

Health Care Reform

What Does It Mean for People Living with Serious Mental Illness?



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HEALTH CARE REFORM

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Health Care and Serious Mental Illness

Today, recovery is the expectation for people who experience mental illness and co-occurring disorders. We know that treatment works--if you can get it. However, there is an average delay of eight to ten years between onset of mental illness and when people typically get treatment.

Without prompt help for mental illness, conditions can worsen and become more resistant to treatment. Yet, getting timely treatment is challenging. With over 46 million uninsured people nationwide and revenue shortfalls impacting community mental health and Medicaid program eligibility and services, many children and adults with serious or chronic mental health needs have little or no access to care. And, for those who are insured, existing laws (such as pre-existing condition exclusions) often create barriers to getting needed treatment for mental health and co-occurring disorders.

Federal health care reform addresses many of the challenges people with serious mental illness and co-occurring disorders have in getting and keeping health care coverage. As health care reform is implemented, it is important for Virginians to understand changes that can most significantly impact people with serious mental illness and co-occurring disorders. It is expected that the new health care law will expand coverage to an additional 32 million U.S. citizens and legal immigrants by 2019. This will happen through a combination of state-based private insurance exchanges and expanded Medicaid coverage for low-income adults. In addition to these measures, the new law includes a range of insurance market reforms as well as efforts designed to slow the growth of health care costs and improve quality of care.

Virginia's Uninsured: Who Are They?

According to the Current Population Survey (CPS), **an estimated one million Virginians (15.1 percent) under the age of 65 lacked health insurance** in 2007-2008ⁱ.

- The majority of the nonelderly uninsured in Virginia live in **working families**. Nearly two-thirds of the uninsured (64.6 percent) live in families with at least one full-time worker, 15.2 percent live in families with at least one part-time worker, and 20.2 percent live in families with no working adults.ⁱⁱ
- Some 62.0 percent of uninsured nonelderly Virginians have income **at or below 200 percent of the federal poverty level (FPL)**. Over one third (35.2 percent) live at or below the federal poverty level.ⁱⁱⁱ
- **Close to 70 percent of uninsured children live in low-income families** (income at or below 200 percent of the FPL).^{iv}

- **The nonelderly uninsured are from diverse racial/ethnic backgrounds:** about half are white, non-Hispanic (50.1 percent); 21.3 percent are black, non-Hispanic; 19.7 percent are Hispanic; and 8.9 percent are of other racial/ethnic backgrounds.^v
- **The majority of the nonelderly uninsured are U.S. citizens** (80.6 percent). Among uninsured children, 94.0 percent are U.S. citizens, as are 77.6 percent of uninsured adults.^{vi} Although specific statistics are unavailable, people with mental illnesses are significantly represented among those Virginians who are uninsured.^{vii}

Prevalence of Mental Illness

Mental disorders are common. An estimated 26.2 percent of adults—about 1 in 4—experience a diagnosable mental disorder every year.^{viii} About 6 percent, or 1 in 17, has a serious mental illness, such as schizophrenia, major depression or bipolar disorder, and about 5%-9% of children have a serious emotional disturbance.^{ix}

Based on national prevalence rates, about 298,000 adult Virginians have a serious mental illness at any time during a given year.^x Symptoms may affect these individuals' ability to work or care for themselves, and may involve a suicide attempt. National prevalence rates suggest that about 102,000 children and adolescents in Virginia have a serious emotional disturbance, and 65,000 of them are extremely impaired.^{xi}

Data compiled by the National Association of State Mental Health Program Directors (NASMHPD) in 2006 revealed that adults with serious mental illness have a life expectancy that averages 25 years below the general population due to significantly higher rates of medical co-morbidities such as diabetes, heart disease, pulmonary disease, asthma, and cancer, as well as poor access to primary care.

The Costs of Untreated Mental Illness

Lost productivity

- Nationally, mental illnesses and substance use disorders resulted in \$193 billion in lost productivity in 2002. By 2013 this loss is estimated to rise to more than \$300 billion.^{xii}

Reliance on more costly care

- Without access to appropriate treatment, people living with mental illnesses and co-occurring substance use disorder are more likely to experience crises, leading them to rely on more costly emergency room care or inpatient psychiatric care.
- Untreated mental illnesses and substance use disorders (SUDs) increase spending in other sectors of healthcare and people with these disorders are more likely to present to emergency rooms for acute care. In fact, one in five hospital stays involves a primary or secondary diagnosis of mental illness.^{xiii}
- In 2007, 12.0 million emergency department visits involved a diagnosis related to a mental health and/or substance abuse condition, accounting for 12.5 percent of all ED visits in the U.S., or one out of every eight ED visits.^{xiv}

Incarceration and Homelessness

- People with untreated mental illnesses are 4-6 times more likely to be incarcerated, often for crimes related to homelessness or other result of their illness. A 2005 survey revealed that 16% of Virginia jail inmates have a serious mental illness. These numbers increased to 18.5% in 2007. Today, our jails and prisons are turning into psychiatric wards--at a high cost to our communities.
- Studies show that people with disabilities are over-represented within the homeless population. They are more likely to have repeated episodes of homeless and to remain homeless for longer periods of time.^{xv}
- According to the Substance Abuse and Mental Health Services Administration (SAMHSA), 20 to 25 percent of the homeless population in the United States has some form of serious mental illness. In a 2008 survey performed by the U.S. Conference of Mayors, mental illness was the third largest cause of homelessness for single adults.^{xvi}

Treatment Works

Investments in effective treatments and services for mental illnesses save lives and money.

- Treatment outcomes for people with even the most serious mental illnesses are comparable to outcomes for well-established general medical or surgical treatments for other chronic diseases. The early treatment success rates for mental illnesses are 60-80 percent, well above the approximately 40 to 60 percent success rates for common surgical treatments for heart disease

The right treatments make a difference:

- Assertive Community Treatment (ACT) reduces costly hospitalizations and is no more expensive than traditional care. In Virginia, people served by PACT teams used 76% fewer state hospital days after enrollment than in an equivalent period before. And 92% had no arrests during the year and 83% experienced stable housing.^{xvii}
- Illness management programs reduce symptom relapses and hospitalizations.^{xviii}
- Supportive housing for homeless people with serious mental illnesses relieves the burden on publicly funded systems, resulting in a marked reduction in shelter use, hospitalizations (regardless of type), and involvement with the criminal justice system. These reductions offset virtually all (95 percent) of the costs of supportive housing, including operating, service, and debt service costs.^{xix}
- For children, multi-systemic therapy (MST) reduces out-of-home placements, contact with the juvenile justice system, and substance abuse. Research shows it may be more cost-effective than traditional services provided to at-risk youth.^{xx}

When “Tom” was diagnosed with schizoaffective disorder he was 28 and had just completed several college degrees and several years in the United States Air Force. He started down the road of a long journey of hospitalizations and treatment. After finding the right care, treatment, and supports he needed to get and stay well, Tom has become a mentor and peer to others, helping to educate and support others in their own journey to recovery and wellness.

A true story from Virginia

Coverage for and access to mental illness and addictions care has the potential to save states money, but access to treatment has an even greater human impact for individuals who have mental illness or are dealing with an addiction.^{xxi}

The first-ever Surgeon General’s report on mental health, published in 1999, recognized mental health as fundamental to overall health and made a single explicit recommendation that all Americans should seek help if they have a mental illness or think they have symptoms for a mental disorder.^{xxii} Yet even though a range of treatments exist for most mental health problems and the effectiveness of these treatments is well documented, one of the primary reasons that people do not seek the care that they need is because of concerns about being able to afford it^{xxiii}.

In *Achieving the Promise: Transforming Mental Health Care in America*, the final report of the President’s New Freedom Commission on Mental Health, the importance of early detection of and access to treatment and supports for mental illness is emphasized as a means to impact the lives and health of people with mental illness^{xxiv}. Emerging research indicates that early intervention can interrupt the negative course of some mental illnesses and may in some cases lessen long-term disability.

Access to treatment that is affordable and effective helps people with mental illness and co-occurring disorders regain their lives, and become healthier citizens who are part of the community through family and friends, work, and other forms of meaningful community involvement.

Changes in Health Care Reform

“Help! The insurance company denied coverage to my adult son because of his bipolar disorder. What do we do?”
-Fairfax County Resident

Private Insurance Market Reforms

The new law addresses barriers in the private insurance market that have often prevented people with serious mental illness and co-occurring disorders from obtaining health insurance. Starting in 2014 – and in 2010 for children up to age 19 – insurance companies will no longer be allowed to deny coverage based on pre-existing conditions, including schizophrenia, bipolar disorder and major depression. The law also prohibits annual and lifetime limits on coverage, which will help people who have chronic conditions that require expensive and long-term treatments. And the law prohibits a practice known as “rescission” in which the insurance company retroactively cancels a policy for nearly any reason, including discovering that a person has received treatment for serious mental illness or substance use disorder.

Expanding Coverage for Low-Income Adults: Medicaid

Starting in 2014, Medicaid will be expanded to serve individuals with incomes up to 133 percent of the Federal Poverty Level (FPL). Currently, Virginia’s eligibility for the Aged, Blind, and Disabled (ABD) population for Medicaid is 80% of FPL, one of the lowest standards in the nation. It is estimated that approximately 275,000 – 400,000 additional people will become eligible for health care services under expanded Medicaid coverage. Under Medicaid expansion, Virginians with annual incomes of about \$14,404 for individuals and \$29,327 for a family of four will be eligible for this coverage.

Raising the eligibility level is important because it will include childless adults living with mental illness who qualify. However, although plans are required to offer mental health and substance use benefits, these benefits may not be as broad as those received by traditional Medicaid enrollees. As Virginia defines what it will cover for enrollees in the expanded Medicaid program, it will be critical for coverage to include services with proven effectiveness, such as Assertive Community Treatment (ACT), intensive case management, multi-systemic therapy and other evidence-based practices for youth, and access to a full range of psychiatric medications. The law also increases the reimbursement rates to primary care providers, which should help to increase the number of providers willing to serve Medicaid enrollees.

State-Based Insurance Exchange

Starting in 2014, Virginia will have a new state-based health insurance exchange through which consumers can review and compare a variety of private health insurance plans. Consumers will be able to compare covered services, premiums, co-pays and deductibles, as well as out-of-pocket limits on expenses. The federal law provides premium and cost-sharing assistance to reduce the cost of health insurance for those with incomes up to 400 percent of the federal poverty level, and will provide tax credits for insurance costs for small businesses. The Commonwealth Institute for Fiscal Analysis reports that at least 400,000 currently uninsured Virginia families with annual income below \$88,000 will be eligible for private

insurance subsidies to bring the cost of insurance within reach.

As a child, “Shannon” experienced debilitating anxiety and panic attacks, affecting her ability to relate and spend time with others. She struggled through adolescence and young adulthood without seeking help. Eventually the illness took a huge toll. She would go on to be hospitalized 29 times over a 9 year period. During periods of wellness she was able to go to college, and eventually earned two degrees. She began to learn more about mental illness through psychology courses. Eventually she became enrolled in a health insurance program for low-income people. She was able to access doctors, therapists, and outpatient mental health supports that were essential to her recovery. Shannon is now a community volunteer who helps others with mental illness overcome serious challenges. Shannon credits access to health insurance with enabling her to educate herself and obtain the services she needed to get and stay healthy.

A true story from Virginia

“I tried month after month to get an appointment for my depression but was told because I didn’t have Medicaid, I’d have to go to the back of the line. I couldn’t get anyone to see me”.

-Louisa County Resident

The federal law requires that all health plans offered through the state-based exchange

- 1) Include mental illness and addiction treatment on the list of essential benefits that must be covered in new plans offered to the uninsured
- 2) Comply with the 2008 Wellstone-Domenici Mental Health Parity and Addiction Equity Act. You can find additional information about the Wellstone-Domenici Mental Health Parity and Addiction Equity Act at www.nami.org/parity.

Prevention and Care Coordination

The federal health care law places significant emphasis on strategies to promote prevention and wellness, including improving care coordination and promoting primary care integration including:

- A new Medicaid state plan option to establish community-based “health homes” for people with at least two chronic care conditions or at least one serious mental health condition; 90 percent federal funding is provided for this health home model.
- A new grant program to support co-location of primary and specialty care services in community-based mental health settings.
- A new Medicaid state plan option that will cover immunizations and federally recommended preventive services for adults with no cost-sharing; 1% increase in federal Medicaid funding.

Children’s and Adolescents’ Access to Mental Health Care

Virginia should be proud of the strides it has made to cover poor and low-income children and adolescents through its Family Access to Medical Insurance Security (FAMIS) program. FAMIS covers children up to 200% of the Federal Poverty Level. FPL is defined as approximately \$22,000 in income per year for a family of four. This still leaves about

180,000 children per year who are uninsured^{xxv}. Fortunately, the new law provides several ways to improve accessibility, quality, and affordability to health care:

- Effective September 23, 2010 for children under age 19, insurers may not deny coverage, charge a higher premium, or provide coverage that excludes coverage of essential health benefits due to a pre-existing medical condition or past history of a medical condition
- Allows young adults to remain on their parents' or guardians' health plan to age 26
- Qualified health plans must provide, at a minimum, coverage without cost-sharing for preventive services rated A or B by the U.S. Preventive Services Task Force, recommended immunizations, and preventive care for infants, children, and adolescents
- In 2019, full Medicaid coverage will be available to former foster care children up to age 25

Conclusion

The new health care law addresses many of the challenges people have in getting and keeping health care coverage. It will help provide Virginians with serious mental illness and co-occurring disorders access to care and treatment that may not have been available to them otherwise. It provides tangible benefits, removes barriers, and improves security for families. And the new health care law presents opportunities for Virginia to embrace innovative and effective service-delivery methods that focus on prevention and wellness. The law is an important step forward in improving the health and vitality of Virginians with serious mental illness and co-occurring disorders so that they may be fully engaged citizens of the Commonwealth at work, home, and in the community.

Resources

National Alliance on Mental Illness (NAMI) Health Care Reform Website
www.nami.org/healthcare

Robert Wood Johnson Foundation Health Care Reform GPS
www.healthreformgps.org

The Kaiser Family Foundation Health Care Reform Website
www.healthcarereform.kff.org

Families USA Health Reform Website
www.familiesusa.org/health-reform-central/

Appendix

True Stories of Virginians with Mental Illness

Uninsured and Scared

My 31-year old daughter is completely uninsured. She was diagnosed with bipolar disorder in 2002. She isn't ill enough to qualify for disability, not poor enough to qualify for Medicaid, and she was denied coverage for private insurance a few years ago because of her mental illness and for being overweight. I've been paying for doctor appointments when I could afford them, along with medications. But now I can't afford to pay at all. I'm deep in credit card debt because I used them to pay for her medication and doctor bills when I could.

In order to see a doctor, she goes to the emergency room. When I last checked to see about insurance, I found out that a diagnosis of bipolar disorder is a disqualifier for insurance. And because she's overweight, that's another disqualifier. The only insurance I could get if her bipolar disorder was not considered was \$400 a month. I simply cannot afford it even though I work full-time.

I live in constant fear that she will get cancer or diabetes or something else like that. I could never recover from knowing that she was either denied health insurance or received less-than-adequate care because she was uninsured.

Caught in a Hopeless Cycle

I have dealt with major depression for as long as I can remember. Since I began the time in my life when most people begin doing what they do when they "grow up" I have been unable to hold a steady job. At most, I have been able to hold part time, low paying jobs with no health care.

I begin working with hope and optimism, but eventually my mental health suffers, which also causes me physical symptoms. Because I have no health care coverage, I have been unable to seek medical help. Because I can't afford medical help, I am too ill to work a meaning job with a livable wage. I am now 32 years old and in worse health than ever. I have never had a job with health care or that paid more than \$10 an hour. I have, however, had thousands of dollars of medical bills. Last year I made less than \$12,000 and had over \$8000 in medical bills. I saw a specialist because I was throwing up every day. They were unable to find a reason for it but that didn't change the bills.

It is incredibly stressful to live a life with no health insurance. It is hard not to be hopeless when you have no money, bad health, and no end in sight.

Learning from the Past, Hopeful About the Future

I was caught without insurance during a series of mental health hospital stays and it cost me and my family going into bankruptcy and starting from ground zero. I was declared disabled shortly thereafter and since then that has helped with putting food on the table. But we learned a valuable lesson to try and keep any job with benefits before switching jobs and we also learned that pre-existing conditions are often not covered, especially mental illnesses like schizoaffective disorder.

My wife has held good jobs since that time but we still find it hard to keep up with co-pay on medications and doctor visits. We spend a fifth of our income on medical premiums and co-pays.

We're hopeful that our 19-year old daughter will soon be able to be covered until she is 26 years old. She is also a person that lives with mental illness and has had trouble staying in college. We are hopeful that with the change in this law she will remain on our insurance.

Just Getting By

I have gotten services at my local CSB on and off for the past 6 years. They helped me stabilize but it has not always been easy. I had some relapses and burned bridges with a lot of people who cared about me but I am learning. I'm on the road to recovery and it feels good. After a long struggle and a period of homelessness, I was diagnosed with bipolar disorder. In my darkest days I spent many nights homeless in my city. It was awful. Looking for food and wondering what to do. I am lucky to have the support of my family.

I don't have Medicaid. I don't have anything. They said I don't qualify. I pay a sliding scale for services. I now have a part-time job that I love and I make small payments for my appointments. It's hard to keep up with the payments but I try my best.

Uncertain Future

We recently tried to get long-term care for our daughter. It turns out that you can't. The agent we were working with called around but no one would provide coverage. No company would insure someone with a mental illness. We're getting older and trying to make plans for her for when we are gone. There don't seem to be a lot of options.

Having access to a clubhouse has been the most positive aid in our daughter's recovery. It was a safe-haven for her. She became involved over time and took on leadership roles. She had peer support from others in her shoes.

There is no question in my mind that health care services need to be better coordinated. Wellness and prevention have to be part of the focus. Our daughter's primary care physician is very concerned about the effect of her drugs which have caused weight gain and pre-diabetic condition.

The "Luxury" of Health Care

I have Medicare Parts A, B and D. I have just reached the donut hole in the Medicare Part D plan so my medication now costs over \$300 per month. Because of this I have discontinued using the medication because I can't afford it. This subjects me to severe withdrawal and has the potential to derail my recovery. I have also had to discontinue another medication for the same reason and don't know if my psychosis will return. Receiving SSDI and working a minimum wage job does not afford me the luxury of taking the drugs I need.

Family Stress

Despite the decisions of my daughter's doctors, my insurance company denied coverage. In order to give my daughter the treatment that she needed according to the clinical judgment, I closed out all of my IRAs and 401K to pay for doctor and hospital bills. My family was placed in severe debt. The only success I have learned is working things out the hard way. Resources are scattered and the dots are not connected. The stress of all of this combined with family crisis is too much.

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