of being in medical school and having his classmates—who were going into other branches of medicine—ask him, “Why don’t you become a real doctor?” The jokes about psychiatrists are probably only exceeded by the jokes about lawyers. Yet they are invaluable when it comes to treating the biological component of these illnesses. In-patient treatment under the care of a psychiatrist may be needed at state hospitals or at private facilities. But best practices today strive to treat people in the least restrictive environments.

You will soon learn that there are serious inequities in the system of treatment, public and private. Many health insurance plans do not cover mental illnesses, or cover with reduced benefits, and the public system serves primarily those who qualify for Medicaid.

Yet there is hope from many sources. My wife and I nearly went under emotionally until we became part of the family education movement by taking and teaching courses to family members and professionals sponsored by the National Alliance for Mental Illness, known by the acronym NAMI. The family education movement has gained its impetus from an inspired clinical psychologist in Vermont named Joyce Burland who has a daughter and aunt with schizophrenia. Dr. Burland went back to school later in life than most and received a doctorate in psychology and has spent many years designing and field testing national courses that can educate us intellectually and emotionally on how to deal with major mental illnesses. Resources to help anyone affected by mental illness are given on the resource handout. [See “Resources for Mental Health Education” below.]

One of the greatest experiences we had in learning how we must treat each other occurred when we were living in Hawaii. Like mental illness, leprosy is a disease that has carried a great deal of stigma for centuries. In biblical times leprosy was thought to be caused by sin and those who had it were considered “unclean.” Christ healed people with this disease.

Kalaupapa is a colony on a peninsula separated from the topside of the island of Molokai in Hawaii by 3000 ft. cliffs. Those with leprosy were sent to the peninsula from 1866 on. It was thought to be a highly contagious illness. In some ways this is like earlier practices in our country of sending large numbers to mental hospitals. Father Damien spent many years ministering to those at Kalaupapa. In 1873 Armauer Hansen discovered that leprosy was caused by a bacillus bacteria and for many years after it was referred to by Hansen’s disease—which for some people was less stigmatizing. Now we knew that it wasn’t from sin or some other type of ritual uncleanness. And it is not highly communicable. Sulfone drugs were eventually (in 1946) used to arrest the disease and eventually those diagnosed were no longer sent to colonies. Modern medicine has likewise helped us understand mental illness, but it is later in coming than the treatment for leprosy.

Jack Sing had leprosy and was treated with sulfone drugs, but not before the disease had done a lot of damage. He was the branch president in Kalaupapa for 31 years. In 1978 he was given a distinguished service award at BYU–Hawaii. When he came to campus in his tennis shoes and baseball cap to receive the award, President Spencer W. Kimball attended the

ceremony. By this time Jack's face and hands were very disfigured from the disease and you could see that many were reluctant even to shake hands with him. I saw President Kimball come up to him, put his arms around him and say, "Jack, you are my brother!" He then kissed Jack Sing. This was one of the most compassionate acts I have ever witnessed and a great example to all of us. May we follow Pres. Kimball's example and fight stigma by embracing those with mental illness and consider them our brothers and our sisters.