The Colorado Health Foundation™

Long-Term Supports May Start Young, But Needs are the Same for All

A Q&A with engineer and activist Joshua Winkler

Editor's Note: *Colorado has a deep history of disability activists encouraging – and sometimes forcing – change in state and federal policy to better serve the long-term services and supports needs of state residents. Joshua Winkler is a longtime activist who now sits on numerous government advisory panels and community boards, including the Community First Choice Development and Implementation Council, which is advising the state Department of Health Care Policy & Financing as it considers launching a CFC program for Colorado. He also is on the board of The Arc of Colorado, the Colorado Cross-Disability Coalition and other activist groups. Winkler, a mechanical engineer who works in adaptive technology, overcame a childhood disability only to suffer a spinal cord injury in his teens. We met recently in Winkler's high-tech garage workshop to speak about where Colorado's disabled services need to go next.*

It sounds like you had the mentality from the beginning of your injury to do whatever you needed to do to get back to what you wanted, which was working with your hands.

I'm 34 this year; I was hurt when I was 17. When I broke my neck, it was something new, but life deals you these things and you move on. I was hurt in Pennsylvania and did my rehabilitation at Craig Hospital. I was thinking, I'm going to need a degree; I'm going to need a piece of paper to get a decent-paying job. Originally I had the thought, if I'm ever going to get off Medicaid, I have to have enough money to pay for my services – roughly $30,000 to $40,000 a year in out-of-pocket expense even with a good insurance policy. That's the home health

aide that private insurance doesn't pay for. I came out with a degree in engineering in 2005. I'd wanted to work for NASCAR because motocross was my thing before I got hurt. I got lucky and got involved with the Furniture Row racing team here in Denver – an internship and then got a full-time job. Then the economy dropped, and furniture sales and advertising also dropped, so they had to cut back on the team.

Colorado didn't have a Medicaid buy-in program. I started looking for states that did. California did. I wanted to work; maybe I needed to move. Well-educated, 29, I wanted to work and run my own company. I stumbled on the fact that Colorado was actually working on a Medicaid buy-in, though it took three years of meetings to do it. I contacted (the Department of Health Care Policy & Financing); they said they were working on it. What I wanted was consumer direction, because then you can get the home health aides you can hire yourself and get to show up at your house at 6 in the morning so you can get to work by 7 or 8. That was 2012.

Where do you think Colorado, in general, sat at that time in terms of its policies for long-term services and supports?

Our LTSS were probably in the top three or four in the country at that point. We had a pretty solid home health system here. Rural areas are decently covered; we have full consumer direction under Consumer-Directed Attendant Support Services. Those pilots started in 2005 for people under the Elderly, Blind, and Disabled Waiver, and it's been extended to other waivers.

When the activist community started pushing the state hard in about 2012 to formalize its long-term services plan and respond to Olmstead Decision mandates, at that moment where would you say Colorado's services were in

comparison to others? You said we were maybe among the three or four best states in the nation. Can you elaborate on what we were doing well at that time and what still needed to be done?

Colorado is the Medicaid waiver king. At our peak I believe we had 13, and from 1981 when they were authorized under Reagan until the Affordable Care Act, they offered the best way to provide LTSS to the various populations who needed them. The downside to the waivers is that the targeting criteria force segregation of services based on diagnosis. This has left individuals with developmental disabilities wanting services folks with physical disabilities get, and folks with physical disabilities wanting services only brain injuries get, etc. One well-known example is access to consumer-directed service delivery through In-Home Support Services and Consumer-Directed Attendant Support Services, which are great for the folks who have access to them and are desperately needed by many of the people on the IDD waivers.

What exactly was pushing the activist community at that time to take over meetings and be more vocal in its demands from the state agencies?

Complacency. Several state agency directors were happy to be one of the best states at providing LTSS, but advocates knew we could still do better.

In general, has Colorado been successful in emphasizing home- and community-based services over institutional care? You had mentioned some states were one-third/two-thirds on that split of spending, and Colorado was the opposite.

Absolutely. And this goes back to the birth of the independent living movement and the birth of ADAPT in Denver. (Editor's note: *ADAPT has been a prominent and widely effective advocate of independent living for people with disabilities.*

While Colorado is moving forward on waivers and reformulating its programs to better meet community needs, there is one larger need you have mentioned.

The current rental market has created a big challenge: The housing vouchers all have a cap on what the apartment market rate is, and currently, apartments are renting for 150 percent or more of the market rate. We need more affordable, integrated, accessible apartments to be built, and that will require incentivizing builders in some manner. Until the Democrats in the Legislature back off on construction defects liabilities for condo developers, the Republicans are refusing to pass any low-income rental incentives, so we are at a stalemate until the housing market in Colorado crashes again. Colorado was recently awarded funding for 411 units under Section 811 rules (federal money specifically for housing for the disabled); these aren't as good as Section 8 (federal vouchers allowing more freedom in choosing units), but are better than nothing, if the state can get builders to take the money to create the units.

What is Community First Choice and why could it be helpful to users of long-term services who want to direct more of their own needs?

Community First Choice is an optional Medicaid program authorized under the ACA. CFC would move services that assist with activities of daily living and instrumental activities of daily living from waivers to the state Medicaid plan. In order to be eligible for these services, clients would still be required to meet level of care requirements. One example of a “pro” in CFC is that it opens up the delivery model to allow for the clients’ needs and gives them more ability to direct

services. The clients receive services outside of their homes – if you need an attendant to help while you are at work or at school, at the park – so that you can continue to go to all of those places. It's a big step to simplifying the waivers.

What's the barrier to the state in joining the optional CFC? Too high a bill for the Legislature?

The biggest barrier is the projected cost to the state general fund. CFC services would receive an enhanced 6 percent match from the federal government, but early cost projections indicated it would still cost Colorado more money as services are expected to be utilized at a higher level under CFC due to the availability across disability types. The CFC Development and Implementation Council is working with HCPF and contractors to ensure cost estimates are accurate and to find ways to reduce costs without gutting the services offered under CFC.

How have we done on the seemingly innovative Money Follows the Person? Can we meet those targets?

MFP is a great program, but delays in getting it rolling in Colorado combined with a tough housing market will likely cause us to miss the target of 500 people transitioned out of institutions in five years. Momentum has picked up, but we are barely over 100 in three years.

From an outsider's perspective, it might seem that the needs of a younger disabled person who wants to live alone would be very different from those of a 78-year-old person who may be on the verge of a nursing home decision. Are there common needs that make your

activism apply to everyone in Colorado?

Absolutely. Maslow's hierarchy of needs applies to all of us. People want to feel safe (housing and medical insurance), healthy (medical insurance and good living environment), loved (access to community, friends, family, church, etc.), mobile (ambulatory, with wheelchair/scooter/walker/crutches and by car/taxi/bus/paratransit) and free to make their own decisions (which institutions take away). The biggest area where older and younger folks differ is on employment, and Colorado is making concerted efforts to improve employment opportunities for younger folks with disabilities. Nobody wants to be a burden on their parents, their children, or their friends and extended family.

Disruptive technologies like Uber would seem to offer potential for many disabled people – both as a rider and as a potential driver – for earning income. Can you talk about Uber and Lyft from both a rider's and a potential driver's perspective?

Unfortunately tech startups have a history of ignoring or directly discriminating against people with disabilities. In recent years, Google and Apple have instead seen the disability market as a huge customer base and put effort into meeting our unique needs. Uber and Lyft have done everything they can to get around the laws that govern public transit, including laws that prohibit discrimination. Many media outlets have covered it. Wheelchair-modified vehicles are extremely expensive – around $50,000 – so it is a difficult issue to solve. The idea of folks like myself who already have adapted vans becoming Uber drivers often comes up. But my inability to strap down a passenger's wheelchair would make it unsafe, and Uber's "our drivers are independent contractors" stance would open me up for personal liability.

As the baby boomer population ages and more young disabled people are living longer and healthier lives, will we face a shortage of workers who can help make LTSS better? You have mentioned the need to loosen rules on whether a nurse, for example, is required to do a certain assistance job when someone with other training might do as well.

The Nurse Practice Act and Nurse Aide Practice Act both are important in acute care settings and in long-term care facilities. But for most of us receiving LTSS in the community, it is more important that our attendants are trained to perform specific tasks the way we want them done rather than being able to pass a test about how a book says things should be done. Much of the LTSS work done is not medical in nature, but rather daily activity assistance we as clients are unable to do ourselves. Getting attendants who listen, are trustworthy and who will stick around as employees for years is very important. These folks know every detail of our lives.

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