

I am a 46-year-old female, severely disabled with motor neuron disease, dysautonomia, colonic inertia, gastroparesis, cerebellum atrophy and several other disorders. Other than two hours a day, I am bedbound. I leave my house for doctor appointments and hospital admissions.

I have had 3 surgeries for neurogenic bladder and have a neuro stimulator placed in my lower back. I have a port in my chest where I receive hydration twice a week in my home. I am on a special liquid diet. My body is unable to process solids. I have lost eighty pounds and am trying to postpone the use of a feeding tube.

My husband and I divorced about 4 years ago. At that time, my sister and her husband started helping me. I was not having the severe health issues I have now. I could leave my house. I could enjoy life.

However, things have changed.

My sister found that she could be my Independent Provider and care for me and allow me to stay at home. I live on the first floor with her above me in another apartment. It makes caring for me more personal and allows me to stay in my home. Otherwise, I would need 24 hour care in a nursing facility.

If Independent Providers are phased out or we are forced to go to self direct. I will lose my home, as she will need to seek employment elsewhere. Agencies are out of the question as a regular agency will pay a fraction of what my Independent Provider makes and the quality of those who work within agencies is far inferior to her care.

The self direct plan is out of the question for me as I do not want to be an employer, it's too confusing, it's too much work for me, I physically mentally and emotionally cannot handle it, and I do not want the turnaround of agency people in my home.

I feel like I have been given a sentence of doom. If independent providers are taken away and again I stress Or I am given the only choice of self direct i can't. I don't want to go to a nursing home and if self direct is put into action I will also lose my provider as it would be a large decrease in pay and she could not handle that and provide for her family, so yet again I will still lose my provider and a place to live.

I need around-the-clock care for my bladder and colon issues. I never know when I'm going to need to use the restroom or other assistance. Therefore, I am unable to use a regular agency that will only come and help me for a few specified hours a day. That kind of care will not work for me. At the age of 46, I do not want to have to live in a nursing home. Would living in a nursing facility with many people several decades older and not in the least restrictive environment at 46 be anyone's choice?

I was informed that agency workers cannot transport you out of your home, so how would I even get to my doctor appointments, I have no friends or family that could take me, there's another problem with the plan! Who will take me [at midnight](#) when I need to go to the hospital and sit with me all night, an agency workers certainly isn't going to do that, and I have no one besides my independent provider that can do this for me. So essentially this would stop my access to health care. As getting me anywhere is a time-consuming job as I have to also take a very large portable lift with me so I can transfer back-and-forth to tables at the doctors office and to use the restroom so that has to be pushed around as well as me in a wheelchair. So using public transportation for the disabled is also out of the question because I have no one to take me there anyway.

My sister has been my Independent Provider for approximately 10 years. I realize that many do not have the opportunity to be cared for by a family member but they do have a say in the person that has that responsibility. With an Independent Provider, individuals have the final say as to who cares for them. I'm going to lose a caregiver that is invested in me and have one or more care givers sent by an agency. I may have a say in who attends to me but the turnover and interim caretakers through an agency would be a detriment to my overall health. The alternative would be ending up in a nursing home for the rest of my life!

My parents are older and struggle with ailments of their own. They are unable to care for me. I trust and rely on my sister for the constant care I need. I also know other people with disabilities that have had to rely on an agency. They find that the care is so much less professional as the pay is equal to a position at a local fast-food chain. Although it is not the only factor in the care of individuals, pay is a consideration in the quality of the care provider. I live on SSI and Medicaid. I, along with many others, do not have the luxury of hiring private care in case of illness.

I am not speaking for just myself. I am speaking for many others that are unable to speak for themselves. If you take away our Independent Providers you are, in essence, taking away the freedoms allotted us through the U.S. Supreme Court Olmsted ruling, also forcing people the only option of agency or self direct is control. That is no choice. The state needs to stand up for it's most vulnerable. The physically and mentally disabled. Not pick on them.

Where would all of the individuals that are displaced by this new bill go? There are already two residential center facilities being closed in Ohio. One in Montgomery county and the other in Mahoning county. There will be a multitude of individuals that will be pulled from their homes. Is there enough proper housing to meet the individual needs like Independent Providers currently do? What would that housing look like? How would they be staffed? Most importantly, who will explain to these individuals why they can no longer live with those they know and trust?

WE THE PEOPLE are not happy.

This is why I plead with you help prevent the ELIMINATION OF INDEPENDENT PROVIDERS or the self direct plan!! We should not be forced into a plan no one of us wants. And the ones that can't handle it will be institutionalized.  
I ask you, is that fair?

Sincerely,

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