

‘Can you help me get out of here?’ — Utah sued over ‘inadequate’ system of care for developmentally disabled adults

Disability Law Center says hundreds of adults are unnecessarily kept in rigid, overcrowded private care facilities instead of in community-based programs.

Link: <https://www.sltrib.com/news/2018/01/13/can-you-help-me-get-out-of-here-utah-sued-over-inadequate-system-of-care-for-developmentally-disabled-adults/>

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By [Luke Ramseth](#)
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Four years ago, attorneys with Utah’s Disability Law Center began noticing several worrisome trends when visiting care facilities for the state’s intellectually disabled.

The places throughout Utah, they said, were packed. They lacked privacy, with several people to a bedroom and many sharing the same bathroom. Residents said they were tired of the rigorous structure of life in the facilities, which often deprived them of pursuing personal goals. Many wanted desperately to leave, but — under the state’s system for delivering care services — they could not, said Nate Crippes, a Disability Law Center attorney.

Again and again, attorneys heard the same question from facility residents: “Can you help me get out of here?”

On Friday, the Salt Lake City-based legal organization sued the state in federal court, saying health officials — who oversee the private care facilities — have needlessly segregated those with intellectual disabilities in the institutions, where they are sometimes trapped for years or even decades.

Plaintiffs in the lawsuit, filed in U.S. District Court in Salt Lake City, include Staci Christensen, who has Down syndrome, and John Weakly, who has cerebral palsy. Both say they would prefer to live in a community setting but have instead been forced to remain institutionalized.

The lawsuit says Utah has violated federal laws, including the Americans with Disabilities Act, which says states must provide the option of support services in a community-based setting, rather than an institutional facility. In addition, the suit says, when these people are placed in privately run care centers, the state “does not provide an effective mechanism for leaving,” which means, in many cases, “residents will remain in this life, segregated indefinitely.”

The Disability Law Center demands that the state build a new plan that identifies and transitions more intellectually disabled people to community-based services, and that reduces Utah’s reliance on institutional care.

[Disability Law Center lawsuit](#) by [The Salt Lake Tribune](#) on Scribd

A spokesman for the Utah attorney general’s office declined to comment, citing a policy on pending litigation.

The Utah Department of Health said through a spokesman that it could not comment directly on the litigation, but that it was working to improve the program. Officials with the Department of Human Services, also named as a defendant, did not respond to a request for comment Friday afternoon.

Christensen, Weakly and many others like them, according to the lawsuit, “yearn to receive services from the State of Utah that will free them from an institution that lacks privacy, fails to support fulfilling connections to their communities, and subjects them to a life of segregation.”

How Utah’s system works

The Utah Department of Health oversees and licenses these so-called intermediate care facilities, which receive Medicaid funding for their

residents. Meanwhile, the state's Division of Services for People with Disabilities, which is part of the Department of Human Services, operates a parallel community-based service program for intellectually disabled people.

The community-based program has a waitlist for people wanting to receive these services, which can include housing and employment assistance, transportation and home-based care. The suit says residents already living in the care facilities, however, are a low priority when they try to transition to the community services, with "virtually no chance of getting off that list." The average time spent on the waiting list is more than six years, attorneys said.

The most realistic option, then, for those wanting to leave a care facility is a program called Transition, which is also operated by the Division of Services for People with Disabilities. But that program also does not function effectively for facility residents, the lawsuit says, operating in an "arbitrary manner that does not guarantee funding in any given year" and by often not offering residents adequate information on its existence.

"The program functions primarily as a lottery, selecting individuals using an arbitrary mechanism whereby individuals are chosen for community placement by sheer chance," the lawsuit states. "State officials have likened to the program as akin to gambling in Las Vegas." In the Transition program, court documents say, an average of eight people made it out of a care facility and into the community-based program each year between 2006 and 2015.

Across the state, there are about 600 people living in 18 facilities, most privately operated, according to the lawsuit. Many sites have at least 16 beds and are "large, crowded facilities, lacking privacy and any semblance of a home," according to the Disability Law Center. State health officials acknowledged in 2015 that the facilities "must maintain a high bed occupancy rate" to make a profit, the lawsuit notes.

Plaintiffs Christensen, 29, and Weakly, 36, have extensive experience living in these places. Christensen, according to court documents, found

a part-time job at a restaurant, and she would like to live closer to her grandmother but is forced to spend the majority of her time at the care facility. She finds it “uncomfortable and upsetting” and has tried to move out to get community-based services but can’t.

Weakly, meanwhile, shares a bedroom at his care facility with three other people. The room is small and makes it difficult to maneuver his power wheelchair, according to the lawsuit. He seeks more independence and would like a romantic relationship, but he reports that the staff won’t allow one.

He has resided in a care facility for 14 years, despite a “strong desire to live in a community-based setting.”

Similar cases around the country

Attorneys with the Disability Law Center are basing their suit, in part, on a 1999 U.S. Supreme Court case, *Olmstead v. L.C.*, which focused on the plight of two Georgia women with developmental disabilities who were confined for years in a psychiatric unit despite their desire to leave.

The high court ruled that their unjustified segregation amounted to discrimination and violated the Americans with Disabilities Act. The ruling, now referred to in shorthand as “*Olmstead*,” also held that government agencies must provide community-based services to the developmentally disabled whenever possible — as opposed to keeping them inside other institutions for long periods.

Since the Supreme Court ruling was handed down, many states have made significant changes to their programs for the intellectually disabled, sometimes forced by legal action. States have rolled back their reliance on large private facilities and boosted funding for community-based services, Crippes and other attorneys say.

But not Utah, they allege. In fact, the suit says Utah has bucked those national trends, instead “increasing its reliance on institution care.” For example, the complaint says the state’s Medicaid program has

approved at least four more private facilities, for a total of 71 more beds, over the past five years.

In its statement, the Utah Department of Health said it was “engaged in an ongoing process to use funding appropriated by the state Legislature to transition individuals to community settings,” adding that Gov. Gary Herbert’s latest proposed budget includes more funding for the transition program.

“We have communicated with the Disability Law Center over the past year on this issue, and have included them in our stakeholder workgroup that is addressing the transition program,” the Health Department statement said.

The Disability Law Center “has spent years investigating this case, devoting countless hours to working with the institutionalized population,” Executive Director Adina Zahradnikova said in a statement. “We have seen the harm, up close and personal, being done to these individuals,” Zahradnikova added. “We do not take this step lightly, but we believe it is incumbent on the state to remedy their failures and develop a working plan toward de-institutionalization.”

The American Civil Liberties Union of Utah said Friday that it backed the Disability Law Center’s efforts. “The state of Utah cannot isolate, institutionalize, and stigmatize these individuals just because of a disability,” Leah Farrell, staff attorney at the ACLU’s Utah office, said in a statement.

Christensen said she hopes to soon leave her care facility — where she has spent nine years of her life — for good.

“I would like a chance to live out on my own whether it is housing or an apartment — more control over my freedom,” Christensen said in a statement.

“I wanted that for a really long time,” she added. “It would be a dream come true.”