ALCOHOLISM & DRUG ABUSE WEEKLY
News for policy and program decision-makers

Why patient advocacy movement is hidden for addiction

By Alison Knopf -- February 2, 2012

Whether looking for a powerful lobby or a local support group, patients with substance use disorders (SUDs) who are seeking or participating in treatment have a woeful lack of places to turn. There are organizations for people in recovery (like Faces and Voices of Recovery), harm-reduction groups for active drug users (like the Drug Policy Alliance), groups representing people on methadone maintenance (NAMA) or Suboxone (NAABT), and of course treatment providers and their organizations, all of whom have some advocacy indirectly for people who are seeking treatment.

But unlike patients with diabetes, depression, and other medical conditions, who have prominent celebrity spokespeople and can talk to their employers about their medical conditions, people with active SUDs are as unseen as ever.

Faces and Voices of Recovery, which was founded 10 years ago, does represent people with active addiction, as well as people who are in recovery, and probably comes closest to representing the needs of people with addiction when it comes to government advocacy.

“Before Faces and Voices of Recovery, the providers basically filled the void because there wasn’t anybody else,” said Becky Vaughn, chief executive officer of the State Associations of Addiction Services (SAAS). The problem with this is that funders look askance at treatment providers asking for money for treatment. Patients would have more credibility, said Vaughn.

However, stigma gets in the way. “People get into recovery and go back into the community, and they blend right in,” said Vaughn. “They go back to work, and they’re not in a situation to tell their boss they want to go advocate for treatment, because in most cases their boss doesn’t even know they’re in recovery.”

There is no SUD parallel to the National Alliance of Mental Illness (NAMI) because of stigma, said Vaughn. “NAMI is basically made up of parents and family members,” she said. “Parents of children with SUDs don’t want to say anything about it.” For mental illness, the assumption is that the parents didn’t do anything to cause the problem. For SUDs, parents feel at fault, she said. Even when their children have had successful treatment and are doing well, they don’t want to talk about it. “There’s this perception on the part of many people that it must have been bad parenting,” said Vaughn.

Another issue is anonymity, which has been a tenet of belonging to Alcoholics Anonymous or Narcotics Anonymous. However, there is a growing understanding that “standing up for what we need is not the same as breaking anonymity,” said Vaughn.

Public service announcements (PSAs) help encourage advocacy for other chronic diseases. “I wish we had money for more PSAs,” said Vaughn.

Money is a key issue, in fact. Most of the mental health advocacy groups get funding from pharmaceutical organizations, noted Vaughn.

Criminalization

Imani Walker, co-founder and executive director of the Rebecca Project for Human Rights, which promotes family treatment for women and children, said that criminalization of a public health issue is one of the reasons addicts stay in the shadows. "Addiction is the one disease you are criminalized for having," Walker told ADAW. "If you are not in recovery you can be prosecuted, you can lose your job, and you can lose your children," she said.

Walker, who is in recovery, learned when she was an active addict that asking other women whether they had children was taboo. "I was fortunate enough to still have my children," she said. "But I learned you do not ask other women if they have children. So many lost their parental rights. The phrase I hear over and over again is, 'I lost my children to my addiction.'"

The Rebecca Project works with substance abuse treatment providers to train mothers specifically to do policy advocacy work. "We have a network across the country, called the mother's sacred authority, to train clients while they're still in treatment," said Walker. She urges treatment providers to train women who are in recovery "to speak for themselves," she said.

"Until addiction is elevated from the misconceptions and the mental images of the person who is an alcoholic and dying in the gutter, or dying in the crack house or heroin shooting gallery, there will always be shame," said Walker. "No one wants to be associated with that image."

Pat Taylor, executive director of Faces and Voices of Recovery, pointed out that one of the differences between patients in the addiction treatment system and patients with other medical conditions is the lack of an ongoing relationship with health care. "Many people with addiction are not interacting on regular basis with a service system," she told ADAW. As more people get enrolled as a result of health care reform, this will change, she hopes. "We are making progress."

The National Alliance for Medication Assisted Recovery (NAMA) started at the same time as NAMI. Walter Ginter, director of training and recovery services with NAMA, thinks funding from the federal government helped boost mental illness advocacy. "The federal government made a big push 25 years ago to make treatment for mental illness more accessible," Ginter told ADAW. "The stigma around mental illness in those days was worse than it was around drug addiction." Part of the mandate of the Substance Abuse and Mental Health Services Administration (SAMHSA) was to destigmatize mental illness, he said. "There was one person in each state as an advocate, getting about $75,000. We never had anything like that in substance abuse."

Melissa Preshaw, community relations director of CRC Health Group, the largest substance abuse treatment chain in the United States, said one of CRC's strongest contributions to its patients is insurance. "We work really hard to maximize clients' insurance benefits," said Preshaw. "We have trained at the corporate and the facility level on maximizing benefits once someone has come in for treatment."

CRC is also opening "assessment centers" where people with SUDs can get more information and be made aware of treatment options, said Preshaw. These first opened in Pennsylvania, linked to CRC's White Deer Run programs there, and are next slated to open in California, she said.

Rob Morrison, executive director of the National Association of State Alcohol and Drug Abuse Directors (NASADAD), pointed out that one of the reasons the advocacy movement of people with SUDs isn't bigger is that of the 23 million Americans with a problem, only 3 million think they need help. "More is being done to promote people's voice in recovery," said Morrison. "But in this era of patient choice, how does this get applied to addiction, and how should it be applied?"

Resources:

To reach Imani Walker at The Rebecca Project, call 202-265-3908.

For the mission statement of Faces and Voices of Recovery,
go to http://facesandvoicesofrecovery.org/about/goals.php

To read Walter Ginter on advocacy for patients in medication-assisted treatment,
go to www.facesandvoicesofrecovery.org/publications/profiles/walter_ginter.php