

Trying to Look *Forward*

Mary Lay is worried about her son's future. Now she's speaking out and searching for hope.

"It's so frustrating and I worry constantly," Mary confesses as she shares her son's story. "Sam is 29 years old and has spastic quadriplegic cerebral palsy, uses a wheelchair for mobility and is nonverbal, so he requires total care. I don't think that most people understand what total care means. He's a grown man and that means care and assistance with everything that a person does throughout their day. And now, more than ever, finding that care is almost impossible."

Several years ago, Sam's family thought a group home might be a good fit for him but it turned out to be a mistake.

"We knew within six months that it was a mistake, and began taking steps to bring him home," Mary says. "He's back with us, in his own home, but we continue to struggle with the availability of reliable direct care workers to help us care for him, and be a part of his journey towards independence. This takes dedication. We value that in our family and believe that these workers should be paid accordingly. It's the low rate of pay for these workers that is making it so hard. That issue is basically insurmountable."

Right now, Sam's brother and one part-time direct care worker are working to help out, but that's all that Mary has. The one part-time worker has returned to school and in the next few months will be looking for another position.

"It's a crisis. It really is," Mary says. "I mean, right now his hourly rate is \$16.46 an hour. But Sam's care is incredibly challenging and most people won't do all that's required for such a low rate of pay. I'm trying to be realistic, you know, and if they don't increase the rate commensurate with his increased needs, it's just going to stay this way."

For Mary, the threat of returning Sam to a group home always looms in the background.

"I took him from a group home setting. I don't want him ever going back to one," she says. "I need staff. I'm desperate for staff. I'm sixty-five years old, and I have my own health challenges. I'm extremely worried about Sam's future and need to be sure that he's taken care of. Not just his basic needs but also providing a safe, meaningful and happy life that includes being a member of his community, being out in the community that he lives in. I need reliable, well-paid staff to accomplish this."

Mary has used online services like ZipRecruiter, Care.com and Michigan Pure Talent Connect. "Many times, candidates will reply with interest and then when contacted further, they don't respond. It's most likely that in the interim, they found a better paying position. You get ghosted a lot. Some people are too far outside of the geographical area," she says. "Others want to be paid cash and that doesn't work when the funding is Medicaid-based."

"Still, with others, if they work too many hours, they themselves will lose their Medicaid. Many of these workers are single parents. They can't afford for that to happen. The lack of benefits is a barrier. The lack of respect is a barrier. It's frustrating and it's wearing."

Some families, who are able, pay out-of-pocket (adding onto that lower hourly rate), in recruiting or retaining staff. Mary can't do that. She is on a fixed income, as is her son. Can we at the very least raise the hourly rate, keeping our most vulnerable children and adults safe and well cared for?



Michigan needs to pay its direct care workers enough to keep pace with today's job market. That's the only way to ensure quality care and give Mary and other families like hers the the peace of mind they need.