

OVERCOMING THE STIGMA:
A Personal Story of Recovery from Mental Illness

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MENTAL HEALTH CRISIS

- Share a story, a *very* personal story
- Revelle in September 1977
 - Healthy and happy family; 36 years old
 - Seattle City Councilman
 - Re-election campaign (80 percent of primary vote)
 - Back problem from bicycling Lisa
 - Congressional testimony on Energy 1990
- Psychotic episodes
 - Congressional hearing (speechless politician)
 - Babysitting Lisa and Robin; pills and wolves
 - Three weeks of frightening psychotic episodes
 - Episodes with parents (rockery, ferry boat, and crying)
 - The worst episode occurred when I swung a fireplace poker out of control in our living room and almost hit our two young children.
 - My father, a King County Superior Court Judge, had the police take me to Group Health Hospital for diagnosis and treatment.
- Discrimination against mental illness
 - Since Group Health (nor any other health plan) did not cover inpatient mental health services, I had not been able to get admitted to the hospital.
 - My father's ultimatum to the doctor: *"Admit my son to the hospital, or I will admit you to the King County Jail!"*
 - My doctor admitted me for a *bad back*; my first experience with discrimination against mental illness. I could be insured for a *bad back*, but not for a *bad brain!*
 - *Threaten* jail and *lie* about my condition to be admitted
 - After numerous tests for a brain tumor, they concluded I was suffering from bipolar disorder and put me on lithium; stabilized in two days.
 - No public appearances; won the general election (79 percent); *personally irrelevant to my own re-election campaign.*

BIPOLAR DISORDER

- According to the National Institute of Mental Health, almost *six million* American adults are living with bipolar disorder, formerly known as manic-depressive illness.
- Surprised and pleased to learn about famous and successful people who had bipolar disorder (Lincoln, Theodore Roosevelt, Churchill, Handel, Beethoven, Hawthorne, Dickens, Mike Wallace, Patty Duke, and many others)
- Learned a lot about bipolar disorder:
 - Caused by a combination of genetic and environmental factors;
 - Inherited genes can make you vulnerable to bipolar disorder;
 - These genes can cause brain chemicals to become imbalanced; and
 - Bipolar disorder is often triggered by stress.
- World Health Organization estimates bipolar disorder is the *sixth* leading cause of disability worldwide.
- Symptoms include grandiose delusions, racing thoughts and speech, poor judgment, impulsive and reckless behavior, hallucinations, anxiety attacks, and “euphoric manic psychosis.” (I experienced all of these traumatic symptoms.)
- Used lithium *daily* for almost 32 years with no psychotic episodes
- My lasting side effects of lithium include dry mouth, increased thirst, mild tremors of the hands, shaky handwriting, impaired kidney function, and *curly hair!*

BAD NEWS/GOOD NEWS

- Bad news about mental illness
 - According to the National Institute of Mental Health, mental illness is the most common and disabling disease in the United States and worldwide:
 - ✓ Almost *one-half* of adult Americans experience a mental illness at some time in their lives;
 - ✓ In any given year, *one in four* adult Americans has a diagnosable mental illness; *one in ten* has a severe mental illness (such as schizophrenia, depression, or bipolar disorder).
 - ✓ More than *50 million* adults and nearly *10 million* children experience one or more mental disorders in any given year.
 - ✓ Apply these ratios to the audience.
 - Mental illness touches nearly every family and impacts many other chronic diseases (such as heart disease, diabetes, and cancer), as well as most social issues (including education, homelessness, criminal justice, and veterans).

- According to the World Health Organization, mental illnesses account for *five* of the ten leading causes of disability worldwide.
- According to the President’s New Freedom Commission, mental illnesses rank *first* among illnesses that cause disability in the United States and Western Europe.
- *Equal opportunity disease*; attacks anyone regardless of age, gender, race, education, economic status – even politics!
- *All* health insurance plans and most health insurance policies in Washington State still discriminate against people living with a mental illness. Only federal employees, residents of five states, and employees of a growing number of self-insured employers enjoy full mental health parity.
- Instead of receiving compassion and support, people with mental illnesses often experience *hostility, discrimination, and stigma*. As a result, only one in three seeks treatment.
- **Good news about mental illness**
 - Improved ability to diagnose
 - More effective medications
 - As treatable as chronic physical illnesses
 - Progress towards mental health parity
 - Increased public understanding and less stigma.

STIGMA OF MENTAL ILLNESS

- **Overcoming the stigma**
 - Perhaps the most challenging mental health problem facing policymakers, health care providers, and consumers is the impact of *stigma* on people living with a mental illness and their families.
 - Mental illness continues to be stigmatized by *misconceptions, myths, and taboos*.
 - Although the public’s understanding of mental illnesses and their treatment has improved, perceptions and experiences of stigma still exact a heavy toll on individuals, caregivers, and social policy.
 - *Often more difficult to overcome the stigma of mental illness than to recover from the illness itself.*
 - Stigma is associated with the mistaken belief mental illness reflects a *personal weakness, a character flaw, or immoral behavior*. While I may be guilty of all three of these, they have nothing to do with my mental illness.

- Factors creating the stigma are *fear, ignorance, and shame* – *fear* of people living with a mental illness; *ignorance* of the illness; and the inability to overcome *shame* in order to get treatment.
- The ongoing stigma of mental illness prevents people from acknowledging their illness and seeking treatment. The stigma and discrimination tells individuals with a mental illness they are not valued by our society. *No one should be ashamed of having a mental illness.*
- *Father’s advice:* overcome the stigma by *telling the truth* about my mental illness to anyone who asks; very difficult, especially in light of Eagleton
- I had stayed at home for two months. I was absent from the Seattle City Council and did not campaign for the general election. Many people wondered why I was hospitalized and “missing in action.”
- Told the truth for three years as a Seattle City Councilman (1978 to 1980)
- **1981 campaign for King County Executive**
 - Did not advertise my mental illness
 - Continued to respond with the truth
 - Media refused to publish before or during the campaign
 - Statewide media coverage; became a “poster child” for mental illness
 - *Electing a “crazy nut” to run the second most important government*
 - Unexpected public reaction (more than 700 responses; all positive)
 - Staff wanted to roll out the mental health story!
- **What did I learn about the stigma?**
 - Being open and candid about mental illness is never easy. Telling the truth about my mental illness was the hardest thing I have ever done.
 - Overcoming the stigma *is* crucial to leading a productive and enjoyable life.
 - *Two months* to diagnose and treat; *four years* to overcome the stigma
 - Stigma in my mind; not in the hearts of my friends and supporters
 - Best way to overcome the stigma is to *tell the truth* about mental illness
 - Frankly, if everyone followed my father’s advice to tell the truth, most of the stigma would disappear.
 - We must take personal responsibility for overcoming the stigma associated with mental illness.

- Overcoming the stigma of my mental illness required the understanding and support of my family, friends, and colleagues. I would not be successful, however, if I did not take *personal responsibility* for speaking out and overcoming the fear, ignorance, and shame wrongly associated with mental illness.

MENTAL HEALTH PARITY

- As I said before, *all* health insurance plans and most health insurance policies in Washington State discriminate against people living with a mental illness.
- The goal of the 142 organizations in the Washington Coalition for Insurance Parity was to achieve comparable benefits for mental illness, known as “mental health parity”.
- “Mental health parity” means mental health services are covered by insurance in a manner comparable to other health services. Achieving full parity means:
 - Covering a scope of mental health services comparable to the scope of physical health services covered by health insurance; and
 - Prohibiting health plans from imposing different financial requirements or treatment limitations on mental health benefits.
- *The true story of Group Health Cooperative’s annual meeting of consumers*
- Group Health Cooperative has made good progress towards parity. I still belong to Group Health after more than 39 years, and I receive excellent physical and mental health care. Group Health is the only health plan to support Washington’s mental health parity law.
- A major barrier to parity is the myth it costs too much. As President Kennedy once said: *“The great enemy of the truth is very often not the lie – deliberate, contrived, and dishonest – but the myth – persistent, persuasive, and unrealistic.”*
- We overcome myths with *facts*, and here are some facts about parity:
 - Mental health is fundamental to our overall health. Mental health parity increases access to mental health care and thereby reduces the need for costly medical treatments and improves health outcomes for people with heart disease, diabetes, cancer, and other chronic diseases.
 - Many studies and the *actual experience* of the federal government, at least nine states, and numerous self-insured companies demonstrate that implementing parity results in *less than a one percent increase* in health insurance premiums.
 - When you consider the many benefits of parity – including less absenteeism, increased productivity, decreased unemployment and disability claims, reductions in other health care costs, increased ability to learn, and fewer suicides – *parity is a wise investment that saves money and improves our quality of life.*

- Parity has strong public support. An independent national poll of more than 3,000 American voters conducted in October 2006 shows that **89 percent** of them want mental health treatments to be comparable to treatments for general health problems.
- Parity also decreases the stigma attached to mental illness and reduces the social costs of homelessness, hospitalization, imprisonment, and public assistance.
- The need for mental health parity is unquestionable. Everyone has a family member, friend, or colleague who has experienced mental illness. We know treatment is effective and can improve people’s lives. We also know parity is cost effective and saves money.
- While parity will not address all the challenges of mental illness, it is a very important reform of the mental health system. Parity will have a profound impact on the quality of life of people living with a mental illness.
- ***Most importantly, mental health parity is simply the right thing to do!***
- As Martin Luther King, Jr. said:

“Cowardice asks the question, ‘Is it safe?’ Expediency asks the question, ‘Is it politic?’ Vanity asks the question, ‘Is it popular?’ But, conscience asks the question, ‘Is it right?’ And there comes a time when one must take a position that is neither safe, nor politic, nor popular, but one must take it because one’s conscience tells one that it is right.”
- After 10 years of advocacy by the parity coalition, in 2007 Washington State finished enacting one of the best mental health parity laws in the country. The law protects more than two million Washingtonians from health insurance discrimination.
- The ***good news*** is that the U.S. Congress finally enacted a federal mental health parity law in 2008. The ***bad news*** is the law is much weaker than Washington State’s mental health parity law, as well as the parity laws of at least 11 other states.
- The disappointing federal parity law demonstrates why continued advocacy is needed at the federal and state levels to achieve full mental health parity. We have much more work to do before we end insurance discrimination against mental illness throughout the United States. We must also continue our efforts to eliminate the stigma of mental illness in our society.

HOW YOU CAN HELP

- Based on my own experience, we can help people living with a mental illness in many ways, especially the following:
 - ***First***, help overcome the stigma by learning about mental illness and challenging the myths and stereotypes that misrepresent the illness.
 - ***Second***, tell the truth about mental illness and share your own experience, if any, with the illness;

- **Third**, avoid using derogatory, stereotypical, or stigmatizing language when discussing mental illness or describing people living with the illness;
 - **Fourth**, support mental health organizations with your time, talent, and treasure; and
 - **Fifth**, provide personal understanding and active support to people with a mental illness and their families. Learn to recognize the warning signs of the illness and encourage those who need help to seek appropriate diagnosis and treatment.
- Each of us can make a difference in the lives of people living with a mental illness. As Robert Kennedy said in a 1966 speech to South African students:

*“Few will have the greatness to bend history itself, but each of us can work to change a small portion of events, *** Each time a man stands up for an ideal, or acts to improve the lot of others, or strikes out against injustice, he sends forth a tiny ripple of hope, and crossing each other from a million different centers of energy and daring, those ripples build a current which can sweep down the mightiest walls of oppression and resistance.”*

CONCLUSION

- I have lived with a serious mental illness since I was first diagnosed with bipolar disorder almost 32 years ago in October 1977. At that time, I was convinced I would lose my family and friends, my political career, and my mind. Fortunately, I was wrong.
- I have been lucky to have the resources needed to cope with a serious mental illness. After overcoming discrimination, I received an accurate diagnosis, as well as appropriate medication and treatment.
- I have also been blessed with a loving family, supportive friends and colleagues, an excellent education, and enough money to pay for my mental health care.
- As a result, I have been able to recover from my mental illness, overcome the stigma, and lead a productive and enjoyable life. I can only imagine what it is like for people with a mental illness – especially the homeless living with a mental illness – to cope without these resources.
- Thank you for the opportunity to share my personal story of mental illness. It is never easy to tell my story, but I hope the lessons learned from my experience will help you cope with mental illness in your own lives.
- Please remember: people with a mental illness deserve **parity**, not discrimination; **compassion**, not indifference; **understanding**, not ignorance; and **respect**, not stigma.
- Working together, we can help create a **just, humane, and healthy society** – a society in which all people are accorded respect, dignity, and the opportunity to achieve their full potential free from stigma and discrimination.

- I will end my personal story with two fundamental lessons:
 - *No one should be ashamed of mental illness. No one!*
 - *Everyone should tell the truth!*
- Thank you for listening.

QUESTIONS, ANSWERS, AND DISCUSSION