

Last year the MyCareOhio program devastated our family. I lost an independent care provider, due to excessively delayed reimbursement by Aetna and her fear that the state would be phasing out independent providers completely in the near future.

Now that fear is justified, and I am very afraid for the future of my son, who has autism and extreme short gut -- a serious medical condition. Because of his developmental, behavioral, and extreme medical issues, we must have consistent, competent, dependable care providers. We used agencies in the past, only to have people not show up for their hours, call off extremely late, text on their phones instead of doing their jobs, or even not be able to communicate sufficiently in English. Can you imagine someone trying to provide care for a child with communication issues who doesn't even speak his same language? That is preposterous.

On one occasion, a sub was sent who appeared to be extremely mentally unstable. Until I could get her to leave voluntarily (and locked the door behind her), I was quite literally in fear for the lives of me and my young children. I couldn't go to the bathroom for the entire four hours that she stayed in my home. Every time I tried to call my husband, she got agitated and demanded to know what I was doing. The agency had assured me that all their employees were carefully screened and that this last-minute person would be a great match. When I called to let them know what had happened, they apologized and told me they wouldn't bill me! I didn't even get assurance that this person wouldn't be sent to another individual's home.

Conversely, when I have hired independent providers, I am able to screen candidates better, set and enforce expectations, and establish long-term relationships that are mutually beneficial. One of my son's providers, who recently moved out of state, was with us for 5 years. Another has been employed for two and a half. They know my son and are able to provide support and make his life better. The longest I had an agency provider was a few months. Please do not take this important option away from individuals with disabilities and their parents/guardians!

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