

Column: Illinois, give them a raise! Show you care about caregivers, people with disabilities



Essie Martin has been working with developmentally disabled adults for 17 years. Despite working more than 50 hours a week and her steadfast dedication to the men she calls her "second family," low wages of less than \$12 an hour prevent her from doing little more than work. (Stacey Wescott / Chicago Tribune)



Rex Huppke Contact Reporter Chicago Tribune
Wednesday, May 24, 2017

Essie Martin is a caregiver, has been for much of her 37 years.

She started taking care of people as a kid in Alabama, going each day to help out her grandmother and other older friends and relatives, helping them with

their medicine or other needs. They lived nearby — Essie still calls it "down the road." The older folks who lived down the road.

She was born in Chicago but grew up in the South. When she returned to the city 17 years ago, she became — naturally and fittingly — a caregiver.

"I thought that might feel right at home," she said. "And it did."

After 17 years as a caregiver for adults with developmental disabilities — the official title is "direct support professional" — Essie is making \$11.99 an hour.

She works six days a week, often 10 or 11 hours a day. And it's barely enough to make ends meet.

If you take a closer look at the compassionate work Essie and other caregivers do, the kind of work that makes them a halo and a set of wings shy of angels, you'll see that kind of pay is ridiculous. It's obscene. And it reveals, once again, the state of Illinois' stunning lack of compassion for people with disabilities.



Portrait of 37 year-old Essie Martin, right, of Chicago, with two of the men she cares for, Eddie Arroyo, center, and Dave Mroz, left, near the group home where she is a caregiver for four developmentally disabled men in Lombard on Monday, May 22, 2017. Martin has worked there for 17 years and she calls the men and their families her "second family." After 17 years, she makes \$11.99 an hour and often works 12 hours days to make ends meet. (Stacey Wescott / Chicago Tribune)

Our state ranks near the bottom each and every year when it comes to caring for and educating children and adults who have developmental disabilities. They aren't victims of the budget impasse or the state's current financial woes. They are members of a demographic long-ignored, callously overlooked because they aren't likely to swing any voting districts or drop big checks into campaign coffers.

Caregivers like Essie — who make an average of about \$9 an hour — haven't seen a raise in nine years. Illinois organizations that help people with disabilities get most of their money from the state, with matching funds from Medicaid.

Kim Zoeller, president and CEO of the Ray Graham Association, a DuPage County-based group that provides support for people with intellectual and developmental disabilities, told me this:

"This situation was not created overnight, and we didn't determine the timing of this. We have not had any significant rate adjustments for more than nine years. We've been in a downward spiral since then. And we haven't kept it a secret either. Constant advocacy, constant communication with legislators. And this is where we are, despite telling legislators that this situation is continuing to worsen because they've neglected us for a decade."

There was a bill last year that would've boosted pay for caregivers, but Gov. Bruce Rauner vetoed it, saying there was no way for the state to cover the \$330 million cost.

Now lawmakers in the House are considering a bill recently passed by the Senate that would make the minimum pay for direct support professionals \$15 an hour. It has to pass the House by May 31, or this issue will again get kicked down the road.

And that would be inexcusable.

I understand the state's fiscal situation. I also refuse to believe any lawmaker who tells me it isn't possible to find the money to properly take care of the people who care for some of the most vulnerable among us.

This isn't an unreasonable request. People like Essie aren't looking for sports car money or lavish perks. They want enough to live on, and organizations like

the Ray Graham Association want to be able to pay good caregivers enough that they'll stick around.

I visited Essie this week at a tidy one-story house in Lombard that's home to four men with developmental disabilities. Take away the house and others like it — called community integrated living arrangements — and many of these residents are in state institutions or nursing homes or on the streets. Any of those options costs the state a lot more than giving caregivers a raise.

Also, to simply call Essie a caregiver doesn't do her justice. She's family to the men she calls "my guys." She loves them. She worries about them on the one day a week she's not working. She calls to check on them, plans errands she knows they'll love, cooks with them, holds their hands when they're frustrated and guides them through challenges few can understand.

She helps them, depending on their needs, with bathing and going to the bathroom and other personal matters — the elements of caring for another human being that some might not want to think about.

And that's where part of the problem resides. Not enough people want to think about men or women with disabilities. They don't take the time to see them as every bit as human as anyone else, as deserving as anyone to a full life, to a home in the community, to a chance to work and pay taxes and contribute.

Essie — like any dedicated caregiver — sees the full humanity of the people she serves.

She goes through the names of her guys and, without pausing to think, recites what makes each man unique.

Kevin is the one everybody turns to and looks out for. He loves sleeping. And milk.

Eddie is the go-getter, loves the Chicago Cubs, always wants to bag groceries when they go to the store because he worked as a bagger for a while.

Terry is 6-foot-5, slim and an eater. Plate after plate he'll go through. And he's fast on his feet. You have to watch him.

Dave is a fan of any kind of sport. He's protective of Essie — "He's my bodyguard," she said — and can't wait for the next trip to Jewel, particularly if the store has free samples of fries or cookies.

"My family are these guys," Essie said. "It's hard work and long hours, but they become part of your family. They grow to you."

Over the years, she has thought about finding a job that pays better, but she can't bring herself to leave them, knowing how crucial continuity is to people with developmental disabilities.

"I've had opportunities to go other places to work," she said. "Then you think about these guys and you just can't do it. It pulls you back."

The work Essie does is vitally important. It's decent and compassionate and hard and something few would be able to handle.

She and so many others like her deserve our appreciation, both as a society and as human beings.

And, surely, they deserve a raise.

Please call your lawmakers and tell them to get it done.

You can find more information on this issue at: <http://instituteonline.net>.

rhuppke@chicagotribune.com

[Twitter @RexHuppke](https://twitter.com/RexHuppke)

Copyright © 2017, Chicago Tribune