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TESTIMONY
Paul Wellstone Mental Health and Education Equity Act
House Education and Labor Committee, Subcommittee on Health

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Introduction

Mr. Chairman and members of the subcommittee, I want to thank you for the opportunity to speak to you this morning on legislation that addresses an extremely critical health issue facing millions of Americans: parity for the treatment of mental illness and substance use disorders.

This legislation is very close to my heart, and I want to thank you, and Cong. Patrick Kennedy and Cong. Jim Ramstad, for honoring my father's legacy by naming this bill in his honor. My brother and I founded Wellstone Action to carry on his work, and through the Wellstone Action organization, hundreds of people are being trained each year to run for office, and to develop grassroots skills in organizing and leadership. But nothing represents my father's passion and commitment more than his work to pass legislation that would end the discrimination against those who suffer from mental illness and substance use disorders. Please accept the gratitude of my family and that of Wellstone Action, for this tribute to my father and our family.

I also want to thank Mrs. Carter for her many years of leadership on this issue and many other issues related to mental illness. She and my father worked closely together on this issue and he was always grateful for her support and leadership.

I have been coming to Washington frequently to speak on behalf of this legislation and a strong mental health and addiction parity bill. But my father started this work years ago.

History

Parity has a long history. Many of you are familiar with its milestones: the 1996 federal law; the 1999 Executive Order that gave federal employees mental health and addiction parity benefits; the many successes at the state level to strengthen their parity laws; the times that Congress came very close to passing the expansion of the federal law; and the endorsement by President Bush in 2002. For my father, these milestones were very personal. His dedication stemmed from his personal observations of the terrible conditions in psychiatric institutions when his own brother, my uncle, was hospitalized in the 1950s. These conditions, and the eventual catastrophic financial toll that my grandparents had to bear, inspired my father to do everything he could to make things right for those in similar circumstances. The legislation that my father and Sen. Domenici passed in 1996 was groundbreaking and important, for it established in law an important first principle of parity – that those with mental illness should not be discriminated against in insurance coverage. But my father knew that it was not enough, and he was never satisfied with the compromises that were made at the time. That is why he immediately began the fight for a more comprehensive federal parity law, one that would include substance use disorders and that would close the loopholes that the insurance industry had immediately started using.

His efforts over the years came close to success several times, including once during his last term in office. But despite promises then, and promises made after he died, the federal parity law has not yet passed. This law is long overdue, and that is why we are here today. The bill has

been negotiated for years, and important compromises and protections have been put in place in the proposed House legislation that is the subject of this hearing today. It is time to move forward, and to recognize that while we delay, people are suffering and dying from lack of care.

This bill is the critically important next step toward ending the persistent discrimination against people who suffer from mental illness and addiction. In the past, some opponents have been satisfied with the reauthorization of the 1996 law, and there is the danger that this could happen again. It is my view that to merely reauthorize the 1996 law is worse than simply allowing the law to lapse. Why? Because we know that the discrimination against the mentally ill and addiction has worsened. As was reported in a GAO report in 2000 (GAO-HEHS-00-95), despite the limited objectives of the 1996 law, there were numerous examples of violations of not only the spirit, but even the letter of the law. GAO found that although most employers complied with the Act, they expanded other discriminatory coverage limits. Eighty-seven percent of the surveyed employers had a limit on mental health benefits lower than what is offered for other medical/surgical benefits, and several states were noncompliant. In a recent study of employer provided benefits, reported in Health Affairs (2007), the cost-sharing for addiction benefits was 46% higher for addiction benefits than for medical or surgical benefits and there were no out of pocket spending caps for addiction spending in 44 % of the plans studied. It is clear from these reports that the gains intended by the 1996 law have not yet been attained and that further federal legislation strengthening and expanding the 1996 law is still badly needed.

Many of you knew my dad, and so you would be aware of how often he expressed his outrage at the injustice that is rampant throughout the health care system in its failure to adequately cover mental illness and addiction care. Over the years, the opposition to the many

legislative efforts focused on whatever they could to prevent the bill from going forward, including misinformation, scare tactics, and stalling. Today, although we have made progress, we expect increased opposition as we move forward to ensure patient protections that are in the House bill. I urge you all to stay strong, to fight for the patient protections are in the House bill, to do the right thing, and make this bill the law of the land.

I especially want to commend House and Senate sponsors for their inclusion of substance use disorders in the parity bills. My dad always worked closely with Cong. Ramstad to push for parity for treatment of substance use disorders throughout his Senate terms. This inclusion is long overdue. In recent years, we know that spending for addiction treatment has been drastically shifted from the private sector to the federal government. Private insurance accounts for just 9% of substance use disorders expenditures (Levit et al, 2006). It is past time for the private sector to do its fair share. As my friend, William Moyers, Vice President of the Hazelden Foundation said at the parity field hearing in Minnesota, many individuals who seek addiction treatment also suffer from mental illnesses, and that it is "folly to treat one illness and not the other." I would add that it is also folly to allow insurers and employers to determine in advance, outside of medical considerations, which diagnoses they deem worthy of coverage. And so I am pleased to see that HR 1424 includes substance use disorders, and that it requires that the standard diagnostic manual – the one used by physicians, researchers, government agencies, and insurance companies themselves as the standard for diagnosis, treatment, and reimbursement --- be the standard for mental health and addiction coverage in this bill.

Need

Many of you know the disturbing statistics concerning mental illness and addiction for adults and children with these diseases. The current estimate from the National Institute of Mental Health is that about 26 percent of the U.S. adult population -- over 78 million Americans -- suffer from a diagnosable mental disorder in a given year. Twenty-there million people and their families struggle to recover from the shattered lives that result from untreated addiction. Although the research on children is not as well-documented, the percentage of children affected by mental or emotional disorders is very similar, at 20 percent, with 9 percent severely affected.

We know that mental illness is a real, painful, and sometimes fatal disease. It is also a treatable disease. My father used to say, acknowledging the wisdom of his friend, Dr. Kay Redfield Jamison, that the gap between what we know and what we do is lethal. Available medications and psychological treatments, alone or in combination, can help most people who suffer from mental illness and addiction. But without adequate treatment, these illnesses can continue or worsen in severity. Suicide is the third leading cause of death of young people in the U.S. Each year, 30,000 Americans take their lives, hundreds of thousands attempt to do so, and in 90% of these situations, the cause is untreated mental illness. This is one of the true costs of delaying this legislation: Every 16 minutes, a child or adult takes their lives because of the unmitigated, searing pain of depression or another mental illness.

HR 1424 – Important Provisions:

The House bill has other very important provisions that will improve care for mental health and addiction patients.

DSM

I have mentioned the diagnostic manual that has long been used to guide diagnostic and treatment decisions. Much debate has occurred around this manual, the Diagnostic and Statistical Manual (DSM), a handbook and codebook that lists mental illness disorders and the diagnostic criteria for each based on current research. The DSM is the coding manual that is used by many government agencies, researchers, physicians, and the public and private insurance industry to code mandatory health data, understand and diagnose illness, frame research, and develop treatment guidelines. The House legislation recognizes the essential role of the DSM in ensuring high quality treatment and diagnostic decision-making by requiring the DSM as the basis for coverage. Without this clarity, insurers and employers could decide, without the benefit of science or medical expertise, what kinds of mental or addictive disorders should be covered. I applaud the efforts of the House sponsors to stand firm in its effort to ensure that mental illness and addiction are treated no differently than medical/surgical conditions. The DSM is part of the International Classification of Disease (ICD), a similar manual that includes codes for over 12,000 medical and surgical conditions. The DSM, by contrast, has a few hundred codes. It is essential that the scientific and research findings that developed the DSM, and contribute to high quality care, be the basis for mental health and addiction treatment. When it became clear in past negotiations that the insurers may undermine the parity legislation by restricting coverage by diagnosis, my father fought hard against these weakening amendments that could turn into a dangerous loophole. I urge you to stand firm on this principle and prevent any effort to allow discrimination by diagnosis. The way to do so is to keep the standard of the science as the standard in this bill.

State Protections

HR 1424 also has important protections for parity laws in the states. One positive outcome of the 1996 law was a major surge in the passage of parity-related laws in a majority of the states. These laws reflect the positive efforts of grass-roots advocacy whereby those in need can seek democratic change with their local elected representatives. Though not all of these laws are stronger than the proposed federal law, many of them are. Unfortunately, in the current debate, there is an effort underway to have the federal parity law preempt stronger state laws. Contrary to this view, my father vehemently opposed any effort to preempt stronger state laws, and even advocated for the inclusion of such protective language to prevent this in earlier versions of the bills he sponsored. Such preemption would severely undermine the benefits of health coverage for those for whom the federal law would not apply, as attested to in recent analysis by Mila Kaufman of Georgetown University. In keeping with this principle of protecting state law, the House legislation includes important language, and I would urge you to keep those protections. I ask you to consider what kind of federal parity law it would be if it were to change decades of health care protections in the states, and do so on the backs of those with mental illness and substance use disorders.

Medical necessity

With this legislation, the devil is always in the details and that is why the details in HR 1424 are so important. The more I have talked with people about the need for this legislation, the more I have understood that the problems go beyond just parity, as critically important as this is. Decisions around so-called "medical necessity" are often the basis for denial of care, and while

these problems may continue even after a strong parity bill is enacted, I want to applaud the sponsors of this bill for recognizing that patients have a right to know on what basis their care is being denied, and that this information should be transparent and made quickly available to patients. When Kitty Westin's daughter Anna's daughter was in the hospital, critically ill, she was denied care and sent home while the insurer determined whether it was 'medically necessary' to treat her severe eating disorder. This kind of callous disregard for her disease and her life contributed to enormous suffering for her and her family, and in the end, Anna died from her disease, leaving behind a grieving family to endure this loss and this injustice.

I have had the honor to get to know Kitty, one of my father's closest friends. She is a fellow Minnesotan, the founder of the Anna Westin Foundation, the President of the Eating Disorders Coalition, and most importantly, the mother of Anna. Kitty and I have met with many of you, and you have heard about the tragedy that her family endured, when Anna was repeatedly denied insurance coverage for her eating disorder. What happened to Anna and her family, and millions of others, embodies the outrage my father spoke about so often. Kitty spoke at the recent House Ways and Means subcommittee hearing on this bill, and despite her tragic loss, she spoke about hope. She talked about her hope that the system can and will change, hope that those in need will finally have access to care, and hope that the voices of those who are suffering will be heard. The passage of this bill is a life or death issue for millions of Americans. This is fact that we can understand in our minds. Kitty and her family live with that tragic reality every day. As a country, we owe Kitty and her family a debt of gratitude for coming forward with their

story and their grief, in order to make positive changes in Minnesota, and to make positive changes in the federal law.

Cost

Another issue we often hear about in relation to this bill is cost. Today, you will hear powerful testimony about how badly this treatment coverage is needed, how mental illness and substance use disorder have affected the lives of so many Americans throughout our country, and how the costs for such treatment are very low. Numerous past reports have shown that fair and equitable mental health treatment can be offered as part of a health benefit package without escalating costs. Today, we have even more compelling evidence that this is so. There should be no further doubt that treatment for mental illness and substance use disorder is a health care benefit that our country can afford, and even more important, it is one that the our country should and must provide for the millions of Americans covered by private insurance. It is time to lay the issue of cost to rest, for we know that with the appropriate medical oversight, costs are low. It is no longer a question of <u>can</u> we afford it, but rather, can we afford <u>not</u> to provide health care for the millions who suffer from mental illness and addiction?

Many employers already do recognize this basic fact. A series of articles published in the Wall Street Journal in 2001 recounted the growing recognition of employers that mental illness is a reality in the workplace and can be documented as a workplace cost. At the same time, the articles noted that when employees are given access and benefits to receive proper treatment, companies are able to retain highly able and productive employees. The articles noted that the stigma associated with mental illness can lead to untreated illnesses that turn up as other

healthcare costs, lost productivity, or absenteeism, so that attempts to reduce overall health care costs by targeting those with mental illness may in fact lead to other workplace costs, in addition to greater suffering. I have provided citation information for these articles below.

In terms of cost, parity legislation has already been tested for years. Testimony by Dr. Howard Goldman in the House Energy and Commerce subcommittee on June 15, 2007, attested to the low cost of the federal employee parity provision, the fact that no plans dropped out of the federal program, and that there was a significant decline in out of pocket spending on the part of patients.

The opponents who still cite cost issues do not recognize these low treatment costs, nor do they acknowledge that proper treatment of mental illness actually saves money. They fail to recognize that untreated mental illness and addiction costs over $100 billion per year, and that our country picks up the cost of untreated mental illness and addiction in any case, for untreated illnesses don't just go away. Children with mental illness and addiction disorders often end up in public institutions, foster care, or jail because their parents cannot afford their care. Adults who have private insurance are often forced into public health care systems financed through State governments, Medicare, and Medicaid. These systems are then forced to take scarce resources from those who have no insurance. Families are forced into bankruptcy; lives are broken; and lives are lost.

Stigma

When cost is set aside as the reason for denial of parity, what is left is stigma and discrimination. In our country, mental illness and substance use disorder continue to be

stigmatized as diseases for which one should feel shame. People are made to feel that they are lucky or should feel grateful when they get any coverage, even when they are routinely denied adequate treatment. Why? The stigma associated with the illness is one reason, for it not only doubly burdens the person who suffers from this illness, but it makes it easier for insurance companies to deny treatment, knowing that the person may not want to or be able to file public appeals or bring this matter to their employer. A cloak of secrecy has surrounded this disease, and people with mental illness and addiction are often ashamed and afraid to seek treatment. They fear that they may lose their jobs or even their friends and family. For those "lucky" enough to obtain care, the benefit is discriminatory – with co-payments, deductibles and day and visit limits that are both higher and more restrictive than for any other illness. When more care is needed, the cost is borne by others, i.e., families, taxpayers, or the generosity of donors, as John Schwarzlose from the Betty Ford Center recently testified. This is, plain and simple, unjust and unfair. And sometimes, it is lethal. People die when care is denied, as in the case of Kitty Westin's daughter, Anna.

Historic Opportunity

Congress has a chance with this legislation to play an important historic role. The movement for parity for treatment for mental illness and substance use disorders is growing. Over these past years, the principle of parity in insurance coverage for mental health and addiction treatment has received the strong support of numerous administrations, including President Bush and his New Freedom Commission on Mental Health, the Surgeon General, and many leading figures in medicine, business, government, journalism, and entertainment who

have suffered from mental illness and addiction and have been successfully treated. Federal employees, including members of Congress, receive full mental health and substance abuse treatment parity. Many states have stronger state laws or are moving toward enacting them. Mental health and addiction hearings on the Hill have frequently highlighted recent major advances in scientific information about the diseases, the biological causes or consequences of mental illness and addiction, the effectiveness and low cost of treatment, as well as many painful, personal stories of people, including children, who have been denied treatment. Changes are being made or proposed in mental health and addiction coverage in other systems of health care, such as the military, the VA, Medicare, and children's health insurance. We do not discriminate against other illnesses where the brain is affected. Why do we continue to discriminate against mental illness and addiction? It is time for the federal government to enact legislation that will help move us toward full treatment parity for mental illness and addiction. This Congress has the chance to be remembered as the one that had the courage and leadership to complete this effort.

Conclusion

People have asked me while I'm here in Washington why I am so involved in this issue. I am involved because of my father, of course. I loved him and I miss him, and I have learned that many others here in Washington and throughout the country miss him too, especially his courage and his compassion. He fought hard for those who had no voice, and he had a strong personal commitment to helping those with mental illness and addiction. Congressional members honored him and my family by promising to name the parity bill after my dad, and I am grateful. But I do know the kind of man my father was, and the kind of parity bill he would have wanted

finally passed into law, and I wanted to help ensure that the final bill is one worthy of his name. The protections for patients that have been included in HR 1424, such as protections of stronger state laws, full diagnosis coverage, and transparency of medical necessity, are essential to a strong law and I urge you to include them in your final markup and passage.

I, along with millions of Americans, look forward to the day when people with mental illness and substance use disorder receive decent, humane, and timely care for mental illness and substance use disorders. Thank you for your courage and commitment to do the right thing, and know that I will be by your side throughout your efforts to pass this legislation.

Thank you.

Citations:

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