

It was Christmastime in the Valley – a harrying season for many people, but even harder for those marooned by the isolation of mental illness. The woman’s family had noticed disturbing behaviors and feared she may soon harm herself or even others.

They petitioned Maricopa County court to evaluate her through Arizona’s involuntary commitment process – a process much touted after accused Tucson shooter Jared Loughner, who many believe is schizophrenic, drew attention to the importance of treating mental illness before a crime is committed.

Authorities admitted the woman into the county psychiatric hospital, where she was stabilized for two weeks, diagnosed seriously mentally ill, court ordered to receive outpatient treatment, released, and then... the case was dismissed.

Because there was no treatment. Not in Arizona’s new mental health desert.

Shortly after her release, the woman had another episode, and her family faced the prospect of reinitiating a commitment process that was essentially a bridge to nowhere. What will happen to the woman? She may resort to the desperate methods of the teenage girl who repeatedly sought help but, unable to get into the Valley’s backlogged clinics in time, sliced her arms so she’d be rushed to an emergency room. Or she may end up like the man who’s become a regular at Phoenix’s Urgent Psychiatric Care Center (UPC), stuck in a so-called “revolving door,” spinning in and out of crisis, seemingly no way to step out into the light.

Faced with a \$1 billion-plus budget deficit, the state has slashed mental health care funding by more than \$60 million in the last few years. The most significant slices came in the past year, first with the suspension of *Arnold v. Sarn*, a decades-old lawsuit requiring the state to provide services to the seriously mentally ill (SMI), who currently number 42,000 and suffer from conditions such as schizophrenia, bipolar disorder and major depression.

That paved the way for service cuts that affected some 12,000 adults and 2,000 children. As of July 2010, SMI individuals who do not qualify for AHCCCS, Arizona’s Medicaid program, no longer receive therapy, case managers, housing, transportation or brand-name medication. Non-AHCCCS adults receive only crisis services, generic medication and doctor visits related to prescriptions. Children are given only crisis services.

Translation: They’ve taken the “mental” out of mental health care.

“The Arizona behavioral health system is a very well established system that’s been a national model for years and is now under attack from many different

fronts,” says Dr. Chris Carson, CEO of Connections AZ, which runs the UPC. “It’s in turmoil.”

But the dismemberment of Arizona’s mental health care system is no *One Flew over the Cuckoo’s Nest* story, with the state playing Nurse Ratched’s icicle-hearted overlord, severing patients’ lifelines with a distant signature and a deft scalpel. Rather, the state is more like canyoneer Aron Ralston in *127 Hours*, who, trapped under a boulder, takes time to examine the alternatives, feels he has no choice, and then deliberately and consciously cuts off an arm.

Except, in this case, there may have been other choices. In this case, the choice will likely come back to haunt us. And in this case, an even bigger rock is about to fall.

His name was John Goss, and he was one of “those people” – the ones shuffling along the streets every day, the ones we give a wide berth. Nights, he probably slept under a bridge, or if he was lucky, in one of Downtown Phoenix’s “schlock supervisory care homes that comprised what I then called a mental health ghetto,” says mental health lawyer Charles “Chick” Arnold.

It was 1981, in the wake of the deinstitutionalization of the ’60s and ’70s, when states unshackled their electro-shock therapy patients and took a wrecking ball to insane asylums, releasing the mentally ill into a new vision of recovery-focused community treatment programs.

Arizona was a bellwether in that vision, becoming the first state – and remaining the only state, Arnold says – to enact a statute mandating the creation of a full range of community-based services and residences for anyone with a serious mental illness, regardless of financial or other qualification. Arizona also became the first state to create an office of a public guardian who would connect the mentally ill with those services. Arnold became the guardian of 600 people in Maricopa County, one of whom was John Goss.

Goss was a smart man who had read the statute, and he came to Arnold’s office daily, complaining that the reason he was aimlessly ambling the streets was that these community mental health services didn’t actually exist. So Arnold filed a class action lawsuit, *Arnold v. Sarn*, and with characteristic governmental swiftness, 10 years later the Arizona Supreme Court had decided the state was indeed violating its statute, and the plaintiffs and Arizona Department of Health Services (ADHS) had agreed upon a blueprint to do something about it.

That blueprint gave rise to Arizona’s unique and multilayered mental health care system: The health department contracts with a handful of for-profit and nonprofit Regional Behavioral Health Authorities (RBHAs), which in turn

contract with several Provider Network Organizations (PNOs) to run community clinics. The system included a range of subsidized group and individual residences, case managers and a court monitor who served as a watchdog for the system and an ombudsman for the mentally ill.

But the lawsuit remained open, because the court monitor's audits continually gave the system "dreadful" reviews, Arnold says. The state complained that the audits' questions weren't indicative of patient recovery, and that adhering to all the mandates would cost hundreds of millions of dollars.

Still, thanks to the statute and lawsuit, Arizona had built a mental health system with robust laws, a smorgasbord of services and numerous dedicated advocates, including a woman in government who continually championed for the seriously mentally ill, because her son is one of them.

Ronald Brewer has schizophrenia and has lived in Arizona's state mental hospital for the past two decades, after being found not guilty of sexual assault and kidnapping by reason of insanity. For much of that time, his mother, Jan Brewer, fought to maintain state funding for mental health care.

"There were conversations back in 2008, 2009 to the director of the health department [where Brewer said], 'If I tell you to cut X million dollars, where are you gonna get it from, and you can't take it from behavioral health,'" says Laura Nelson, deputy director of the Division of Behavioral Health Services at ADHS. "She said that about as long as she could say it."

Then in January 2010, Republican Governor Jan Brewer released her new budget, which included two shocking blows to behavioral health: \$36 million in cuts, and the repeal of the state statute.

The plaintiffs in *Arnold v. Sarn* tried to persuade Brewer to keep the state statute, Arnold says. They made a deal: Brewer would erase the repeal order from her budget if the plaintiffs would agree to suspend *Arnold v. Sarn* and dissolve the office of the court monitor until June 2012.

"I was livid," says Arnold, who had gone into private practice and was no longer directly involved in the lawsuit. He appealed to the new judge on the case, Karen O'Connor, telling her she had to hold a hearing. "The deal was made on a Thursday," he says. "The judge is told Thursday afternoon by Joe Kanefield, appointee for the governor, that she has to have a hearing Friday, the next day, because if you don't, the legislature is going to repeal the statute.... It's extortion. It's outrageous pressure."

Not surprisingly, no one came to the Friday hearing. O'Connor held another hearing the following Monday, "and 28 people showed up; 27 of them spoke against the deal," Arnold says. "Anyone who knew anything about this said, 'You can't do this. It's the only safety net.' The judge says, 'I'll take it under advisement.' Then she goes into her office and signs the deal."

With that, the state took its mental health care system's watchdog to the pound, and many insiders believe it will be permanently put to sleep. "This case is over," Arnold says. "It will never come back. The governor, who was seen as an advocate, has severely compromised the interests of the mental health community. And I don't see us coming back from that."

With Fido out of the way, the government could break its state statute and cut services to SMIs without fearing the lawsuit's bite.

The young man received a letter in May 2010 from Magellan, Maricopa County's RBHA, informing him that since he was not eligible for AHCCCS, he would no longer receive brand-name medication, case management, therapy or other non-medical services starting July 1. He was given information on community resources and resource fairs and told to contact his clinical team to help him create an individual plan for the transition.

But he was nervous. The brand-name medication he was taking was helping him and, like many new drugs, had no generic alternative. He knew that older, generic antipsychotics increase the risk of a permanent neurological disorder. He became so anxious he had to be hospitalized for two days. While there, representatives from Magellan and provider networks visited him, talking to him about his options and creating a plan. A few months later he was taking generics and doing well. At a grassroots mental health organization meeting, he commended the work of the providers, saying, "It was a horrible thing you guys had to do, but it was a very sensitive way you approached it."

"We do not come from a place where we just send someone a letter saying, 'It's been nice but unfortunately we can't do this anymore,'" says the health department's Nelson. "This whole process has been an incredibly individualized approach to each person."

Before the cuts, Nelson explains, the mentally ill got the same services whether they were on AHCCCS or not. So there was no incentive to apply for AHCCCS. Now, AHCCCS-covered people still get all the services (counseling, case managers, name-brand medication) that AHCCCS-eligible people lost. So health care workers converted thousands of eligible individuals to AHCCCS. This saved the state money because it moved people from a state-funded program to a largely federally funded Medicaid program. Richard Clarke, CEO of Magellan of

Arizona, explains how that was done: “On the adult side, there were 7,508 individuals [in Maricopa County] who were affected by the cut. We converted 1,690 of them to Title-XIX (AHCCCS) status doing a high-touch, high-relationship process – meet every person, assess their financial status, design individualized treatment for them.

“There were about 2,769 who had third-party insurance that were never being billed because the state was paying for it. So we got them connected with their third-party insurance. Then we had to transition everybody else to this new benefit structure, and we did it by going one person at a time. It took us six months. We made a commitment that we would not transition anybody till we felt we all had a competent transition plan.”

One of the biggest concerns was that because of the housing cut, thousands of SMIs would be booted onto the street. Not so, Clarke says, rattling the figures off the top of his head: “In Maricopa we have 21,000 individuals suffering the challenges of a serious mental illness. This [housing] cut only affected 231 people who were receiving the state subsidy. We found that 90 of them could be on Medicaid, so we converted them to Medicaid. Then we transitioned 79 into independent living. Forty-six went into assisted living because they actually needed a higher level of care. Eight were transitioned to live with their families, and we supported the families through that transition. Six are still receiving their housing from VA. We still have two individuals that almost a year later we haven’t been able to find a safe alternative for them, so we’re funding them.”

The loss of the other services was harder to compensate for. Case managers helped mentally ill people navigate the nerve-wracking health care system, supported them through crises, arranged psychiatrist appointments and often drove them to the doctor. With many case managers being laid off, state mental health providers and grassroots organizations held classes to train people’s family and friends to be de facto case managers.

Organizations at every level also set up hotlines and so-called “warm lines” that people could call to talk about their problems.

“Social isolation is one of the biggest concerns,” Nelson says. “When this service went away people reacted more strongly to the loss of their case manager than to the medication issue, so I think the warm line has helped with that.”

Meanwhile, some local peer-run mental health clinics, which are run by people who have suffered from a mental illness or substance abuse problem, stepped up to offer some free services to SMIs who no longer receive therapy.

One such organization is Phoenix's Visions of Hope. "I got a grant for anyone that's schizophrenic and non-Title XIX (non-AHCCCS)," says Visions' CEO, James Russo. "Presently we have 12 people that have been receiving services since July 1 [2010] up until the money runs out around May 30 [2011]... They can go through our recovery classes, receive medication, meals and any type of training they want at our facility." In addition, Visions offers a free get-together twice a month for anyone non-Title XIX. They get transportation, a meal and participate in a group activity.

But one of the most difficult cuts for SMIs was medication. "When people call into the hotline, that's their No. 1 complaint: 'I don't qualify for those medication assistance programs, and I have a choice between paying my rent or buying a medication that I know works for me,'" says Bill Kennard, executive director of the National Alliance on Mental Illness (NAMI) in Arizona.

With antipsychotic drugs, the difference between name-brand and generic is not like the difference between Advil and plain ibuprofen. It is usually the difference between the new generation of drugs, which do not yet have generic alternatives, and the older generation. Both generations can be equally effective (though this varies by person) and both come with the risk of severe side effects. But the older drugs significantly increase patients' risk of developing Parkinson's-like rigidity and tremors, and with long-term use, the majority of patients develop an often permanent, bizarre neurological disorder characterized by constant lip smacking, blinking and grimacing.

Patients who do not fare well on older-generation generics and can afford to pay for a name-brand were put on pharmaceutical companies' patient-assistance programs and given county-funded prescription discount cards. But even with a discount, name-brand medication can still cost around \$500 to \$800 a month. SMIs who can't afford that must make do with \$4-a-month generics that may or may not work for them.

"I think that what's really inspirational was the way the community bounded together to really make the best of a really bad set of circumstances," Kennard says. "Still, despite the innovative and exemplary actions of everybody... the fact of the matter is that it was an unconscionable act."

The man had a job, a place to live, and, thanks to new-generation antipsychotic medication, his symptoms were manageable. But then he had to switch to an older generic drug and was never the same again. His work performance suffered. He lost his job and couldn't pay rent. Now he's out on the street.

“It’s very, very scary for them to be out there with the lack of support,” says Sue Jantzen, manager of clinical services at Banner Behavioral Hospital in Scottsdale, where the man sought help.

She says the hospital does everything it can, employing a specialist dedicated to helping people get on AHCCCS and referring patients to an array of charitable organizations providing free or sliding-scale-priced counseling, such as churches, the Fresh Start Women’s Resource Center, the University of Phoenix and Arizona State University. “But they’re very limited,” she says. “If you get someone who’s really severe in their mental health issues, we’re talking interns who are doing the counseling.”

Jantzen says the hospital tries to rally support from patients’ families, but oftentimes the family is made up of drug addicts and schizophrenics.

And for many mentally ill people, there is no family, not a single friend, and no place to call home but a cold, lonely sidewalk. Many people pinball between hospitals and homeless shelters. “We have patients say they’re panhandling to get the \$4 for their meds,” Jantzen says. “It’s heartbreaking.”

She says the elimination of state-provided transportation has become a huge issue for mentally ill people, many of whom cannot drive or afford vehicles and have trouble getting to doctor’s appointments and charitable resource centers.

Even people on AHCCCS must often wait weeks for doctor and counseling appointments because the budget cuts resulted in a consolidation of clinics, Jantzen says. People new to AHCCCS must often stay in hospitals or languish in homeless shelters while on the waiting list for subsidized housing.

In this desert of services, hospital emergency rooms and crisis centers are becoming oases of support, quenching the burning demands previously served by case managers and clinics. “Our EDs are inundated with psychiatric patients needing help,” Jantzen says, adding that patients are staying longer – up to three weeks – while hospital staff stabilize them or try to get them onto AHCCCS. That’s extremely pricey, and it’s all at the hospitals’ expense.

The budget cuts may have resulted in some cost-saving streamlining, but many of these measures are not cost-savers but cost-shifters. Brewer’s budget even stated that the cuts would likely result in uncompensated care, and it’s easy enough to eliminate something you can’t afford if you know someone else who can’t afford it will shoulder it anyway.

“We’re very compassionate about our care here,” Jantzen says. “If that patient needs to be here while we’re trying to get as much services for that patient as we can, we’re going to do that.”

“We will to the dying breath keep the doors open to people who need care,” says Dr. Chris Carson of the UPC, the largest of the Valley’s three psychiatric crisis centers. This small Downtown building is where anyone can come, 24/7, regardless of insurance or AHCCCS status, whether you just need to see a psychiatrist to get a Prozac prescription or you’re dragged here in shackles by the police.

But Carson is worried. In January 2009, the UPC saw 1,224 people. In January 2011, 1,850. That’s a 50 percent increase with the same amount of staff, barely any more funding and only 15 beds onsite and 40 offsite at St. Luke’s Hospital.

The UPC has increased its efficiency, reducing average wait time from five to two hours, but psychiatrists are still seeing patients in the lobby. Staff help the mentally ill get on AHCCCS and connect with community resources, but Carson says they discharge people to homeless shelters and inadequate plans every day, because there are simply not enough services available.

“We can do a really good job here,” Carson says. “But if we discharge that person into nothing, no services, then the likelihood of them continuing to deteriorate or relapsing with alcohol or methamphetamine, or quit taking their medicine because they can’t afford it, then all the stabilization work and discharge planning we do is for naught.”

Hospitals and crisis centers are already being crushed under a three-ton boulder: decreased funding, decreased statewide services and increasing patients. Now, a rockslide is heading their way.

Brewer’s newest budget proposal could slash AHCCCS eligibility for up to 280,000 childless adults, including about 5,200 SMIs and thousands more with general mental illnesses. That would undo all the work people have done to get the mentally ill onto the safety net of AHCCCS.

The health department has determined that 80 percent of those SMIs cut might be able to qualify for AHCCCS under a different, more paperwork-heavy category. But Brewer also wants to shrink AHCCCS by changing eligibility requirements from 100 percent of the poverty level (\$22,350 for a family of four) to 33 percent of the poverty level (\$7,375 for a family of four). And another bill on the table to eliminate AHCCCS could effectively obliterate the mental health care system.



“That’s going to change the world,” Carson says. “We simply could not handle that, because that would also be accompanied by a cut in our reimbursements. I can’t even imagine. I just dread that.”

Already many people have suggested the government is going about the cuts the wrong way, basing them on financial need (both the individual’s and the government’s) rather than clinical need.

“SMI people, theoretically the most vulnerable, the least able to take care of themselves, we’re cutting them off,” Carson says. “Then you have some guy who’s Title XIX, and he just has depression. He can get a case manager, but the other guy who’s been at the state hospital for three years can’t? Would it have been better to say everybody can theoretically access [benefits], but there are prior authorization criteria, meaning you have to be schizophrenic to access it, but [not] if you’re just depressed?”

“I believe you can get as much mileage in a more strategic way than has always been used so far,” he says.

Meanwhile, all these cuts, these short-term fixes, create cracks in our community. The mentally ill are the first to fall through, but in time, the fissures and weak points create “an unstable society,” Jantzen says. “If people fall through the cracks, where are they? That’s going to have a great impact on all of us, and the question is, how does this help any of us?”

“As we go through these changes, it takes brave leadership that can look at these things from the person’s perspective,” Carson says. “At this point, we’re down to flesh and bone, and we’re going to have to be way more thoughtful about how these cuts are made. You can’t just cut off an arm.”