My Turn: Capitalism isn't the answer; care for those with developmental disabilities at risk

By CATHY SPINNEY For the Monitor Thursday, August 15, 2013 (Published in print: Friday, August 16, 2013)

I appreciate the basic tenants of capitalism. I guess I am a capitalist since I own and operate a small business. I have employees, and I charge a fee for services that earn me my living. But I believe in some, very specific instances, it isn't the best model for getting things done.

Long-term care for people with developmental disabilities shouldn't be the means for other people getting rich. A nonprofit system, where the providers receive living wages and are rewarded for excellence – but where the fees charged aren't so exorbitant as to net excesses for distribution to "investors" – is a far superior model. My latest struggle with forprofit versus nonprofit systems is the unfolding of New Hampshire's planned move to commercial managed care for long-term Medicaid services.

"Managing" people's acute medical care has been proven to be efficient and effective, I'm told. I'll take their word for it. But the move toward using commercial (for-profit) managed care organizations to oversee (profit from) long-term care for people with developmental disabilities is fundamentally wrong, especially when they have no experience doing it.

People in New Hampshire who have disabilities have come a long way since the state institution closed in 1991. People with disabilities now live in real homes, in real neighborhoods, with real relationships, going to real schools and striving to have ordinary lives like all of us. People with disabilities vote, are employed, are loved and contribute to the greater society, volunteering and being politically active. They are actual citizens with actual rights who need some supports from the greater civil society to realize dreams and goals. Seems simple.

Why move the responsibility for administering those supports away from the independent, nonprofit New Hampshire companies with 30-plus years experience to out-of-state, for-profit

corporations with no experience with this type of service delivery system? That doesn't make sense.

Most adults with disabilities already live with their families, who provide the home, food and related expenses of daily life, as well as being there to directly support their loved ones with the gift of countless hours of their time. We are told moving to this for-profit system will save the state money. How? Show us the math.

All the supports families give are offered to the state for free – and are valued in the hundreds of millions of dollars. The nonprofit area agencies, the current providers of supports, are governed by volunteer boards of directors comprised of people with disabilities, their family members and concerned New Hampshire residents.

I sit on one of those boards. We squeeze every possible nickel out of allocated funding to provide supports to people. We are not frivolous, and we take our fiduciary responsibilities seriously. Agency staff is paid modestly and often go without raises due to tight budget constraints. But they stay because they are dedicated and believe in the agencies' various missions. The managed care organizations will take a large cut of available money right off the top to cover their larger overhead expenses, pay their CEOs millions of dollars and, of course, garnish their profits. They are not constrained by mission statements and value systems. They are guided by the goal of enriching their shareholders. That's appropriate for companies that make and sell products, but it is not appropriate for companies that are charged with helping real people live good and valued lives.

My daughter is 31 now. She has a developmental disability. She is not chronically ill. Her disability is her "normal." She is supported by one of the nonprofit area agencies. The earnest care my family receives allows me to work long hours, so I can continue providing a home for us and continue being an employer as well.

The people who work at the area agency are extensions of our family. I can call them anytime. I have their cell phone numbers, I know where they live. I know if we need them, they will show up — even in the middle of the night or on the weekend. None of the CEOs of the three managed care organizations, to whom responsibility for my daughter's future is set to be given, will offer me their cell phone numbers. None of them will show up if needed. They will see my daughter as "Client No. X" whose supports will be designed around a model of "medical necessity" and "outcomes for dollars spent." The area agency that is there for us sees her as "Kelly" and provides supports around a model of helping her access her "life, liberty and pursuit of happiness."

Which model would you want for your loved ones?

Our governor, senators and representatives, our executive councilors and our commissioner need to see the folly in this move and do whatever it takes to allow the family-governed, family-built area agency system to retain control of the funding stream for long-term supports for people with disabilities, and continue to do what evidence has shown they do best. New Hampshire is ranked second in the country by United Cerebral Palsy for our developmental service system and in the lower third for dollars spent. I ask my fellow citizens to insist New Hampshire not give away our resources to enrich out of state

companies and investors when the funds are best administered locally for their intended purpose.

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