



*Gail Frizzell with her daughter Lauren at Lauren's home in Franklin, NJ*

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# New Jersey's DSP Crisis

## A Family Perspective

By Jonathan Jaffe

As people and families cope with the growing lack of Direct Support Professionals (DSPs) in New Jersey, and try to shore up the profession with qualified individuals before this shortage crisis worsens, there is a coalition desperate to bring the issue to the forefront.

Last October, a group of ten members from the Family Support Coalition formed the Direct Support Workforce Crisis Workgroup, comprising parents and others throughout New Jersey who are eager to share their stories about the critical need for well-trained, experienced, and compassionate DSPs in the ongoing care of their

loved ones. Many are concerned by the shrinking pool of DSPs across New Jersey and the nation, and what it all means to those with a lifetime of significant disabilities.

This workgroup considers the low pay of the profession a vital issue and will be working with the newly-formed Coalition for a DSP Living Wage this fall to hopefully secure additional state funding to boost salaries. The workgroup also has established a website—<http://directsupportcrisis.org/>—to educate the public and to encourage action.

Gail Frizzell of Wantage, who chaired the Direct Support Workforce Crisis Workgroup,

is balancing her time between this important advocacy work and caring for her 30-year-old daughter, Lauren. Securing qualified DSPs, and providing the necessary training, is an endless task.

Frizzell knows all about the budget limitations that plague the state year after year. But the need for better paid DSPs is too great to ignore. While asking for more money from the state coffers is a thankless task, it must be a necessary focus in the upcoming months, she says.

Life has been an ongoing juggling act for Frizzell. In June of this year, she lost a live-in caregiver who retired and had covered two shifts of her daughter's care. An advocate for 30 years on the state level, Frizzell says her daughter's disability and the necessary advocacy work is a full-time job, with endless nights and weekends.

"For four months, I searched on my own for a qualified DSP. Then I started working with a home health care agency—who couldn't find DSPs either," she says. "Fortunately, someone started on June 27 for one shift. Then, it took a few more weeks to find someone for the other shift, with the help of this agency."

"We have an ongoing vacancy to help with the weekend shift which I have been trying to find for two years," she adds. "I asked the agency to help. But the job is under a different funding stream and the reimbursement rate is low, so the agency won't consider taking us. Other agencies won't even come into Sussex County, where I live. So, our weekend coverage goes weekend by weekend. We never know."

Five years ago, Lauren moved from her parent's house to her own home about 20 minutes away in Franklin, NJ, where there is 24-hour staffing. Frizzell, who is 60, and her husband, who is 80, recognize there are physical limitations in how they can care for Lauren, after spending so many decades tending to a daughter with a rare disorder, multiple disabilities, seizures, and an inability to walk, talk, or feed herself.

Frizzell says many of the DSPs begin with wages of around \$9 an hour, adding it is unfair to ask them to handle the toileting, feeding, diapering, and ongoing care of a full-sized adult while working at such a low wage. "If we were able to pay more money to DSPs, we would be tapping into a broader pool of caregivers and recognizing the level of skill and responsibility needed for this work," she says.

The state Department of Human Services (DHS) contracts with about 300 agencies and organizations to provide residential and community services/programs to more than 40,000 people with developmental disabilities in New Jersey, says Nicole Brossoie, DHS assistant commissioner for public affairs.

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— Lorraine D'Sylva-Lee

These agencies engage in recruitment efforts, as needed, to promote and expand the services they offer. They also determine the rate at which their employees are paid. The state does not dictate their employee pay scales, she adds.

It is important to note, however, that the state *does* set reimbursement rates that provider agencies receive.

### **A "Perfect Storm"**

Last year, the New Jersey Association of Community Providers (NJACP) conducted a survey about DSP wages, aimed at determining the disparity between what positions are paid in the community with comparable positions in the developmental centers, as well as what the salaries averaged for large, medium, and small agencies. Benefits were also considered.



*Lauren Frizzell and her DSP Cheryl Nance. Cheryl has been working with Lauren for six years. DSPs help people with disabilities, like Lauren, with much more than their physical needs. They provide emotional and behavioral support and companionship, and make it possible for many people with disabilities to lead full lives in our communities.*

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The average salary for a DSP in the community was \$24,257, (Federal poverty level for a family of four is \$24,250), while the same position in the state run developmental centers averaged \$40,350. Those salaries are governed by title, longevity, and duties, as prescribed by union contracts, Brossoie says.

About half of DSPs in New Jersey require some form of federal assistance, such as Medicaid and food stamps, to make ends meet, NJACP reports.

There are other important issues, such as the fact that only about half of the agencies are able to provide paid holidays, sick days, personnel days, and vacation days.

Agencies have also had to deal with no contractual revenue increases from the state in eight years, with any and all surplus required

to be given back to the state Division of Developmental Disabilities, NJACP reports.

NJACP considers the DSP shortage a “perfect storm,” as none of these five glaring issues appear to have a solution:

- Unlike home health aides or personal care assistants, DSPs may serve individuals with complex intellectual and behavioral health conditions whose challenges in navigating everyday life are far more than physical.
- DSPs must understand and act upon behavioral health plans developed by Masters and PhD level professionals, providing education and habilitation services to allow individuals with I/DD to further develop knowledge and master daily life skills.

- DSPs must complete extensive training to ensure a knowledgeable and competent workforce.
- DSPs must understand and comply with a significant number of complex regulations.
- DSPs are continually at risk of job-related injuries due to behavioral and mental health challenges of some of the individuals they serve.

## Life with DSPs

Tom and Carol Hopkins have spent years working with DSPs, who have come and gone from their Bridgewater home. Some stay a few years, some stay a few months, some may even be around for just a few weeks.

They help care for the couple's 45-year-old son, Bobby, who has cerebral palsy and functions at the same level as a nine-month-old baby. Bobby has seizures, is non-ambulatory, non-verbal, and requires 24-hour-a-day care.

Carol Hopkins says her son has been involved in the Real Life Choices program for 10 years, in which the family manages his budget, hires staff, and handles his care—often challenging because of his uncontrolled seizures. Through the program, Bobby is able to remain living with his parents, with special bedding and a fully accessible house. Moreover, his living situation allows him to be involved in a day program run through the Somerset Arc.

Hopkins says the family is given a budget through Real Life Choices to support Bobby at home. The mother, who is a retired banker, likens the relationship to running a business. Sometimes, she interviews part-time DSPs through agencies, sometimes she finds them on her own. But the Hopkins family is responsible for coordinating scheduling and ensuring the DSPs are best qualified to handle her son, who she describes as being on the most profound end of the disability spectrum.

"Many DSPs want to work with clients who they can take to the mall or to the park," she says. "But, with Bobby, we need DSPs who are willing to spend the day inside, at our home. He can sit up, but he's non-verbal. So, any DSP would focus on feeding him, diapering him, and bathing him. It is a certain type of DSP who would want to do that work."

Hopkins says she has not really dealt with the common concerns of DSPs, such as the industry's low pay or lack of career advancement. The struggle, she says, is to find trained DSPs who are prepared to work with Bobby. She says the training for such work could be four to six months and that limits the pool of candidates that she can consider.

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Lorraine D'Sylva-Lee has been directing her daughter's care since 1998. Aaliya D'sylva has five DSPs; two full-time and three part-time, who come to the condo in Phillipsburg where the 33-year-old woman has lived since 2012.

"We have opted to self-hire our DSPs, which means that I end up the supervisor, the CEO, the trainer, the time-sheet keeper, and handler of all the needs associated with supporting my daughter," D'Sylva-Lee says. "There is a very specific reason why Aaliya lives in Phillipsburg; it is where there is a large concentration of potential DSPs that we can recruit. It is 20 minutes from our home in Changewater; the urban area of Warren County."

D'Sylva-Lee says she has been very strategic in securing DSPs, while remaining vigilant on



Lauren Frizzell and Julie McMichael, another one of her DSPs, who has been working with Lauren full time for over two months

state polices and legislation that could affect her daughter's care. She recognizes that only a precious few families are in her position to have such laser focus, and has empathy for many parents around New Jersey who she contends are completely lost in the system.

"The state is encouraging more and more families to be innovative in the approach to providing services," D'Sylva-Lee says. "We can't bury our heads in the sand and hope the system will somehow take care of us. We need to be more proactive, but there are no supports in the system to help families do that. We shouldn't be left to flounder on our own."

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Training and workforce development for DSPs is provided through the College of Direct Support (CDS), an internet-based educational program for professionals that provides more than 30 competency-based online courses about disabilities, Brossoie says.

All private service providers that receive funding through the New Jersey Medicaid Community Care Waiver have been given access to the CDS programs and have been provided with technical assistance by the Elizabeth Boggs Center on Developmental Disabilities at Rutgers University in New Brunswick on the use of this curriculum as well as the online management system to record and track courses taken by staff members, she adds.

Through coordination by The Boggs Center, the voluntary "Career Path" program uses the College of Direct Support (CDS) in combination with onsite mentors to enhance professionals' skills, the state official notes.

While the CDS is a highly valuable tool for the training and development of qualified DSPs, issues do persist, particularly for individuals and families who seek to hire staff themselves. Many individuals and families do not have as much time to train their self-hired staff as provider agencies would. Particularly for those with barriers to computer access, literacy, or language, the ability to fully utilize CDS training materials can be problematic. Especially when they don't have existing DSP staff to provide care while new staff is trained.

## The Future

DSPs have their struggles; so do the agencies that provide them. NJACP says there are changes to federal regulations that can negatively impact providers. There is concern that many agencies will close shop or remove essential services from people with disabilities who rely on them. Of paramount concern:

- The Department of Labor is increasing the current threshold for the overtime exemption from \$23,660 to \$47,476, costing providers millions in overtime expenses. The threshold will be updated every three years based on the national salary averages in the lowest census region in the US, which is the south.
- There is no commensurate increase in the Medicaid reimbursement to cover additional overtime expenses.
- There are increased costs to comply with Home and Community Based (HCBS) Final Rule and New Jersey's State Plan.
- There are additional costs associated with the State Transition Plan; providers must now absorb the cost of assuming responsibility as landlords resulting in more administration/regulatory requirements.

D'Sylva-Lee says DSPs must no longer be devalued in society. Families should no longer have to compete with the likes of Walmart or McDonald's in recruiting low-income people to serve as caregivers. "There are no efforts in New Jersey to recruit people for this type of career," she says. "We need to work with community colleges. We need to help families recruit. We need to raise the hourly wage!"

"We need to elevate DSPs to the level where the work is respected and acknowledged as lifeline for families," she says. "This is not babysitting. This is not glamorous work. But DSPs give my daughter a life of dignity, filled with humanity. They deserve so much more." **P&F**

**The Direct Support Workforce Crisis Workgroup website:**

<http://directsupportcrisis.org/>