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Advocates: Low pay for workers aiding disabled means high turnover, disruption for clients

By Crissa Shoemaker DeBree, staff writer 15 hrs ago



Yasmine Barionette helps Bob Trumbauer with his lunch. Sam Jamison, left, can usually eat without help. Both men live in an Upper Southampton, Pennsylvania, group home where Barionette works as a direct service professional, or DSP. It's run by KenCrest, a provider of services for adults with intellectual disabilities.

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Yasmine Barionette loves her job. The people she works with, day in and day out, have become like family.

Yet supporting her own family requires working long hours, sometimes in back-to-back shifts, caring for those who cannot care for themselves.

Barionette is a direct service professional, a title given to those who provide support to children and adults with disabilities. That care is designed to enable the residents to live, work and participate in the community. The jobs may be in group homes in the community, day programs or in private homes.

It's a difficult, often exhausting job. And it's one that pays, on average, between \$10 and \$12 an hour — a wage that advocates say makes it difficult to attract and retain qualified individuals at a time when they're serving more people with more complex needs.

"It is a nationwide problem," said Tom Baffuto, executive director of [The Arc of New Jersey](#), part of an organization around the USA that advocates for and provides services to those with disabilities. "It's a very bad problem getting worse."



Ivory Tillman helps Bob Trumbauer out of his recliner and into a wheelchair so he can move to the dining area for lunch. Bob and two other men with developmental disabilities live in an Upper Southampton, Pennsylvania, group home, where Tillman is one of about a dozen direct service professionals who care for them.

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Wages for direct support professionals, or DSPs as they're known in social service circles, come from the pot of money agencies receive from the state and federal governments to provide services to adults with disabilities. Pay rates haven't increased in years, advocates say.

Some help coming

Thanks, in part, to a push from disability advocates, Pennsylvania and New Jersey lawmakers added money to boost DSP wages in next year's budgets. In New Jersey, an additional \$20 million will go directly toward raising the pay rate for DSPs by an estimated 70 cents an hour. In Pennsylvania, \$150 million will help increase support and services, as well as bump the average starting pay for DSPs to \$12 an hour.

“Ninety percent of the services we deliver is dependent on the effort of direct support professionals — the (workers) who are side by side, helping individuals get through their day,” said Nancy Thaler, deputy secretary for Pennsylvania’s Office of Developmental Programs. “They are essential.”

Agency leaders said the additional funds are a good start to addressing the issue. Yet they worry the fight isn’t over. They say proposed federal changes to Medicaid — the main source of funds to serve those with intellectual and developmental disabilities, such as autism — could impact future wage increases, as well as the continued ability to provide services.

“The Medicaid discussion totally paralyzes us,” said Maureen Cronin, executive director of [The Arc of Pennsylvania](#). “The states decide how much to spend and who’s eligible, and the feds do a match. If the feds put a cap (on spending), the states would have to find a different (way of funding). That is beyond scary.”

Competing for workers

DSPs like Barionette say their love of the work and the people they serve is why they stay in their jobs despite the low wages.

“It’s not about the money,” said Sharon Mitchell, who works in a group home in Medford. “It really isn’t. I like building relationships.”

Searching for meaningful relationships led Mitchell to leave her job as a manager at Starbucks five months ago to work for [Bancroft](#), one of the region’s largest providers of services to children and adults with autism, intellectual disabilities and brain injuries.



Sharon Mitchell, a direct service professional for adults with developmental disabilities in Medford, says the job isn’t all about the money. It’s about building relationships with the people she serves.

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Yet agencies say many DSPs head in the opposite direction, lured to jobs in retail and fast food that promise higher wages for easier work. That exodus has gotten worse in recent years, as the economy has improved and pay has increased, particularly for jobs that once were minimum wage.

“People are not just leaving because it’s hard,” said Marian Baldini, president and CEO of [KenCrest](#), a Montgomery County-based services provider that runs the Upper Southampton home where Barionette works. “It’s hard and it doesn’t pay well. We’re directly competing with Wendy’s and places like that.”

In Pennsylvania, DSPs make an average of \$11.26 an hour, although pay varies based on experience, the agencies they work for and the severity of clients' disabilities. Pennsylvania has about 35,000 DSPs and roughly a third, or 9,500, leave each year for better-paying jobs, according to [Pennsylvania Advocacy and Resources for Autism and Intellectual Disability](#), or PAR, an advocacy group. About 4,200 positions remain unfilled.

Finding, keeping DSPs

"We're having a harder and harder and harder time finding people who are willing to work for those wages," said PAR President and CEO Shirley Walker. "As soon as they find another job that can pay better wages, they're gone."

In New Jersey, the starting salary for DSPs is about \$10.50 an hour. About 20 percent of DSP jobs are vacant, and 44 percent of workers leave after just six months, according to the [Coalition for a DSP Living Wage](#), a group of New Jersey service providers that is lobbying to increase DSP starting wages to \$16.75 an hour by 2022. The state has about 23,500 DSPs.

WAGES FOR DIRECT SERVICE PROFESSIONALS

The U.S. Bureau of Labor Statistics lists direct service professionals in the job category of personal care aides, which also include those who work with the elderly and those with physical disabilities.



1,492,250

Number of people employed



26%

Expected growth in number of jobs,
2014-2024



\$10.54

Median hourly pay



\$21,920

Median annual pay

Source: BLS' Occupational Employment Statistics, May 2016

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Because of the low wages, nearly half of DSPs rely on some form of public assistance, such as Medicaid or food stamps, according to the coalition. Many work multiple jobs to make ends meet, and end up burning out from the stress, advocates said.

"To see a (meaningful) check, you have to work overtime," said Sharita Johnson, a longtime direct service professional who supervises the community home in Upper Southampton, Pennsylvania. "You have to crawl home."

In addition to state and federal dollars, agencies also rely on donations and other outside funding to operate. Some agencies supplement DSP wages with that extra money, but others say they raise just enough to cover the costs that aren't paid for by the government.

The Indian Creek Foundation in Franconia, Pennsylvania, raised its starting wage for DSPs by \$1.50 an hour this year, to \$12, said Dean Stoetz, the nonprofit service provider's CEO. It achieved the pay raise by "consistent belt-tightening" in areas such as contracts and management, plus "generous donations" from supporters, he said. Still, Stoetz expects a budget deficit at year's end.

And Indian Creek still needs to hire 150 to 200 additional DSPs, roughly 20 percent of its current employee base, to meet demand, Stoetz said.

"We've done a good job at improving our retention, year over year, by 35 percent, which is huge for us," Stoetz said. "But we haven't improved our hiring, even with that \$1.50 (increase). The economy has continued to improve, and we're competing with an awful lot of people at the \$12 range. It's a struggle."

Wages affect clients

Low wages don't just impact DSPs, agency leaders said. The constant turnover also affects the people they serve.

"You just have to get the basics done," said Baldini, of KenCrest. "It's just about making sure that someone has fire safety training, someone's been oriented to the plan, someone's counting the medications. It becomes very focused on just getting through the minimum rather than thinking about what could I do to help this person participate in their neighborhood."

New DSPs also might struggle to communicate with clients, many of whom have limited or no verbal skills, advocates said. That can lead to client stress, frustration, and sometimes, behavioral outbursts.

"Being able to communicate and understand an individual's needs is hard," said PAR's Walker. "When there's turnover that is frequent, it means that there's no way the DSP can really know what the person needs and wants. There's much less opportunity for the individual to direct their own life, and to be able to get the proper support they need, simply because DSPs aren't there long enough to learn about the individual."

'Symbiotic' relationship

Kevin Nunez considers himself lucky because he can communicate his needs to the DSPs who work with him in a day program and at his home in Willingboro.



Twins Kevin (left), and Abner Nunez, 30, both need direct service professionals to help them with the chores of daily living. The Willingboro twins have cerebral palsy. [Buy Photo](#)
 Nancy Rokos/Photojournalist

Both Kevin Nunez and his twin brother, Abner, have cerebral palsy, a muscle disorder caused by brain damage before, during or immediately after birth. Kevin Nunez, an advocate and member of the [New Jersey Council on Developmental Disabilities](#), said he's gotten so used to the "revolving door" of DSPs that he has jokes ready to break the ice the first time new aides have to help him to the bathroom.

"It's more awkward for them than it is for me," he said. "I've become so used to dealing with different personalities and adapting to them."

But it's not only personal care that Kevin and Abner Nunez need. DSPs ensure the brothers have a social life, taking them to the movies and other places. The DSPs become part of the brothers' family; current and former DSPs came to wish the brothers well when they celebrated their 30th birthdays earlier this month. Kevin said he's even met the families of his support professionals.

Kevin Nunez said he and his brother are fortunate because they live with their father and grandmother, but he worries what will happen to him and his brother when they can't care for the twins anymore.

Having dedicated DSPs who can make their own living while caring for him and his brother is key, Kevin Nunez said.

"It's a symbiotic relationship," he said. "They're getting paid. I'm living my life."

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