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The sting of stigma

Expert: Mental illness is one of the last ‘acceptable’ forms of discrimination

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Facing mental illness



Dave Slover has a smile that's contagious. He ignites like a spark plug when he talks about working on cars, and his own Chevy Monte Carlo, which he lovingly built, holds a special place in his heart. He has dreams of someday becoming a certified mechanic, and has a penchant for writing poetry and other thoughts, which are scribbled in the weathered notebook he carries with him. He loves to talk.

Like his personality, Slover's appearance is typical of a 25-year-old guy. He wears relaxed-fit jeans and a T-shirt bearing words that are at once sage, witty and slightly irreverent: "Never take life too seriously, nobody gets out alive anyway." He has a pierced ear.

He also has mental illness.

Slover, diagnosed with bipolar II and attention deficit hyperactivity disorder (ADHD), is representative of the one in four people who have a mental health disorder.

"These two mental health issues stole a lot from me," Slover, a Jackson resident, said. "I was tortured inside my own head for 20-some-odd years."

Combined with that torture was the pain of growing up with an abusive father who passed away when Slover was 9, a

long road to getting the right treatment, and ongoing battles with the stigma that comes with being labeled mentally ill.

“Societal stigmas are definitely an issue that people with mental illness face,” said Jay Yudof, vice president of programs for the National Alliance on Mental Illness (NAMI) of Greater Monmouth. “It’s one of the last ‘acceptable’ forms of discrimination.”

Slover can attest to that. Since childhood, when he attended any number of special education schools without receiving proper treatment, he has felt the sting of stigma.



“I hate to say this, but I feel my family’s pride is the reason I didn’t go on medications [sooner],” he said, adding that he doesn’t blame his mother, who has been a source of great support to him.

But stigma and discrimination don’t cease to exist in the world of mental healthcare providers.

According to Yudof, costs of malpractice insurance for psychiatrists don’t increase from year to year like that of their medical counterparts, because it is extremely rare that a psychiatric patient emerges successful in a malpractice case.

Last year, Slover got a taste of the system behaving badly. After a subpar experience with a doctor who, he said, gave an inadequate evaluation and handled his medications poorly, Slover was thrilled to switch to a doctor who specialized in ADHD. “I looked forward to it like a holiday,” he said, adding that his happiness ended in devastation when the psychiatrist told him negative messages about himself, then suggested an intensive course of care that he neither needed nor could afford.

“They were trying to make money off me in that place,” he said. “They treated me like [expletive] over there. She had a look on her face like I was an insect.”

To get a second opinion, Slover talked about it with Linda VanMelis — his community support person, as well as a board member with NAMI of Ocean County and Children and Adults with ADHD — who confirmed his feelings.



Dave Slover, who is diagnosed with attention deficit hyperactivity disorder and bipolar II, finds healing and empowerment by giving and receiving peer support, as well as doing outreach to educate the public on mental illness. JEFF GRANIT staff

When he reported the incident to higherups at the agency, he was told the issue should be discussed between him and the doctor in question.

“I left there feeling three times as bad as when I went in,” Slover said.

Despite the setback, he didn't give up on finding the right treatment. He advises others dealing with mental illness to do the same.

“If you are going to a doctor and feel that something is not right with the way they treated you, it's probably true,” he said, adding that such cases should be reported.

Stigma and issues with clinicians aren't the only barriers to treatment for those with mental illness. As with anything else, economics play a major role. According to John Mans, president and CEO of CPC Behavioral Healthcare — a nonprofit agency that is one of the largest mental-health providers in Monmouth County — despite an uptick in demand for services, there has been a slight but steady decrease in contract dollars from the state and county. Dan Burns, the CFO at CPC, said the agency is under contract with the state to provide services regardless of one's ability to pay.

This disparity in supply and demand results in waiting lists bearing the names of those seeking help.

“That concerns me,” Mans said. “We're very sensitive to that. But we're not alone. The resources are just not meeting the demand, and they haven't for a number of years.”

Sylvia Axelrod, executive director of NAMI New Jersey, said the goal is to create a comprehensive system of treatment programs, but funding cuts have created an obstacle.

“I always get concerned when programs have to be competing with other programs for the same funding,” she said. “You need a range of programs.”

A lack of adequate funding, Yudof said, can be seen as discrimination on the part of insurance companies and programs such as Medicare and Medicaid. For physical healthcare, insurance companies impose no cap on hospitalization, he said, but insurance will only cover 190 days of psychiatric care over a payee's lifetime.

Although Slover is now covered by Medicare through his disability benefits, there were times when he was unable to stay on his medications because of a lack of insurance. He recalled several times when he was suicidal, but didn't go to the hospital because he couldn't pay the bill.

Those were tough times for Slover, but he was able to muddle through. He researched nutritional remedies, which included omega-3s and caffeine for ADHD, among others, and used writing and exercise to combat suicidal thoughts.

Not everyone is able to persevere like him. According to Aruna Rao, associate director at NAMI New Jersey, lack of treatment and support often converge to become the perfect storm.

“All these things can come together and lead to a feeling of hopelessness,” she said.

According to Mans, factors like the ailing economy, 9/11 and tragedies like those at Virginia Tech, Aurora and Newtown have contributed to an increased demand for services from those dealing with depression and anxiety.

“The industry has really taken a lot of effort into de-stigmatizing mental health,” he said. “People have been a little bit more open about coming forward and seeking treatment.”

Unfortunately, knee-jerk reactions like those that came in the wake of the Newtown school shooting can set back such efforts a long way. Media reports following the shooting stated that shooter Adam Lanza may have been diagnosed with a type of autism. Though it is not considered a violent disorder, many perceived it as a possible explanation for his actions.

“If there’s a link to mental illness ... people get so focused on it,” Axelrod said. “Because they can’t explain it.”

While acknowledging that it was never determined whether Lanza truly had a mental illness, Slover gave his perspective.

“I have way more wrong with me, and I would never think of hurting another human being,” he said.

President Barack Obama’s response to the Newtown rampage in December included a promise to help combat stigma surrounding mental illness, as well as to create parity in insurance coverage for those with mental illness. Other initiatives, like Gov. Chris Christie’s NJ SAFE Task Force, were also created in the wake of the tragedy to address mental health and other issues.

While Axelrod acknowledged that these are great strides, she lamented that mental illness seems to only enter the public dialogue after a violent incident.

However, as innumerable experts and the president himself have stated, most mentally ill people are not violent.

“The majority of people who have mental illness are very rarely a threat to others,” Rao said. “They are much more often a threat to themselves. Why is no one talking about the suicide rate? This should be considered a public health crisis.”

A person with a major mental illness lives a life 25 percent shorter than the average person, Yudof said.

A ray of light for Slover and others who may have otherwise lost hope comes from community or peer support programs, which have persons with mental illness providing help to others going through the same struggles.

“I use some of my experiences to help other people in the group,” Slover said, adding that the first time he attended the No Stigma support group, “I felt so free.”

Such groups are not only healing, but also empowering for those dealing with mental illness.

“Self-help groups often get involved in trying to change the system,” Yudof said.

It’s a far cry from the days before the Olmstead Act, which in 1999 mandated a move away from institutionalization for the mentally ill, instead aiming to integrate such persons into the community.

“We believe that living productive, integrated lives leads to recovery,” Yudof said.

Yudof, who is diagnosed with attention deficit disorder, started off in such programs as a layperson, then turned it into a career as a mental-health educator.

As part of that role, he takes part in a NAMI program called “In Our Own Voice — Living with Mental Illness,” which is aimed at educating the public.

Slover also is doing his part to raise awareness about mental illness, speaking about it at his church and disclosing his status to those close to him.

Although he has been harassed for years by peers and endures being called “Crazy Dave” by some, he manages to rise above.

Some have advised him not to be so open about it, but he disagrees.

“I feel being open about it, I’m beating it even more,” he said. “The only way to get rid of a stigma is to be wide open about it.”

RESOURCES

Free community and peer support

Collaborative Support Programs of New

Jersey: <http://cspnj.org>

New Jersey Self-Help Group

Clearinghouse: www.njgroups.org,

800-367-6274

No Stigma Network Support Group:

Email onthego77@att.net, 732-533-7632

Monmouth-Ocean CHADD (Children and

Adults with ADHD):

meetup.com/Monmouth-ocean-CHADD.

To learn about mental illness from people who have been there:

“In Our Own Voice — Living with Mental Illness” is an educational program appropriate for schools, churches, publicservice agencies, personnel departments, mental-health audiences and others:
866-464-3267

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