Medical Xpress

Colorado—a national hub for eating disorder treatment—hopes to slow surging rate of stigmatized illness

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Two weeks after a routine trip to a health clinic turned into a psychiatric hospitalization, Emma Troughton was on a plane to Denver.

The intervention had been building: By early 2017, Troughton had struggled with body image and eating for years, first as a high schooler in Indiana piecing through their gender identity (Troughton is nonbinary) and then as a college student in California processing personal trauma. School-issued laptops sent Troughton down social media rabbit holes of unhealthy weight loss strategies. A password-protected blog became a repository for body measurements and bad information.

Troughton crashed their car because of the brain fog and cognitive decline caused by their malnourishment. Providers at a campus health clinic were so alarmed they wouldn't allow Troughton to return to class. After two weeks in a psychiatric unit, Troughton left for Denver. The city, they had learned, was a national hub for eating disorder treatment.

"I felt this existential detachment from my body," said Troughton, who now works for Mental Health Colorado. "Any attempt I had at re-integrating (with my body), I felt flooded with anger and a sense of helplessness. I re-acquainted strongly with my eating disorder going into college."

Troughton spent the next three years in and out of Denver facilities, navigating treatment they considered to be both traumatic and life-saving. The city is home to Denver Health's ACUTE, considered one of the highest-level eating disorder facilities in the country. The Eating Recovery Center, a national for-profit treatment provider, is based here, too. That's where Troughton was treated, and their last time there—in 2020—came as COVID-19 arrived in Colorado.

The pandemic would ignite a series of societal disruptions that have led to an explosion of eating disorder diagnoses among youth in Colorado and across the United States. Providers here say demands for their services have increased and that the pandemic's impact on eating disorders will endure for years.

"The severity of kids that we saw during the worst part of the pandemic was really intense," said Jennifer Hagman, the director of the disorder eating program at Children's Hospital Colorado. "Almost every kid, to a person, talked about the impact of being isolated at home and being on social media and starting to get even more body focused than they already were."

The surge in cases—coupled with concerns about treatment raised by patients like Troughton—have gained the attention of Colorado lawmakers and mental health advocates. A leading Democrat in the state Senate has introduced legislation in recent weeks that seeks both to prevent eating disorders from developing and to regulate the treatment that's provided when that prevention fails.

The two bills—one to establish a statewide office of disordered eating prevention, the other to limit the availability of diet pills and to better oversee medical practices—are unique in the country, several local and national experts told the Denver Post. Their introduction, those experts said, signal an increased focus on a long-neglected and stigmatized disease that is among the deadliest mental illnesses.

The diseases—like anorexia and bulimia—are often portrayed as physical diseases affecting teen girls and models. While women and LGBT people are more commonly affected, men and boys are vulnerable, too, and often go undiagnosed. Six former patients who spoke to the Denver Post described their condition as psychologically torturous and all-consuming, often born of a desire for control, a

response to trauma or a trigger point around weight or healthy eating. Hagman said the diseases can be enduring and as severe as schizophrenia, and they often develop hand-in-hand with anxiety and depression.

"It's like being held hostage," said Sarah Staron, who struggled with an eating disorder for a decade. She's now the policy coordinator for the advocacy group Young Invincibles, which is supporting the legislation. "By yourself, by society or by the plate of food that's in front of you."

Several former eating disorder patients who spoke to the Post for this story said they had attempted suicide. Many said the disease was like having a voice in their head, forever focused on food, dominating their first and final thoughts each day.

After the pandemic began, first-time attendance at the Denver-based Eating Disorder Foundation's family support groups spiked more a 1,000%, the foundation's program director said. ACUTE, the Denver Health clinic, saw its patient load jump 32% between 2019 and 2021. The Colorado Department of Public Health and Environment does not collect data on the prevalence of the diseases here, but a Harvard analysis suggested that 9% of the state—roughly 501,000 residents—will develop an eating disorder in their lifetimes.

Through these two bills, lawmakers and advocates say they want to curtail eating disorders here, working in schools and establishing preventative practices, like banning diet pills and educating adults to identify the diseases early. Beyond that, they want to ensure that treatment facilities are operating under set standards governing patient care and dignity, something several patients said is lacking in the current system. Both bills are set for their first committee hearing in late March.

"It's quite novel what we're attempting to accomplish here," said Sen.

Dominick Moreno, a Commerce City Democrat and the sponsor of the two eating disorder bills. "It's novel because eating disorder issues don't get a whole lot of attention. It's the first time in as long as I've been at the Capitol that eating disorders have really taken the spotlight."

Prevention

That spotlight, Moreno said, is thanks to people like Aimee Resnick.

Resnick helped draft the legislation as a member of the Colorado Youth Advisory Council. She remembered learning about calorie counting, weight loss and the ideal body-mass index in her high school health class. Her eating disorder developed from there, she said. Then the pandemic washed over Colorado, and her health spiraled.

"Part of why we saw such a big spike in symptoms of disordered eating over the pandemic is it felt like the world was out of control for everyone," said Resnick, who's now a student at Northwestern University in Illinois, "and disordered eating offers that sense of control for everyone."

Dr. Guido Frank, a psychiatry professor and eating disorder researcher at the University of California San Diego, said the control offered by eating disorders is an illusion. It can give patients—who, Frank said, are often high-achievers, perfectionists and athletes—a sense of autonomy. But quickly the disorder can take over and become self-reinforcing.

"Then you have a real problem, right, because you have in your thinking, in your belief system, you finally found something that helps you feel better in a way, and then the next problem starts," Frank said. "If you change your eating, and you get out of a certain normal range of how your body should be fed, then you change your brain."

As Resnick's condition worsened, she feared she would be hospitalized. She attempted suicide. After an initial hospital stay, she ran into one of the paradoxes of eating disorders: She wasn't skinny enough to qualify for treatment.

The body-mass index—calculated using a person's height and weight—was created by a Belgian mathematician in the 19th century, 30 years before the Civil War. It's now used as a key metric in determining the severity of a patient's eating disorder and the level of care they should receive. That means that some eating disorder patients who meet all other criteria to receive treatment aren't admitted—either by the facility or by their insurer—because they haven't lost enough weight.

"Only 6% of folks with eating disorders are underweight," said Lydia Rhino, the program director for the Eating Disorder Foundation. "If you think about the scope of the folks that (metric) is missing and leaving out as not receiving care or not having insurance coverage due to their BMI, we're neglecting to treat a large majority of folks."

With Resnick's help, Moreno's bills would change that. The regulatory legislation—SB23-176—would ban the use of BMI in assessing the necessity of treatment for an eating disorder patient. That would be a first nationally, experts and providers said, and it reflects the reality that eating disorders extend beyond a person's size.

Anne Marie O'Melia, the chief medical and clinical officer for Eating Recovery Center, was more hesitant to endorse the BMI change. She understood the intent but noted that professional guidance for eating disorder treatment included the use of BMI. If state law prohibited its use, she said, then providers would have to choose between statute and clinical standards.

Moreno said he didn't want weight to dictate who gets care. That

decision should be collaborative between patient and providers and ultimately based on total need, he said.

The two bills would also set up a statewide prevention office to coordinate research, best practices and education. The legislation would also ban the sale of diet pills, which Dr. Bryn Austin, a researcher and professor at Harvard and Boston Children's Hospital, said was a pervasive problem among youth in particular. She compared the regulatory environment overseeing the pills and the industry pumping them out to the "Wild West," she said. Meanwhile, Austin said, 10% of Latina girls and 6% of white girls have used weight-loss pills in the past month, quoting data from the Centers for Disease Control and Prevention.

"These are commercial industries that profit from eating disorders and profit from promoting poor body image," she said. "They profit from making consumers feel bad about their bodies."

Treatment

Though there has been some concern from grocers about the extent of the supplemental regulation, Moreno's proposals around prevention and diet pills are largely non-controversial. But his plan to better regulate treatment facilities is set to be more contentious.

His bill would require that the newly launched Behavioral Health Administration establish specific regulations and rules for eating disorder facilities. As it stands now, those facilities have varying degrees of oversight as medical facilities, governing what Moreno described as "routine" issues like general safety and cleanliness.

But there are fewer rules specific to the type of care they provide and disorders they treat, he and others said.

"They have treatment guidelines for eating disorders, which is very helpful," said Frank, the University of California San Diego researcher. "But there is not necessarily a unified approach for eating disorders treatment, and that is clearly a problem."

Moreno's bill would institute that baseline, another national first. Troughton and other former Eating Recovery Center patients told the Post about standing in lines waiting for the scale with other patients, naked except for light robes. Patients would be directed to do jumping jacks to ensure they weren't hiding weights.

To address those concerns, the legislation would direct the BHA to create rules around trauma-based care, institute bathroom policies that are inclusive to all gender identities, and require privacy standards for patients, like that they not be nude when weighed, that they be sufficiently covered when waiting to be weighed and they not be required to do exercises before being weighed.

Dr. Patricia Westmoreland, the legislative chair for the Colorado Psychiatric Society, said treatment facilities already have oversight and that the bill paints a draconian image of this type of mental health care. She said she was supportive of the rest of the legislation but had concerns about what she cast as redundant regulations.

"It sounds as though they're dealing with (facilities) that are set out to torture individuals with eating disorders or punish them, when that's actually not the case," she said.

More regulation would also be required of more intensive treatment, like keeping a client in their rooms or the use of involuntary feeding tubes. Lizzy Earhart, a 21-year-old who said her eating disorder began to develop when she was 13, said she was kept in her room at a treatment facility for so long that she began having panic attacks. She feared being

placed on a feeding tube. She and others described a punitive atmosphere, in which patients had little control and felt trapped between rigid treatment protocols and a disease that could kill them.

Moreno said he wanted scrutiny on those practices and treatment in general.

"Any practices that a facility has in place should be scrutinized," he said. "This is one where there are some bizarre practices that I'm not sure are rooted in best practices for either medicine or mental health."

Westmoreland and O'Melia, the chief clinical officer of the Denver-based Eating Recovery Center, both said facilities already had sufficient oversight. Eating disorders, O'Melia said, are complex, life-threatening illnesses that actively push back against treatment. Feeding tubes already require court intervention, she said. Restrictions around weigh-ins—like a prohibition on exercises or requiring certain clothing—could inhibit providers' ability to get accurate weights, she said.

She said patients with concerns could raise them to their providers. Her take on the bill—and patients' concerns overall—is that providers needed to do a better job communicating with the people they're serving.

"Care practices do need to be individualized for each patient," O'Melia said. "It's very important to note that eating disorders can be life-threatening, they can be very tricky to treat. It's important to have the ability to provide what might seem like unusual interventions in order to protect a patient from their illness and prevent their death."

Troughton, who was a patient at Eating Recovery Center, said they understood the severity of their disease. But they wanted a tighter focus on its prevention and treatment.

"A lot of these practices are essential," they said. "Eating disorders are tricky. They thrive in secrecy, they cause a lot of lying, they can be competitive. It's very hard to be a provider for an eating disorder patient. But at the same time, a lot of these things unknowingly replicate the worst aspects of my eating disorder."

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