



TESTIMONY OF DORIS A. FULLER

**MENTAL HEALTH BRIEFING ON THE  
INSTITUTIONS OF MENTAL DISEASE (IMD)  
EXCLUSION TO MEDICAID**

JULY 30, 2014

Good afternoon. My name is Doris Fuller, and I am executive director of the Treatment Advocacy Center.

Today we hold a briefing in conjunction with the Congressional Homelessness Caucus on the IMD exclusion and the dual discrimination faced by minority Medicaid eligibles and beneficiaries with mental illness. Thank you for joining us.

As the law currently stands, because of the IMD exclusion, Medicaid provides no reimbursement to so-called “institutions of mental disease” if they contain more than 16 beds and more than half their patients are adults below the age of 65 with psychiatric disease. Yes, in addition to all the forms of discrimination people with mental illness suffer, coverage of their psychiatric and medical treatment in all but the smallest dedicated facilities is banned by federal law. If only these critically ill individuals needed inpatient or long-term care for ... heart disease or diabetes or dementia or literally any other acute or chronic condition: Medicaid would cover their *medically necessary care*. But ... because they are mentally ill, it does not.

We are focusing today on this topic because of how uniquely egregious the IMD exclusion is and how disastrously it discriminates against the poor and minorities and limits their chances of meaningful recovery.

I am joined here by leaders in the fight against discrimination, barriers to treatment for mental illness and homelessness, and I welcome our distinguished panel of experts. They will be sharing invaluable insights into a range of issues impacting vulnerable populations and how those issues are related to the IMD exclusion.

We are also here today because, ultimately, it will take an act of Congress to end the statutory ban on treatment to this population with the waiver, modification or repeal of the IMD exclusion.

Some loudly and repeatedly say it would cost too much to remove the IMD exclusion from federal law. This is a rationale that effectively wraps unequal treatment of society’s most vulnerable population in the cloak of unexamined fiscal promises. Equivalent discrimination

against any other medically compromised population – cancer patients, for example, or individuals with Parkinson’s disease – is unimaginable.

What’s more, the rationale itself is insupportable. While it does cost money to provide treatment to individuals with mental illness, cost savings from banning their treatment are an illusion. Numerous studies have found that short-length hospitalization of individuals in psychiatric crisis is associated with higher rehospitalization rates, and revolving-door hospitalization is extremely expensive. Also costly are the forensic beds, jail and prison cells and homelessness services that become the default “institutions of mental disease” for psychiatrically fragile people who do not receive the medically necessary treatment they need to function safely and successfully in the community. The *savings* from treating them in a timely and effective manner is well-documented.

Others, albeit less loudly in recent years, point to Congressional intent as justification for perpetuating the IMD exclusion, that intent being to incentivize states to replace what President John F. Kennedy called the “cold mercy of custodial isolation” with “the open warmth of community concern and capability.” The need to motivate states to close their public hospitals is long gone. The incentive worked. Public psychiatric beds are all but extinct. We have today 7.5% of the public hospital beds we had in 1965, when the IMD exclusion was enacted, and more are lost almost daily.

Community care has a necessary and important role in America’s mental health armamentarium. But the centers of “warmth” and “community concern” that were supposed to replace the “cold” public hospitals were mostly never built, and the ones that were built are dedicated almost exclusively the needs of people not ill enough to require inpatient care and ill-equipped to handle those with the most severe illnesses. In ignoring the limitations of community-based treatment, we ignore the need for appropriate inpatient treatment of people who cannot participate in these programs and who require IMD care. As you will hear today, those needs are not being met.

It is not rational, humane or cost-effective to deny Medicaid coverage for medically necessary treatment to a specific population of poor people with disabilities, a practice that falls disproportionately on minorities overrepresented below the poverty line. The exclusion is already waived for the young and the elderly. It is only for adults between 22 and 65 – in what could be the prime of their working and family lives but is not – that coverage is denied.

I have personally seen the effects of this discrimination at work. I have a beautiful 28-year-old daughter with a severe and persistent mental illness. When she initially fell ill, she lived in a state where IMDs of more than 16 beds were reimbursed. Whenever she was hospitalized there, her discharge was contingent on the discharge hospital making sure a follow-up residential bed in an IMD was waiting for her. One of the facilities where she stayed had 64 beds, virtually all of them occupied by individuals unable to succeed or perhaps even survive outside a residential facility. Some were still acutely ill. Some were chronically ill. A few had developmental or intellectual disabilities. Virtually all of them were poor. They could live there receiving services indefinitely. Their care was covered by a combination of their government benefits and Medicaid.

I still remember what Medicaid paid for the skilled nursing services she received in the early 2000s: \$30 a day. \$900 a month. Less than a few hours in an ER. Less than the cost of a single day of psychiatric hospitalization. Less than the cost of a jail cell. Less than what cities spend on average daily for each of their homeless individuals. She stayed as long as it took for her to be ready to move back to the community and, once back in the community, she resumed her previous life at essentially the same level.

Contrast this with what I saw when she relapsed late last year in Virginia, where the IMD exclusion is in full effect. When she was deemed “ready” for hospital discharge – after an impossibly short two- or three-day stay that did not begin to stabilize her – I was told that – if she didn’t have a home to return to – the hospital would give her a one-week supply of medications and cab fare to a homeless shelter. In the span of four months, she was admitted to three hospitals through their ERs and did not stabilize until the fourth hospital provided unreimbursed inpatient care for two full months.

Residential beds exist where waiver or other exemption from the IMD exclusion makes them economically viable because of Medicaid reimbursement. They don’t exist in Virginia – and most everywhere in America – because the IMD exclusion makes them economically non-viable.

The Treatment Advocacy Center is the only national nonprofit dedicated exclusively to removing barriers that limit access to needed treatment for severe mental illness – barriers that erect hurdles to recovery and – in the case of the IMD exclusion – legally bar individuals like my daughter from receiving the care they would receive if they had any medical condition other than mental illness.

As part of our focus on making treatment possible, we help reform laws, assist grassroots advocates, raise public and official awareness of mental illness treatment issues and support the development of innovative treatments for and research into the causes of severe and persistent psychiatric diseases. In our 16 years, we have worked with innumerable legislators from all parties to improve mental health laws and policies in more than half the U.S. states.

As executive director of the Treatment Advocacy Center, I am honored to be joined by our distinguished panel.

**Congresswoman Eddie Bernice Johnson** is serving her 11th term representing the 30th Congressional District of Texas, encompassing a large portion of the city of Dallas as well as surrounding cities. In December 2010, Congresswoman Johnson was elected as the first African-American and the first female ranking member of the House Committee on Science, Space and Technology. Congresswoman Johnson is a member of the House Transportation and Infrastructure Committee and has been since being elected in 1992. She is also the highest ranking Texan on this committee. Congresswoman Johnson additionally serves on the Aviation Subcommittee, Highways and Transit Subcommittee and Water Resources and Environment Subcommittee.

Congresswoman Johnson is co-chair of the Congressional Homelessness Caucus and had the honor to serve as chair of the Congressional Black Caucus during the 107th Congress.

Congresswoman Johnson has worked tirelessly to improve access to mental health treatment for individuals with mental illness. She has introduced legislation to repeal the IMD Exclusion to Medicaid for four consecutive Congresses and has worked closely with Rep. Tim Murphy on H.R. 3717, which includes a fix to the IMD Exclusion to Medicaid. As a non-practicing psychiatric nurse, Congresswoman Johnson has witnessed firsthand the consequences of the IMD Exclusion's implementation and will continue to fight for individuals to gain access to the mental health treatment they deserve.

**Congressman Tim Murphy** (R-PA) is serving his sixth term in Congress as the Representative for the 18th District of Pennsylvania. A psychologist by training, Congressman Murphy is co-chair of the Mental Health Caucus, a founding member of the GOP Doctors Caucus, and Chairman of Oversight and Investigations for the House Energy and Commerce Committee. He is also sponsor of HR 3717, the most comprehensive piece of mental health legislation devoted to meeting the treatment needs of Americans with the most severe mental illnesses in half a century.

Our panelists also include.

**Bob Davison, Executive Director of Mental Health Association of Essex County**

Bob Davison is executive director of the Montclair, NJ-based Mental Health Association of Essex County. In his role as ED, Mr. Davison manages the overall operations of a comprehensive community mental health facility that each day serves the needs of more than 1000 individuals and their families who are confronted with mental illnesses or emotional disturbances. He served as chair of New Jersey Governor Codey's Task Force on Mental Health, which provided a blueprint for comprehensive reform of New Jersey's mental health system.

**Dr. Ray Patterson, general and forensic psychiatrist**

Dr. Patterson has extensive experience (more than 30 years) in both corrections and public mental health systems, including serving as Commissioner of Mental Health for the District of Columbia Mental Health System, Chief Psychiatrist for the D.C. Jail, Director of Forensic Services for the Maryland Mental Hygiene Administration, and Chief Psychiatrist for the Maryland Department of Public Safety and Corrections. He has also served as a court-appointed expert to review and or monitor mental health problems in correctional settings in states including New Jersey, California, and Illinois.

**Bill Bailey, President and Chief Executive Officer of Cenikor Foundation**

Mr. Bailey is here today to discuss the impact the IMD exclusion has on the substance abuse treatment community. For nearly 50 years, Cenikor has provided behavioral health treatment to help people with substance abuse issues achieve better health and better lives.

The impact of substance abuse is large. It contributes to the prevalence of mental illness separately and through co-occurring disorders and exacerbates housing instability. More than half of Cenikor's clients have experienced homelessness at some point during their addiction. There are many options for improving access to treatment for individuals who need substance abuse treatment. Cenikor is hoping to

provide these services in flexible, community-based programs that provide the best opportunity for recovery.

**Steve Baron, director of the District of Columbia Department of Behavioral Health**

Mr. Baron will provide an overview of Washington, D.C.'s experience with the Medicaid Emergency Psychiatric demonstration project incorporated in the Affordable Care Act.

Mr. Baron was appointed last October as the first director of the newly established DC Department of Behavioral Health, where he is responsible for leading the integration of mental health and substance use disorder treatment services and supports. Mr. Baron previously directed the Department of Mental Health for seven years. While director, he established emergency mobile crisis services, an urgent care clinic at Superior Court for on-the-spot referrals to mental health treatment, and a crisis intervention training program for police officers. Under his leadership, the Department ended the 37-year court oversight of the District's mental health services.

As you listen to these distinguished panelists, we ask you to ponder the moral and social implications of a federal law that systematically denies reimbursement for treatment to some of our nation's most vulnerable citizens and consider the abundant practical reasons to increase efficiency and lower costs by providing mentally ill poor adults with the medically necessary care they need in the settings that are most appropriate to promoting their recovery.