Long under Congress' radar, eating disorder treatment advocates on verge of pushing through reforms

By Brianna Ehley
Politico Pro

08/11/2016 10:30 AM EDT

After decades of failing to push through reforms from Congress, advocates representing more than 30 million Americans with eating disorders are celebrating a rare moment of progress on Capitol Hill.

For the first time ever, legislation specifically aimed at combating and expanding access to treatment for anorexia and bulimia among other disorders is quietly moving through Congress and has a shot at passage this fall.

The Anna Westin Act, which is tucked into broader bipartisan mental health reform legislation approved by the House this summer, targets insurers who deny coverage for expensive inpatient treatments that cost tens of thousands of dollars - a common practice despite existing laws requiring equal coverage of mental health care, advocates say. It also creates first-of-their-kind federal programs for prevention and early detection activities, such as training staff at schools to spot signs of eating disorders.

Even as the stigma around mental health and substance abuse disorders has been reduced in recent years - especially amid a deadly nationwide opioid epidemic - advocates say patients with eating disorders are still overlooked. That's even though eating disorders rank among the deadliest mental health conditions, according to the National Eating Disorder Coalition.

"Eating disorders have always been the redheaded stepchild of mental health," said Katrina Velasquez, the group's policy director. "The biggest challenge for us has been overcoming the stigma throughout the years, but staffers on the Hill are getting more receptive."

That stigma is one of the most common reasons most people with eating disorders don't receive treatment. Just about one-third of people with anorexia and 6 percent of people with bulimia receive treatment. But access is another major hurdle, which is why advocates pushed hard for insurance parity in the legislation.

Insurers often deny full or partial coverage for inpatient treatment that on average can cost $30,000 for a 30-day stay at a facility, according to the most common estimates.

Patients with severe disorders may need to stay as long as three to six months, followed by outpatient therapy. Without coverage, these lengthy and intensive treatments are often unaffordable.

Insurers say they follow parity laws, but they said coverage is sometimes denied for inpatient eating disorder treatment because many residential treatment centers are out of network.
Health plans typically cover anorexia or bulimia as part of the Affordable Care Act's 10 essential benefits under mental health, said America's Health Insurance Plans spokeswoman Clare Krusing. However, other conditions, like binge eating disorder, are associated with obesity and may be considered bariatric treatment not covered by the essential benefits.

Rep. Ted Deutch (D-Fla.) introduced his bill last year after meeting with constituents who had been denied coverage for eating disorder treatments. Though similar legislation has been introduced in previous years, it never made it past committee. But Deutch said he saw an opportunity last fall when Rep. Tim Murphy's (R-Pa.) broader mental health reform bill started to move through the Energy and Commerce Committee.

"I brought the advocates' stories directly to Chairman [Fred] Upton, Rep. Murphy, Ranking Member [Frank] Pallone, and others on the committee," Deutch said. "If you take a few moments to listen to the pain that eating disorders have caused these families you can see how we were able to overcome the cynicism that makes it difficult to get things done in Washington."

He sat down with Upton and Murphy to work out the details. They were concerned about adding money for new programs, and insurers were wary of any provisions that might be interpreted as coverage mandates. Ultimately, the lawmakers agreed to authorize programs and let Congress appropriate new money separately - so the bill wouldn't cost anything up front - and parity language was tweaked to clarify that only plans with eating disorder coverage had to cover it on par with other medical treatments.

The measure sailed through committee without any debate around the eating disorder language, and it was tacked onto the major mental health reform bill that overwhelmingly passed the House in July.

The bill isn't as strong as advocates would like - they prefer a blanket mandate for all insurers to cover eating disorders equally. But the current version has support from health insurers.

The mental health bill is now awaiting action in the Senate, where battles over emergency funding for Zika and the Defense spending bill, among other things, have curtailed progress on anything else. The bill has also been slowed by discussion of adding NRA-supported background check language for guns - a nonstarter for Democrats.

Even without federal action this year, some states have recently taken steps to strengthen existing federal parity laws. Missouri last year became the first state to approve legislation that spelled out what types of eating disorder treatments insurers must cover. Since 2009, Massachusetts has banned insurers from placing certain limits on treatments for patients with eating disorders. Still, advocates stress, many states don't have strict parity laws or enforcement mechanisms.