

Thursday, March 29, 2012

Penny wise

Lack of funds and common-sense oversight hinders aid to those with disabilities

By Hadley Vandiver



Even at midday, the mobile home of Edward Celas is dark. The blinds are drawn and the only source of light is a small lamp in the corner. But Celas does not mind the darkness. He is legally blind.

Since losing his eyesight, becoming asthmatic and contracting chronic obstructive pulmonary disorder, Celas' life has been a constant battle to survive. He has lived in seedy motels surrounded by drug dealers and shootings. His life savings were stolen from his bank account after he failed to realize his checkbooks were missing. Celas lost his left index finger when two men, one wielding a knife, entered his apartment, attacked him and stole the money from his recently cashed disability check. He lay bleeding on the floor of his apartment for two days following the attack.

"There are a lot of people out there who want to take advantage of you because you're blind, because you have a disability," Celas says. "So you know, life is not that easy. I have to figure out different ways to handle everything, and deal with not much money. I can use all the help I can get."

Like almost 500,000 other people in the state of Colorado, Celas now lives independently with his disabilities. He is able to do so only with the help of local disability service providers.

Celas receives three meals a day from Meals on Wheels of East Boulder County. A nurse from Adult Care Management Inc. comes to his house once a week to organize his daily medications and help him clean. His groceries come from the food bank of Sister Carmen, a local community center that provides assistance to those in need of "a little extra help." Celas receives a Social Security disability check for \$1,017 every month, which he uses to pay rent at the Skylark Mobile Home Park, pay for his utility and phone bills and buy any medications not covered by Medicaid. A woman from the American Council for the Blind, whom Celas refers to only as "an angel," helped him find his current home and leave the dangerous conditions he was in before.

Local disability service providers work to give people like Celas the help they need. However, they are often limited by a lack of funding and a tangled bureaucratic system, which some critics say wastes more money than it saves. When these organizations must cut programs due to budget cuts or inefficient use of funds, it is their disabled clients who suffer most.

"Unfortunately, the way the system maintains systemic oppression, and I mean the system, not the people, is by dividing us into competing interests so we're all fighting over funds," says Ian Engle, executive director of the Center for People with Disabilities (CPWD) in Boulder. "We end up with senior services competing with people with disabilities, like ourselves. Or we end up competing for dollars with folks who are looking for education funding for kids, and that's just bogus."

Though disability service providers have long fought the funding battle, conditions worsened after the economic downturn. Still, funding is not the only problem, or even the biggest problem.

A bureaucratic system overseen by too many people with little understanding of the situations often holds disability service providers back from effectively helping their clients, Engle says. At the state level, the Department of Health Care Policy and Finance, the Division of Housing, the Division of Vocational Rehabilitation and the Department of Health and Human Services all have a hand in governing some aspect of disability services. Furthermore, at the federal level, the Centers for Medicare and Medicaid (CMS) and the U.S. Social Security Administration also make decisions that affect the disabled and their providers.

Because many clients are receiving help from all these different levels, including locally, coordinating their services becomes a huge problem, Engle says. When changes occur at any level of clients' help, all aspects of their aid might be affected.

"It gets really ugly," Engle says. "For instance, recently the federal government, the Social Security Administration, gave everybody an increase in their disability checks. So on the one hand you get this increase from the feds, but then as soon as you get this increase in your income, your state

food assistance gets dropped, so you have to pay more for food. Not only that, but your housing assistance gets dropped. So you might have gotten a \$40 increase on your monthly check, but overall, you took a \$60 hit.”

This bureaucracy also leads to a tendency in the U.S. toward institutionalization rather than independent living. The bias comes mostly with Medicaid, which is a joint federal and state program, and has two main components: institutions, such as nursing homes, and home health.

“When the state cuts programs, the federal law doesn’t allow them to cut the institutional side,” says Tim Wheat, community organizer for CPWD. “But it does allow them to cut what they call ‘optional services,’ which is personal home health care service. In the last budgets, it is only home health that has experienced cuts. We took a 6 percent cut this year.”

CMS openly acknowledges this institutional bias in its long-term care services, even commissioning the National Balancing Indicator Project in 2004 to analyze whether states were doing enough to combat it. This institutional bias presents a large problem because it leads to people being placed in nursing homes unnecessarily, and ultimately costs the state and the federal government a great deal more money.

Though at the national level efforts have been made to reduce the institutional bias, the problem has not gone away.

Mike Tennant is currently struggling with this institutional bias. He has lived in the Mesa Vista nursing home in Boulder for 21 months, but is ready to move out, and has been since last October.

Unfortunately, at around the same time that Tennant was ready to leave Mesa Vista, the Supportive Housing Program (SHP) of the Colorado Department of Local Affairs froze turnover vouchers in the Housing Choice Voucher Program. These vouchers previously helped people with disabilities transition back into the community from nursing homes or other institutions. The turnover vouchers come into play when a person using a voucher moves, dies or for some reason no longer needs their voucher. The leftover voucher money is then given to another person who is waiting for money.

The turnover voucher program was removed so the department could save money and remain within its budget, Wheat says. However, dropping the vouchers will likely end up costing the state more in the long run, especially in cases like Tennant’s.

Tennant suffers from diabetes, and must regulate his blood sugar at least five times a day. At Mesa Vista, the nurses give Tennant his insulin shots and check his blood sugar. Though Tennant admits that he does need a little extra help, he does not need the 24-hour care of the nursing home.

“Right now I’ve got my diabetes under control,” Tennant says. “I don’t need to be in the nursing home. I can do it on my own. I did it once before, I can do it again. I’d rather be out there working, instead of just sitting in here watching TV.”

Tennant carries a blue binder stuffed full of “homework” that Wheat gives him in preparation for leaving the nursing home. Tennant has a meticulously planned budget that includes food, transportation and other general living costs.

He knows how much he will make if he goes back to his job at the Diamond Shamrock convenience store, and how much he will receive from Social Security. He has looked into apartments that he can afford, and has been trained to administer his own insulin.

When the freeze on the turnover vouchers began in October, Tennant and Wheat were hopeful that the freeze would be over in a month. Soon, that turned into two months, then three months, then six months. Then Wheat received an email from the SHP confirming that the vouchers would not be reinstated at all.

“Mike may be in the nursing home indefinitely,” Wheat says.

Another disability service provider in Boulder, Imagine!, must often adapt to these same bureaucratic nightmares and cuts in funding. Imagine! is a community-centered board, meaning that it serves as Boulder’s single entry point into local, state and federally funded programs for people with disabilities. Imagine! also provides its own services for the developmentally, cognitively or physically disabled.

Recently, all Imagine! programs funded by Medicaid were cut by 4.5 percent, while at the same time, the costs of running the programs went up by the same amount, says Mark Emery, executive director of Imagine! Two years ago, the Family Support Service Program (FSSP) of Imagine! also had its budget cut by two-thirds. Since then, the amount of services for people with disabilities that Imagine! is able to provide in the area has dropped dramatically.

“The thing is, Imagine! is not the most affected by this,” Emery says. “The people with disabilities who are living with their families are the most affected by this. These budget cuts happen, and at the same time, their need grows. People with disabilities are living with their parents for a lot longer period of time. The parents are getting older and they need more support, but instead they’re getting less.”

The FSSP provides grant money to families that are the main caretakers for their disabled children. When their funds are cut, the FSSP must decide whether they will decrease the amount of money given in each grant while maintaining the same number of grants, or reduce the number of grants but maintain the amount of money each grant is worth.

For families with two working parents or low incomes, the situation quickly becomes desperate when their grant money is cut or removed altogether, says Heather Forsyth, a member of the FSSP. The grants that Imagine! and the FSSP provide help families pay for the costs of caring for their family member with a developmental disability. This can include “respite care so that the families can get just a little break, medical costs, professional services, transportation and making the home a safer environment, among some other things,” Forsyth says.

Because of their recent funding cuts, the FSSP has decided to shift its support to focus more on young adults attempting to transition from a school environment to living in the community on their own, Forsyth says. Medicaid has programs in place to ease such transitions, which are one part of the larger Home and Community Based Services (HCBS) waiver programs. The waitlists for these waiver programs, however, are obscenely long.

The totals for the number of people on each of the different waitlists were provided at a Joint Budget Committee hearing for the Colorado Department of Human Services in December 2010. At the time, the HCBS Comprehensive Services list had 5,929 people. The HCBS Supported Living Services waitlist had 3,673, while the HCBS Children’s Extensive Support list had 298, and the HCBS Family Support Services waitlist had 4,907 people.

“You can place a child on the waitlist for adult waivers when they are 14,” says Forsyth. “My daughter has been on the waitlist since then, and she was eligible to get one of those waivers when she turned 18. But honestly, I am not anticipating that she will get a waiver for another 10 years or more, and that’s if there is still funding around. You never know how the system can change. So it’s a pretty huge burden.”

Funding cuts and daunting waitlists barely graze the surface of the mountain of difficulties that disability service providers face.

“There is more at work here than the economy,” Emery says. “If all we had to deal with was the economic downturn, I’d be thrilled. But we had to deal with that plus some decisions by the Department of Human Services that really impacted us as well.”

The decisions to which Emery refers were made in 2004, and determined that the Colorado Department of Health Care Policy and Finance would become the authority for issues related to providing services for the developmentally disabled. Since then, the way that the services are funded and delivered has changed greatly, says Fred Hobbs, director of public relations for Imagine!

Disability services are now paid for and defined through a fee-for-service model and a “deficit-based approach,” Hobbs says. This means that the services the client needs are paid for after they have been administered, and the services focus narrowly on one aspect of the client’s problems.

“Now, in a regular hospital, that’s fine,” Hobbs says. “I have insurance so if I break my arm, I go to the hospital, they fix my arm, the insurance pays for it, and it’s done. That makes sense. But in the world of disabilities, that doesn’t make sense. If you have a disability, you don’t go to the hospital, get some treatment and it goes away. That’s not how it works. So if you’re taking this deficit-based approach with these waivers, essentially you’re just putting money into an issue that can’t be solved. It’s just going down the drain.”

The system changed in order to ensure more accountability from the federal government for the appropriation of funds, Emery says. “These decisions were made without an understanding of our difficulties,” he says.

“Now, we’re stuck in a system that is completely unsustainable and can’t survive for much longer. We’re just costing ourselves more money. Something needs to change.”

Those who work for Imagine! and the CPWD have many ideas about how to fix the system. In reality, it is doubtful that disability services will have their funding increased by any significant amount in coming years, barring some miracle economic boom.

Therefore, they are looking for other ways to solve their problems and to better serve the clients. Engle advocates a Money Follows the Person approach, which would allow Medicaid funds to be used flexibly to address a client’s specific needs and preferences.

Though disability service providers may struggle to survive, their clients, like Celas, Tennant and Forsyth, would struggle even more if they were to disappear.

Back in Celas’ dark mobile home, the sound of the oxygen tank pushing air through a tube in his nose becomes the only sound as he contemplates how his life would be without the help of disability service providers.

“If any of these people that help me, if any of it got taken away, I wouldn’t be able to live here on my own anymore,” Celas says. “My life is hard, but I want to live on my own. Nursing homes, they’re like being subliminally in jail. I don’t want to be in there. I don’t want to be put in a home.”

Respond: letters@boulderweekly.com