

# Quality of Life Among People With Mental Illness In The United States

*Laurel Mildred*

*For Daftblogger*

*December 2, 2012*

Years later I remember the woman and her words; in her 60's, dressed from the thrift shop, disheveled and wrapped in scarves for the long walk in the San Francisco night. Visibly worn, she spoke with difficulty. She was unremarkable among members of the **Depression and Bipolar Support Alliance**; everyone looked tired, stressed and cold. It was a few days before Thanksgiving, 1995, and she had been digging under couch cushions in her Tenderloin apartment, looking for change. She was trying to put together \$4.99 for the Thanksgiving special at a nearby Hofbrau so she wouldn't be alone for the holiday; she had a little over \$2 in hand, without much prospect of success. There was an edge of desperation in her voice. Around the circle, people nodded – an ordinary day, an ordinary story.

I had come to this room as a reluctant member of the fellowship after my life slowly, then very rapidly, unwound at the center. I had recently been discharged from St. Francis Hospital, and the support group had been recommended as aftercare.

It was an unprecedented development. I had worked on the political scene in Sacramento for a number of years and was fairly established there, but my mother had died a few months before, which prompted a frenetic life review and a precipitous move to San Francisco to outrun my distress. I was 31 and divorced and I relocated with little planning except for finding a job as a fundraiser in a nonprofit organization. As a small-town girl in a reputedly beautiful city that seemed to me dirty, unsafe and full of crime, I gradually came unhinged.

I presented in the therapist's office suicidal, unable to stop crying. It was the first time we had met. In what I would learn was a rare nod to client preference, she gave me a choice before committing me, saying that she would send me to a place that was not frightening, it was "like a country club." She suggested I think about it for an hour and then come back for a second appointment.

I wandered from her office in a daze. The cars on Geary Boulevard sped by; I pictured throwing myself under the traffic. It was pouring and I spent most of the hour crouching under an umbrella behind the medical building, sobbing, trying not to be noticed by

passersby. I went back for the second appointment and told her I would go. An involuntary commitment order was necessary for insurance coverage to kick in, so I found myself whisked by ambulance to St. Francis. This was completely unnecessary in my view – I wanted to drive myself. When I arrived, the staff promptly took away my belt and mirrored compact, the heavy doors locked behind me. I had officially become a resident of the psych ward, not remotely like a country club.

I felt disjointed, unreal, totally out of place and terrified of the other patients. A man with a deep red weal winding around his neck stared past me with glazed eyes. Wrists were bandaged and stitched. One woman was paranoid; she bristled furiously when startled. She was on crutches after rolling her truck and a long series of other injuries, accidents and self-harm. I gave her a wide berth. Several patients had been transferred from **San Francisco General**, where they had been tied in restraints – not because they were out-of-control, their only danger was to themselves – because the county general hospital was overfull and understaffed, so patients were often put into restraints for “safety” and convenience, after a forcible take-down. It had never occurred to me that people who were so distressed and ill could be treated with violence and disregard, or that I could be vulnerable to that kind of treatment myself.

I had come from work that day in a navy blue blazer; patients asked if I was one of the nurses, and I was soon handling the situation by looking out for fellow inmates, listening to their stories and fending off invasive questions directed their way by the annoying therapist who ran mandatory group sessions. My roommate was a soft-spoken redhead who loved animals; she had been molested by her stepfather throughout childhood. He had once killed her kitten, saying that if she ever told he would do the same to her mother. Now she worked at a shelter but struggled with anorexia and feelings of overwhelm. She had taken a hand-full of pills, then changed her mind and caught the bus to the hospital, where they pumped her stomach and admitted her. It was her third suicide attempt. Another patient was successful and attractive, a software professional. His relationship with his hyper-critical, withholding mother had led him to love affairs with similar women, and after being dumped by the latest, he had tried to kill himself. The three of us spent a couple of hours each day while he taught us to make long-shots at the outdoor basketball court in the center of the building (presumably this was the ‘country club’ aspect).

Staff quickly discerned the tendency to focus on other patients and pointedly suggested that I work on my own problems. When flowers began to arrive, first from my boss and then from the president of our board, they noted that I was valued at work, but made that sound like a negative. After two weeks I was discharged with a succinct theory of my life: my relationship with my seriously mentally ill mother had resulted in a complicated and unresolved bereavement; my experiences of being sexually abused in

childhood required much further healing and deeper understanding of impacts on my current life; and I lived in my work to avoid those issues.

It bothered me that strangers could sum me up so quickly and arbitrarily, but I took note of their analysis, started the hard work to address those issues, gathered up the threads of my life, and moved on. There was rebuilding to be done after crisis. But I also now had a mission and a direction that was deeper than politics – I wanted to work in **mental health policy**. Like many others who work in mental health, I wanted to use my personal experiences to help my peers, my family, people I hadn't even met, and in the process, myself.

The necessity to dig for coins in order to celebrate Thanksgiving with other human beings exemplifies much about the quality of life experienced by many people with mental health conditions. Over the past 15 years I've worked toward improving mental health services and advancing the lives of people who need them, a key lesson is that my own experience was atypical. I had choices because I had health insurance, and I received quality care. I was not tied to a gurney in an emergency room for three days while a bed was located, put into restraints or medicated against my will. I am white, and was not subject to the **disparities** and **differential treatment** that racial and ethnic minorities experience in health and behavioral health services. Most of all, I was not dependent on public mental health services, a "fail-first" system that is severely under-resourced, lacking in outcomes and accountability and directed at controlling negative societal impacts of mental illness rather than toward helping people recover and experience productive, good quality lives. While many dedicated people work in this system and endeavor to make a difference there, it is undeniable that for most people with mental health problems, these are the realities of life, and public attitudes about mental illness – stigma and discrimination – contribute to the perpetuation of these conditions.

The role of stigma and discrimination on life quality of people with mental health problems cannot be overemphasized. Stigma is prejudice – negative stereotypes people hold about mental illness and those who have it. Discrimination is depriving people of opportunities and rights. Together they dominate the work of mental health and the lives of people affected by mental illness. In 1999, the **U.S. Surgeon General** wrote that stigma is the most formidable obstacle to future progress in the arena of mental illness and health:

*Stigma leads others to avoid living, socializing or working with, renting to, or employing people with mental disorders, especially severe disorders such as schizophrenia. It reduces 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 more 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.*

Quality of life depends on several domains; chief among these are health and well-being, economic sufficiency including appropriate housing, and relationships with others. Stigma and discrimination interfere with all of these, and together create conditions that are misery for people who are already struggling with internal pain and suffering. Discrimination in health insurance and coverage for mental health conditions is one of the most pernicious contributors to this cycle. Historically, people with known mental health conditions have had great difficulty getting insurance because of their “pre-existing condition.” For those with health coverage, mental health treatment was unavailable, restricted or rationed. While early identification and treatment can head off many of the worst outcomes of mental illnesses, insurance discrimination has resulted in circumstances where getting appropriate treatment can soon bankrupt a family’s coverage and resources, leaving no recourse except public insurance programs such as **Medicaid**.

However, it is not well-known that many people with serious mental illnesses simply do not qualify for Medicaid under existing rules. Their mental health condition leaves them in “indigent” status, dependent on inadequate and low-quality safety net services. Of an estimated 13 million American adults who have a serious mental illness in any given year, only about 29% receive any treatment at all and of those, only about 15.3% receive minimally adequate care. People often cannot even qualify for these services until they are extremely ill and have reached total crisis. Those who do qualify for Medicaid tend to be segregated in separate mental health systems with low standards and little accountability for the outcomes of treatment, allowing poor access and services to become the standard of care.

The practical outcome of this dysfunction is clear and sobering. Suicide was **the tenth leading cause of death** in the United States in 2010, taking almost 40,000 lives. On average, people with serious mental illness die **25 years sooner** than the general population, largely due to preventable health conditions. This may be the most devastating impact on quality of life for people with mental illness – a quarter of life expectancy can be lost altogether.

Stigma and discrimination have economic consequences that can be devastating as well. Mental illness can make getting or keeping a job extremely difficult; unemployment among people with serious mental illness is estimated as high as 90%, despite the fact that most have the desire and capacity to **work**, and paid employment has been shown to reduce the symptoms of mental illness. Mental health problems do not preclude intelligence, talent or significant contributions in the workplace: a 2000 **research**

**study** by the Center for Psychiatric Rehabilitation of Boston documented that people with mental illness can hold high-level, demanding jobs when given a chance.

Housing is also a chronic problem. Many landlords are extremely reluctant to rent to a person with mental health issues (**Levy and Rubenstein, 1996**). Allegations of housing discrimination based on psychiatric disabilities are very high, and there is a severe lack of affordable housing that people could rent even if they were allowed. The inability to have a safe and stable place to call home is one of the most difficult circumstances of people's lives, relegating them to the couch of a family member or friend, or to board and care homes and similar congregate housing arrangements that charge them nearly all of their public benefit check and typically provide extremely poor food and living conditions. Too often, these circumstances result in homelessness; it is estimated that up to one in three individuals who experience homelessness has a mental illness.

But the greatest barrier to life quality may be the shame, isolation and lack of social support that result from being identified with mental illness. People are painfully aware of how marginal they become when they are labeled "mentally ill" – it is constantly reinforced in distorted media portrayals, the way they are treated in public health systems, in the economic struggles they face every day, and in a deficit of friends and relationships. They internalize these negative feelings and experiences, sometimes avoiding social **contact** altogether. Research has shown that to be devalued and discriminated against can interfere with self-esteem, a sense of purpose and a better **quality of life**, and that fear of stigma and rejection can limit social supports and result in **poor life satisfaction**. Depriving people of social acceptance and human relationships on the basis of their illness may be the most cruel and unnecessary outcome of stigma and discrimination, and the most profound barrier to potential for a good quality life.

Dedicated people – clients, their families, advocates and mental health professionals – have worked tirelessly for years to raise public awareness of these circumstances and address the preventable damage of stigma and discrimination. And after many years of struggle, their efforts have paid off – we are on the eve of significant change. The Pete Domenici and Paul Wellstone **Mental Health Parity and Addiction Equity Act** of 2008 took effect in January 2010, requiring mental health and substance use disorder benefits to be equal to medical and surgical benefits, prohibiting annual and lifetime dollar limits and expanding diagnoses that are covered. Furthermore, **Obamacare**, the **Patient Protection and Affordable Care Act** of 2010 (ACA), implemented and extended parity provisions in ways that will have far-reaching impacts.

In addition to ending insurance discrimination based on pre-existing conditions and expanding Medicaid eligibility so that many more people with serious mental illness will qualify, the ACA parity requirements will apply to all who have public or private health

insurance coverage. Under a separate provision, Medicare is also phasing in mental health parity for outpatient treatment.

By 2014, these changes, taken together, are expected to have a major impact on access to mental health services. In California, an early implementer of the Health Benefits Exchange, it is estimated that **500,000** people with serious mental illness who were previously uninsured will qualify for insurance, and the various parity provisions will improve access to mental health services for all who need them. The next challenge will be to address a severe shortage of qualified mental health professionals to provide appropriate services.

But change comes slowly. There is hope that by addressing the core problem of insurance discrimination against mental health treatment, people will get the help that they need, public health systems will be held to a higher standard of care, treatment will be normalized and social acceptance will improve. But this change is like the ripples in a pond. It starts with each of us accepting that we all have a mind, and that like any other part of our body, our mind can become ill, can be treated and can recover.

The **Surgeon General** has written that mental health and illness are a **continuum**, we are all located along the continuum. For people who have experienced mental illness can also recover and experience wellness. We need to relate to those who have had these experiences with compassion, fairness and acceptance, understanding that anyone – a friend, a loved one, or ourselves – could find ourselves facing a mental health problem.

We would not ostracize or socially outcast someone we loved who experienced such a problem. As a society, we need to extend that acceptance to all human beings who suffer, even those we don't know. Because no one should have to scrounge for coins in the couch in order to feel connected with other members of the human race.