

For Washington patients with serious mental illness, this little-known right may get stronger

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Andrea Boyd's son has been in crisis often enough to know the urgency of getting treatment when he needs it. In his 20s, without proper care and

medication, he drifted onto the streets for nearly a decade.

He also knows the specific kind of care he needs when he's unstable.

"Please call a (designated crisis responder) or take me to emergency room if involuntary treatment is necessary to treat my schizophrenia," wrote the 36-year-old, who now lives in Bellingham. At the hospital, "food, water, medicine and doctor care" will help him stabilize.

His words, written as part of a so-called mental health advance directive, hold legal weight.

In Washington, people with [mental illness](#) have since 2003 had the right to make their own psychiatric care decisions before they hit a crisis point. The directive—a [legal document](#) similar to ones used for end-of-life decisions—allows people to state preferences about their treatment. They can also name a designee to make decisions for them when they can't or won't consent to care.

The problem: Hardly anyone knows this right exists.

"If that document is not available, isn't read, nobody knows about it, you might as well take your (psychiatric advance directive) and throw it in a bottle in the ocean and hope somebody finds it," said Jeffrey Swanson, a medical sociologist at Duke University School of Medicine who runs a national resource center on psychiatric advance directives.

The concept of advanced planning for psychiatric illness emerged in the 1990s; more than half of U.S. states now have a psychiatric directive statute on the books. Interest in such laws coincided with a swell in advocacy against a system that has defaulted to treating people with serious mental illness against their will.

Research suggests such directives can help lessen the odds of involuntary treatment and other potentially traumatic experiences, like being cuffed and taken to a hospital by a police officer. Knowing they have agency over their own care, people might be less prone to get aggressive or resist treatment when they're unwell.

But mental health advance directives never gained steam in patient or health care circles. And like Washington, many states have struggled to implement their psychiatric advance directive laws. The forms are often full of legal jargon, most [health care workers](#) aren't trained to supply them, and retrieving them when they're needed has posed technical and logistical headaches.

Now, as several cities like New York and San Francisco move to expand involuntary commitment in response to the growing mental health crisis, a handful of states including Washington are looking at mental health directives as an alternative. Washington state's Senate, for example, recently cleared legislation that could strengthen existing law.

"The goal of this system is getting people back to that place of self-determination. ... Finding ways to promote that and empower people in our system is one of the most crucial things that we can do," said Elizabeth Perry, a health equity consultant who worked on the legislation.

Boyd says her son's directive has helped him secure voluntary care and avoid another churn through homelessness, involuntary treatment and imprisonment. The Seattle Times isn't naming him because of his concern about future treatment if he falls into crisis again. Boyd and her son are Indigenous and are also concerned about institutional racism in the crisis care system.

"They have it in writing to provide him behavioral health care, whereas

before they didn't have that at all," Boyd said of her son.

"He fell through the cracks."

Gray area

The idea that someone with mental illness should help determine their own course of care raises thorny questions at the center of classic debates over how to best treat people in need.

Who should make care decisions when someone is so ill they can't consent? The arguments over this question typically fall along a spectrum, with paternalism on one end and self-determination on the other.

Individuals making decisions on behalf of their future, mentally unwell selves sits in a gray area, experts say.

"When the illness you have impairs your ability to understand and make decisions in your own best interest, that gets ethically complicated," Swanson said. "It's clinically complicated as well."

Swanson first became interested in advanced planning for mental illness in the 1990s. Back then, he was studying the effectiveness of state laws across the U.S. that mandated outpatient treatment for certain mentally ill patients; in Washington, people can be court-ordered to inpatient or outpatient care. He realized that an advance directive written at a time when a person was competent was a potential alternative to compulsory care. "I was captured by the idea," he said.

According to Swanson, such directives are most effective for people who have periods of stability and are able to write down reasonable, evidence-based care requests. They serve as a kind of "psychiatric

resume"—a guide to what works well, and what doesn't, for individual patients.

What gets tricky, Swanson said, is when people end up resisting the care they previously signed off on.

Swanson recently encountered a woman with schizoaffective disorder who wrote on her mental health advance directive that she was willing to be hospitalized and that electroconvulsive therapy was the only treatment that worked when she was in crisis. But when she ultimately became ill and was hospitalized, he said, she "vociferously" objected to it—and to being hospitalized in general.

"The optics of it and maybe even the legal nature of it," Swanson said, "looks like forced treatment without the due process protections of a commitment hearing."

Legal limits

In Washington, people who fill out a mental health advance directive can list medications they prefer, and physicians or hospitals where they'd like to be treated.

They can also specify drugs or other forms of care they refuse or would only allow under certain circumstances. People can decline [electroconvulsive therapy](#), for instance, or name care they want medical staff to try before they use approaches of last resort, such as arm and leg restraints.

Once the form becomes part of a person's medical record, doctors are legally required to review it.

"It was a really, really well intended law," said Todd Crooks, who is

working on the state's new legislation and is executive director of the mental health advocacy organization Chad's Legacy Project. He's the father of Chad Crooks, the organization's namesake, who died by suicide at age 21.

What the law doesn't do is guarantee treatment.

Filling out a directive can't help someone skip long wait lists for therapy appointments or to secure a bed in a full hospital. It also can't compel health care providers to use unethical treatments or those outside acceptable standard practices.

And it doesn't supersede the involuntary treatment law, which allows the state to commit people to care if they threaten their own safety, that of others, or are so unwell that they've stopped caring for themselves entirely.

The law also wasn't set up with funding or technological support to make it useful, advocates say. Lawmakers didn't fund training for health care providers on when or how to use a mental health directive. There's no statewide repository for the forms. Families might hand them off to a provider or ask that they be included in an electronic health record. Boyd, for instance, is pushing to get her son's record included in a Bellingham emergency medical services database. But there's no standard system for storing these forms.

And perhaps most concerning: Existence of the forms isn't common knowledge.

Lack of awareness is a problem across states that have tried to strengthen the role of mental health directives, said Dr. Marvin Swartz, a psychiatrist and professor of psychiatry at Duke University Medical Center who runs the national mental health advance directive center with

Swanson. "If there's too few of them, then clinicians won't look for them. And health systems won't respond to them."

Crooks' son Chad didn't know about his right to a directive when he told his family he was hearing voices—one of his earliest symptoms of schizophrenia. In 2016, after two inpatient hospitalizations and trying and failing to maintain stability on medication, he took his life.

"All of this stuff that (Chad) was receiving as far as care was being done to him, but none of it was effective," Crooks said. Chad's care was "rudderless" and "reactive," Crooks said. "We lost our son because he lost hope ... Hope is a huge aspect of a well-utilized mental health advance directive because of that participatory element. That's really the crux of it."

Gaining steam

State lawmakers are now aiming for a legal fix.

This session, a bipartisan measure that cruised through the state Senate would help build awareness of people's right to a directive, and potentially help fill in gaps left by the original law.

The legislation would create a work group to study how to safely store and share individuals' directives with those who need access, like first responders or ER doctors. It would also develop ways to train families, peers and providers on how to use the forms. Crooks, who worked on the legislation, said the work group could help roll out pilot projects as soon as this year.

A similar bill died in committee last session; the state's Health Care Authority raised questions about it that weren't answered before a legislative cutoff date, said Crooks. "A lot more people are on board this

year," said state Sen. Matt Boehnke, R-Kennewick, co-sponsor of this year's bill, which is now under consideration in the House.

Some states have worked for years to scale up their own laws, and they offer a window into what Washington is up against. Virginia, for instance, funneled funding into a campaign to train health providers and peer recovery specialists and built an online, interactive map showing where people could get help filling out an advance directive.

The push helped grow awareness and interest, said Heather Zelle, who helped guide the implementation of Virginia's law and is an associate professor of research at the University of Virginia. But tech concerns—Virginia's first responder and care systems are disconnected, like Washington's—and attitudinal ones continue to keep many people from using the forms.

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